Making Sense of Stomach Cancer Inequities
in Aotearoa New Zealand

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Abstract

Background

Stomach cancer is an important disease for Māori in Aotearoa New Zealand. Māori are more likely to be diagnosed with stomach cancer than non-Māori and have poorer survival. The higher incidence in Māori can be attributed to differential distribution of risk factors. Cancer survival, though, is an indicator of the access to and quality of cancer care with ethnic differences in survival providing a marker of the equity of health care delivery.

Objectives

To investigate:

Quantitative Phase

1. Patient, disease, treatment, health care access and outcome characteristics of a cohort of patients with stomach cancer.

2. Whether there were Māori/non-Māori differences in treatment timeliness, quality and quantity.

3. If differences exist, how these differences contributed to Māori/non-Māori stomach cancer survival.

Qualitative Phase

4. What key informants identify as issues for stomach cancer treatment in New Zealand, with a focus on Māori.

5. The interventions key informants identify that may improve access to, and quality of, stomach cancer treatment in New Zealand.
Methods

All Māori diagnosed between January 2006 and December 2008 were identified from the New Zealand Cancer Registry and compared with a randomly-selected equal number of non-Māori. Clinical data were obtained through a clinical notes review. Survival data were obtained from the national mortality database.

Characteristics and treatment of Māori and non-Māori cohorts were compared using age- and sex-standardised prevalence rates. Cancer-specific mortality hazard ratios were sequentially adjusted for demographic factors, disease factors, patient comorbidity, and health care access factors to assess their contribution to survival disparities.

Fifteen key informant interviews were held to investigate those points of the treatment pathway that the quantitative findings suggested were inequitable for Māori.

Results

172 Māori and 163 non-Māori with stomach cancer were compared. Stage and grade distributions were similar between the ethnic groups.

Māori were more likely to live rurally and in highly deprived quintiles, and had higher prevalence of comorbidity than non-Māori. Māori were more likely to be diagnosed with tumours located in the distal stomach (43% Māori, 26% non-Māori, p =<0.05).

Māori and non-Māori stage I-III patients received similar rates of surgical resection. Māori were less likely to have surgery performed by a specialist surgeon (38% Māori, 79% non-Māori, p<0.01), and less likely to be treated in a main centre (43% Māori, 83% non-Māori, p<0.01).

After adjusting for a range of factors Māori appeared to have 30% poorer survival (Hazard ratio 1.30, 95% CI 0.96-1.76).

Key informants indicated that inconsistent delivery of cancer services, especially impacting on smaller, less well-resourced DHBs, was the primary barrier to equitable stomach cancer treatment. Recently implemented health systems initiatives are
expected to standardise care nationally, however a range of further interventions, particularly focussed on better addressing regional care, communication between services and comorbidity, were identified.

**Conclusion**

The findings of this thesis suggest that New Zealand’s health care system delivers better cancer care to non-Māori in a number of respects. Achieving equitable care for Māori will require a variety of interventions along the stomach cancer pathway that combine health system level, health care process level and patient level factors.
Acknowledgements

There are many people who have supported me to complete this thesis and who deserve thanks.

I would like to thank my fantastic supervisors, in particular Diana Sarfati for designing an outstanding study and allowing me to be part of it. Your intellect and commitment are inspiring. Your useful critique, encouragement and good humour have kept me going during both good, and not so good, moments. To Kevin Dew, it has been a pleasure to work with you, your insight into the qualitative research process and steady support has been invaluable. To Jason Gurney, thank you so very much, your capacity for work is amazing, your planning superb and your ability to explain complex ideas in simple ways invaluable. Your humour and continued support have helped me immensely. To Jonathan Koea, thank you very much for your work and support, your clinical input has been critical to this study in so many ways.

I would also like to thank others who have worked on or helped me with this study. James Stanley, thank you for your time. Your ability to also simply explain complex ideas has been invaluable to me. Esther Swart for helping me to learn the intricacies of SAS, I would not have been able to do so well without your guidance. Likewise, Carolyn Hooper for helping me to learn and navigate NVivo, your support was greatly appreciated. To Ruth Cunningham, your help in crafting the paper from this study and steady support throughout our parallel PhD processes has been immeasurable. To Bee Lim who assisted in the note review process, the C3 advisory groups and the other members of the C3 research team, together everyone achieves more, this really has been a team effort and I thank you.

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To the people who help make my ‘other’ work so good, thank you. Charrissa Keenan, Stella Vickers, Gabrielle Baker and team, Justin Wall and the QIG, you are all a pleasure to work with and your commitment to the mahi is inspiring.

To my friends and family who have listened, encouraged and kept me going even when the going was hard, thank you. I give special thanks to Doctor Kanji for always finding a solution, to Kat and Kaz for keeping my body going and to Neil who has come into my life during this process, thank you. I especially thank my sister Louise Signal for always believing in me and for taking the time to tell me so, and my mother Elma Signal for reading this entire thesis and for allowing us to grow up believing that women from small town New Zealand could do anything.

To the people who helped with the note review process, especially those who work within medical records departments throughout New Zealand, your work is valuable and appreciated. To the key informants of the qualitative phase, thank you very much for your time and wisdom and for helping me to make sense of the quantitative results. You added great depth to this study and I thank you.

Finally, to the people affected by stomach cancer in New Zealand, especially those whose lives these data represent, kia kaha. I sincerely hope that this study will help to ensure a better journey for people with stomach cancer and their whânau in the future.
Statement of Participation

This study was part of a wider group of studies on cancer, care and comorbidity (C3) within the Cancer Control and Research Group (CCSRG), Department of Public Health, University of Otago, Wellington. The C3 studies comprised both quantitative and qualitative arms and were funded by the Health Research Council. They were designed and initiated by Diana Sarfati and were undertaken by investigators at the CCSRG in collaboration with investigators at Massey and Victoria Universities.

The C3: *Effect of comorbidity on care and cancer survival inequities* (C3 Quantitative) study investigated the role of comorbidity on ethnic inequities in cancer treatment and survival at a population level. There were nine specific cancer sites being investigated, primarily through the use of national and cancer treatment centre-level administrative data. Stomach cancer was one of the specific cancer sites being investigated; the remaining cancers in the C3 Quantitative study were breast, ovary, uterine, colon, rectal, prostate and liver.

The C3: *Cancer care journeys and clinical decision-making* (C3 Qualitative) study used qualitative methods to investigate the process of clinical decision-making in relation to patients with cancer, particularly Māori patients with comorbidity. This study built on and strengthened the C3 quantitative project by adding depth of knowledge and explanation about findings that might have otherwise been unexplored.

This thesis is based on data obtained by the author as part of the C3 Quantitative study.

The C3 Quantitative study began in October 2010, led by Diana Sarfati as Principal Investigator. Other members of the Quantitative project team were Jason Gurney, James Stanley, Bee Lim, Esther Swart and Josh Chamberlin. The C3 Qualitative study began in October 2011 with Louise Signal and Chris Cunningham as Principal Investigators. Other members of the Qualitative project team were Kevin Dew, Jeannine Stairmand, Emma Britton and Diana Sarfati. The C3 Quantitative study was informed by a Technical Advisory Group while both studies were informed by Clinical and Community/ Māori advisory groups.
I joined the C3 Quantitative team, in October 2010 initially to investigate the accessibility of data from national datasets and to assist the Principal Investigator in project management until the project team was established. A decision was made to undertake a full clinical note review for stomach, rectal and liver cancers as staging data is poorly captured for these three cancers within national datasets and stage is important to both treatment of, and survival from, cancer. I then took on the responsibility for collecting the note review data, including managing the process of questionnaire development for the three cancers within the clinical note review. Some of the work to set up the clinical note review and to collect and input the data was shared with other team members. In the converse some of the work I completed contributed to other outputs of the overarching C3 quantitative study. Where possible these work delineations are identified below.

All work was led by Diana Sarfati. Collecting and managing data from the national datasets, determining the target populations and final study cohorts for the notes review cancers, along with identifying relevant health care providers and gaining approval to access patient records were all the responsibility of Jason Gurney. I managed the majority of clinical note review data collection – 362 Stomach, 212 Rectal, 206 Primary Liver - data were extracted for these three cancers simultaneously; in total 780 patient notes were reviewed over a period of eleven months. I also supervised a research assistant (Bee Lim) to support data extraction within the Auckland region only. Bee Lim entered the study data into an electronic database. Validation checks on data collection and data entry were performed by both Bee and I.

I provided advice and support to Esther Swart and Josh Chamberlin during data analysis of the Rectal and Liver cancer cohorts, and contributed to the publication ‘Ethnicity and rectal cancer management in New Zealand’ (Swart et al., 2013).

For the stomach cancer cohort I amalgamated the study data, cleaned and prepared data ready for analysis and derived the variables used in the analysis. I led all analyses related to the comparison of Māori and non-Māori cohorts, including the development of study models, writing and executing statistical code and interpreting output. James Stanley undertook the work to impute missing tumour site, NZDep and
Urban/Rural data. I then used this imputed data to reanalyse survival models. I accept responsibility for the accuracy of all data and analyses presented in this study.

I led the publication “Indigenous inequities in the presentation and management of stomach cancer in New Zealand: a country with universal health care coverage” (Signal et al., 2014) based on findings of the quantitative phase of this study.

I undertook all aspects of the qualitative phase of this study, including study design, data collection, management and analyses.
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### Glossary of Māori Terms

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<tr>
<td>Aotearoa</td>
<td>New Zealand</td>
</tr>
<tr>
<td>Hauora</td>
<td>Health</td>
</tr>
<tr>
<td>Hikoi</td>
<td>To step, stride, march, walk</td>
</tr>
<tr>
<td>Hui</td>
<td>Gathering, meeting, assembly, seminar, conference</td>
</tr>
<tr>
<td>Iwi</td>
<td>Extended kinship group, tribe, nation - often refers to a large group of people descended from a common ancestor and associated with a distinct territory</td>
</tr>
<tr>
<td>Kohanga reo</td>
<td>Māori language nest/Māori language immersion pre-school</td>
</tr>
<tr>
<td>Kaupapa Māori</td>
<td>Māori approach, agenda, principles or ideology - a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society</td>
</tr>
<tr>
<td>Kura Kaupapa</td>
<td>Māori language immersion school – primary or secondary</td>
</tr>
<tr>
<td>Mainstream</td>
<td>Providers governed by the New Zealand government and its entities</td>
</tr>
<tr>
<td>Mana</td>
<td>Prestige, authority, control, power, influence, status</td>
</tr>
<tr>
<td>Māori</td>
<td>Indigenous person of Aotearoa New Zealand</td>
</tr>
<tr>
<td>Marae</td>
<td>Base or home of an iwi or hapu (family); tribal meeting place (lit. the open area in front of the meeting house, where formal greetings/discussions take place)</td>
</tr>
<tr>
<td>Ora</td>
<td>Health or wellbeing</td>
</tr>
<tr>
<td>Pākehā</td>
<td>New Zealander of European descent</td>
</tr>
<tr>
<td>Tangata Whenua</td>
<td>Local people, hosts, indigenous people - people born of the whenua, i.e. of the land where the people's ancestors have lived and where their placenta are buried</td>
</tr>
<tr>
<td>Te Puni Kōkiri</td>
<td>Ministry of Māori Development</td>
</tr>
<tr>
<td>Tino Rangatiratanga</td>
<td>Self-determination, self-governance, sovereignty, rule, control, power</td>
</tr>
<tr>
<td>Treaty of Waitangi</td>
<td>A treaty first signed on 6 February 1840 by representatives of the British Crown and Māori chiefs, it is considered the founding document of New Zealand</td>
</tr>
<tr>
<td>Waitemata</td>
<td>A region in the West and North of Auckland – Waitemata District Health Board, one of 20 District Health Boards in New Zealand</td>
</tr>
<tr>
<td>Waikato</td>
<td>A region of New Zealand. The collective name of the tribes living in the Waikato Basin; also the name of the river from which they take their name</td>
</tr>
<tr>
<td>Waitangi</td>
<td>A region in Northland, New Zealand. Also a Marae where the Treaty of Waitangi was signed</td>
</tr>
<tr>
<td>Wānanga</td>
<td>A tertiary institution that caters for Māori learning needs - established under the Education Act 1990</td>
</tr>
<tr>
<td>Whānau</td>
<td>Family, extended family, family group</td>
</tr>
<tr>
<td>Whānau Ora</td>
<td>Literally meaning family health. Whānau Ora is also a contemporary cross-government work programme jointly implemented by the Ministry of Health, Te Puni Kōkiri (Ministry of Māori Development) and the Ministry of Social Development</td>
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Chapter 1: Introduction

Stomach cancer is one of the most common malignancies worldwide. In 2008 it was the fourth most commonly diagnosed cancer, behind lung, breast and colorectal cancer. Stomach cancer is also one of the most common causes of cancer mortality worldwide, with a death rate second only to lung cancer (Ferlay et al., 2010). Internationally there is wide geographical variation in both incidence and mortality, primarily due to cancers that arise in the distal (lower) region of the stomach (Kelley and Duggan, 2003; Crew and Neugut, 2006; Dicken et al., 2005; Forman and Burley, 2006). Distally located stomach cancers are strongly associated with infection by helicobacter pylori (H. pylori) (Crew and Neugut, 2006; Blair et al., 2012; Kato and Asaka, 2010; Brenner et al., 2004), and much of this variation in incidence can be explained by differences in infection rates of H. pylori between populations, and over time (Kelley and Duggan, 2003).

Stomach cancer is an important cancer for indigenous populations. Most indigenous populations are more likely to develop stomach cancer when compared to their non-indigenous counterparts (Friborg et al., 2003; Jemal et al., 2004; Paltoo and Chu, 2004; Ward et al., 2004; Supramaniam et al., 2006; Vaksjold et al., 2008; Wiggins et al., 2008; Moore et al., 2010; Tsukanov et al., 2011; Zhang et al., 2011; Arnold et al., 2014), in part driven by higher rates of H. pylori infection among indigenous people (Windsor et al., 2005; Goodman et al., 2008). Indigenous people are also less likely to survive stomach cancer once diagnosed (Young et al., 1984; Gilliland et al., 1998; Jemal et al., 2004; Heise et al., 2009; Morrell et al., 2012).

Stomach cancer is also an important cancer for indigenous Māori in Aotearoa New Zealand. There are well documented and sustained examples of cancer related inequity between Māori and non-Māori (Minister of Health, 2003; Blakely et al., 2004; Jefferys et al., 2005; Robson et al., 2006). New Zealand’s indigenous Māori are not only more likely to get cancer in the first place (Robson et al., 2006); they are less likely than non-Māori to survive their cancer once diagnosed (Soeberg et al., 2012;
Robson et al., 2006; Robson et al., 2010; Jefferys et al., 2005; Haynes et al., 2008). Importantly to this thesis, Māori also have markedly higher incidence of stomach cancer (Robson et al., 2006; Blakely et al., 2010; Arnold et al., 2014; New Zealand Health Information Service, 2012), worse mortality (New Zealand Health Information Service, 2012) and poorer survival than non-Māori (Soeberg et al., 2012; Robson et al., 2006; Jefferys et al., 2005).

Cancer survival can be a useful indicator of the access to, quality and timeliness of a country’s cancer screening, diagnostic and treatment services. Ethnic differences in cancer survival thus provide an indirect marker of the equity of health care delivery. The underlying reasons for poorer survival among Māori are likely to be a complex mix of factors, in part stemming from the processes of colonisation which have resulted in an unequal distribution of resources in current society (Orange, 2011; Durie, 1998). However, New Zealand has a publicly funded national health system that provides specialist and hospital care to all residents without charge; theoretically cancer care is equitably accessible to all New Zealanders. Yet Māori are less likely than non-Māori to survive the majority of cancers (Alexander et al., 2010; Brewer et al., 2012b; Dachs et al., 2008; Gill and Martin, 2002; Haynes et al., 2008; Hill et al., 2010a; Jeffreys et al., 2009; New Zealand Health Information Service, 2006), including stomach cancer (Soeberg et al., 2012; Jefferys et al., 2005; Robson et al., 2006).

Explanations for differential cancer survival between Māori and non-Māori especially focus on differences in stage at diagnosis and levels of pre-existing comorbid conditions (Jefferys et al., 2005; Stevens et al., 2008b) as these two factors are important predictors of cancer treatment and subsequent survival. However there is also evidence of differential receipt of treatment for Māori in New Zealand with colon (Hill et al., 2010a; Hill et al., 2010b; Sarfati et al., 2009), brain (Alexander et al., 2010), prostate (Lawrenson, 2014; Obertova et al., 2015), lung (Stevens et al., 2008b) and breast cancers (Seneviratne et al., 2014c; Seneviratne et al., 2014a; Seneviratne et al., 2015b; Seneviratne et al., 2015). Importantly, while stage and comorbidity both played some role in the poorer survival profile of Māori with colon (Hill et al., 2010a) and breast cancers (Seneviratne et al., 2015), differential treatment also contributed...
to the poorer survival of Māori in these cancers (Hill et al., 2010a; Seneviratne et al., 2015).

Despite the known worse stomach cancer survival for Māori and the evidence of unequal treatment for a number of cancers, it is not known whether Māori/non-Māori differences in stomach cancer presentation, treatment and management exist. Neither is it known if any ethnic differences in care for stomach cancer impact on survival. Thus the management of stomach cancer in New Zealand warrants further investigation.

This thesis started with the hypothesis that there may be different patterns of stomach cancer care by ethnicity in New Zealand which may in turn affect survival. Thus the primary focus of this thesis is the stomach cancer treatment pathway in New Zealand. It investigated whether there were differences between Māori and non-Māori in access to and through this pathway, and how to best intervene to improve the quality of care. The study was carried out in two phases. Phase one used quantitative methods to examine and compare the presentation, treatment, management and survival of a cohort of Māori and non-Māori patients with stomach cancer in New Zealand. This was carried out to determine if there were any points of the treatment pathway where the quality of care was inequitable, and (if present) whether that inequitable care contributed to ethnic survival inequities. Patients residing in the North Island only were included due to logistical reasons; however the findings are thought to reflect the total New Zealand population. Phase two then used qualitative methods to further examine the stomach cancer treatment pathway and to consider and recommend interventions that may improve access to, and quality of, stomach cancer treatment in New Zealand, with a focus on Māori.

The specific objectives of this study were to investigate:

Quantitative phase

1. Patient (age, sex, comorbidity), disease (stage at diagnosis, tumour site, grade), treatment (receipt and timing of surgery, chemo and radiotherapy), health care access (deprivation, rurality) and outcome (survival) characteristics of a cohort of patients with stomach cancer in New Zealand.
2. Whether there were Māori/non-Māori differences in treatment timeliness, quality and quantity.

3. If differences exist, how these differences contribute to Māori/non-Māori stomach cancer survival.

Qualitative phase

4. What key informants identify as issues for stomach cancer treatment in New Zealand, with a focus on Māori.

5. The interventions key informants identify that may improve access to, and quality of, stomach cancer treatment in New Zealand, with a focus on Māori.

Stomach cancer is a complex disease with a pathway that covers a wide range of activities including primary prevention, screening, diagnosis and staging, treatment and rehabilitation, and palliative care. This thesis primarily focuses on that part of the pathway encompassing the diagnosis and treatment of stomach cancer that occurs within secondary and tertiary health care services, from the point of referral for specialist assessment onwards.

This is, however, a thesis within the discipline public health written by a former registered oncology nurse and health promoter. As stomach cancer has known risk factors and a long latency period it is potentially amenable to both prevention, and early detection through screening or other measures. So while this thesis does not specifically examine cancer prevention or screening, as public health research it was important to capture data on and, where appropriate, discuss these aspects of the stomach cancer pathway. Similarly palliative care also sits outside the main focus of this thesis but is an important facet of the pathway for a group of people with a poor prognosis, as is the case for a substantial proportion of people with stomach cancer. Prevention, screening and palliative care are also important in terms of ethnic inequities in stomach cancer; so while this thesis primarily focuses on the stomach cancer treatment pathway, at appropriate times the entire stomach cancer pathway is discussed.
INTRODUCTION

This thesis takes an explicit position of not blaming the victim, in this case Māori, for their disadvantaged health status. Within that position the thesis also rejects deficit framing. Research from a deficit frame whereby Māori are seen or described as the ‘problem’ and the research implies that the position Māori hold is their own fault or due to a cultural inferiority has been a persistent feature since New Zealand was first colonized. This framing has been detrimental to Māori and to New Zealand society (Reid et al., 2000; Pōmare et al., 1995; Smith, 1999). Instead the thesis looks to the structural and institutional mechanisms that drive disadvantage, especially highlighting the role of institutionalised racism. In this thesis any Māori/non-Māori differences in the treatment or management of stomach cancer are examined in terms of institutionalised racism within New Zealand’s health care system. This thesis assumes the position that health inequity is an outcome of deliberate policy decisions and therefore it must be amenable to intervention. Thus this thesis moves beyond merely describing the problem of inequity into investigating how and where to intervene to improve access to, and the quality of, stomach cancer treatment services. Mandelblatt and colleagues framework regarding equitable access to cancer services (Mandelblatt et al., 1999), the details of which are described in a later chapter, is used as the overarching theoretical approach within this thesis. Using Mandelblatt’s framework enables the thesis and its recommendations to remain focussed on system and provider change rather than on interventions which expect people’s behaviour to change in order to obtain better quality of care.

The Treaty of Waitangi is key in the New Zealand context and to a thesis examining Māori/non-Māori health disparity. The Treaty is New Zealand's founding document (Boulton et al., 2004; Orange) and remains highly relevant in today's society. The Treaty is incorporated within New Zealand legislation (New Zealand Parliament, 2000; New Zealand Government, 1988; New Zealand Government, 1987) and health policy (King, 2000; King, 2001; Ministry of Health, 2002b). It has particular relevance to the role and accessibility of health services and to health equity between Māori and non-Māori. The Treaty of Waitangi provides further impetus to ensure health services, including cancer services provide quality care to all New Zealanders.
INTRODUCTION

As previously stated, stomach cancer is an important cancer for indigenous Māori in New Zealand, yet no previous research has investigated whether unequal treatment for stomach cancer exists in Aotearoa New Zealand. Thus this thesis examines in depth the presentation, management and survival of stomach cancer in a cohort of newly diagnosed Māori and non-Māori New Zealanders. It also explores how the health care system may improve access to, and quality of, stomach cancer services for all New Zealanders, with a focus on Māori.

Study Chapters

The specific chapters and their main purpose within this thesis are as follows:

Chapter 1 – Introduction: introduces the topic, and describes the main research questions and objectives of this thesis. It provides some clarity about the focus of the thesis, what is covered and what is not, and gives a brief outline of the structure and content of each chapter.

Chapter 2 – Background: provides important background and context for this thesis. It sets out in four sections topics of relevance to Māori/non-Māori inequities in stomach cancer treatment and survival.

i. What is stomach cancer - describes stomach cancer, gives a synopsis of the stomach cancer treatment pathway, highlights controversies in its treatment and management and outlines international guidelines for the management of stomach cancer.

ii. The structural and institutional mechanisms of inequity - briefly describes the joint history of Māori and non-Māori in New Zealand.

iii. The position of Māori and non-Māori in current society - describes contemporary Māori/non-Māori access to the determinants of health, including exposure to the risk factors for stomach cancer.
iv. The New Zealand health care system - provides an overview of the health care system along with current cancer policy and interventions.

**Chapter 3 – Literature Review: Indigenous Cancer Inequities:** outlines the evidence regarding inequity in cancer, and stomach cancer, for indigenous people both internationally and in New Zealand. The chapter discusses incidence and mortality inequities first followed by a section on survival inequities.

**Chapter 4 – Understanding Inequity and Interventions:** explores why survival inequities exist and how, and where, it may be possible to intervene to minimise them.

**Chapter 5 – Methods:** describes the methods used in this thesis in two sections.

i. Quantitative Methods outlines the practical details of the quantitative phase of this study including identifying the target population, selecting the study cohort, collecting the data, preparing the data, and data analysis.

ii. Qualitative Methods outlines the practical details of the qualitative phase of this study including participant sampling and recruitment, development of the interview schedule, interviewing and transcription, data management and data analysis.

**Chapter 6 – Quantitative Results:** starts with an overview of the study cohort selection, then following the three research questions pertinent to this phase it provides: a comparison of the Māori and non-Māori study cohorts, a comparison of Māori/non-Māori treatment and management and finally, a comparison of patient survival.

**Chapter 7 – Qualitative Results:** presents the issues identified by key informants along the stomach cancer treatment pathway and for Māori, it then outlines the
interventions suggested by key informants and summarises these according to Mandelblatt’s levels of barriers to access to cancer services (Mandelblatt et al., 1999).

**Chapter 8 – Discussion:** provides a brief summary of the key findings then discusses the strengths and limitations of this study. Next it considers the implications of key findings in light of national and international research, discusses why Māori may receive differential access to cancer care compared to non-Māori and highlights possible solutions. To conclude, key messages in regard to action to improve stomach cancer services in New Zealand and impact on equity are highlighted.
INTRODUCTION

Research with Māori

While this study is primarily interested in stomach cancer equity for Māori, it has been carried out by a non-Māori researcher.

The Health Research Council of New Zealand has guidelines for researchers undertaking research involving Māori participants or research on issues relevant to Māori health (Health Research Council of New Zealand, 2010). These guidelines identify a range of approaches to Māori health research ranging from kaupapa Māori research (Māori controlled) to research where Māori are involved as participants but control remains with mainstream or non-Māori.

This thesis is not kaupapa Māori research; rather it seeks to uphold key principles of Māori centred research, with the overarching objective of facilitating positive outcomes for Māori. The study and its analysis employed the following principles consistent with a Māori-centred research approach:

1. Ensuring Māori are placed at the centre of the research: in Māori-centred research the needs of Māori are given priority and ultimately the research is beneficial to Māori (Cram et al., 2003)

2. Setting out to make a positive difference for Māori (Barnes, 2000; Smith, 1999)

3. Challenging inequity and power relationships: based on the assumption that health inequities are unjust, avoidable, detrimental to the whole of society and that interventions to avoid or address inequity are cost-effective (Woodward and Kawachi, 2000)

4. Avoiding victim-blaming and cultural deficit explanations: using a systems approach where solutions to the problem are focussed on changing systems, rather than changing individuals or those who participate in the systems (Robson and Harris, 2007a).
INTRODUCTION

There is debate in the literature regarding who can carry out appropriate research with Māori (Cram, 1997; Jahnke and Taiapa, 2003; Smith, 1999). However, Māori-centred research does not preclude those who are non-Māori from participating in that research (Smith, 1999; Barnes, 2000), rather it is important to get the approach right, employ appropriate research methods and utilise appropriate people (Smith, 1999; Pipi et al., 2004; Barnes, 2000).

The work described in this thesis has been carried out with the points above in mind. I was privileged to have been supervised by two Māori researchers, one with a clinical focus and one with a research focus. This work also had the oversight of a Māori advisory group which was formed to ensure the overall C3 research was relevant, that the interpretations of results were both appropriate and reasonable, and to ensure the proposed interventions were compatible with community and clinical expectations and priorities. In addition, I have endeavored to ensure my research practice is culturally safe by reflecting on my own cultural values and world-view as a non-Māori New Zealander.

Finally this thesis sets out to make a positive difference for Māori. Stomach cancer is an important cancer for Māori. This thesis seeks to understand the underlying causes of unequal stomach cancer outcomes in New Zealand, particularly focussed on the role that structural and health system factors play in creating, maintaining and potentially reducing these inequities. Inequity is an issue that should concern society as a whole. Certainly inequity is damaging to all New Zealanders not just those who are disadvantaged (Woodward and Kawachi, 2000: 734). If as put forward, inequity arises and is perpetuated from institutionalised racism within ‘mainstream’ organisations, addressing inequity then requires involvement from both Māori and non-Māori (Walker, 2004).
Chapter 2: Background

This chapter provides context to this thesis in four distinct sections:

1/ Section one gives a background of stomach cancer; it presents an overview of stomach cancer and describes the major features of its epidemiology and risk factors. It highlights important clinical and prognostic factors of stomach cancer along with components of its treatment and management. Finally, this section provides an outline of international stomach cancer guidelines that have been developed to guide clinical practice.

2/ Section two outlines two topics of relevance to the current Māori/non-Māori inequities in stomach cancer. These topics are colonisation and neo-liberalism. This thesis in part looks to how and where we can intervene to minimise inequities between Māori and non-Māori but in order to minimise inequities we must first have insight into the mechanisms by which they arise and are perpetuated. Much of the stomach cancer inequity seen in in New Zealand today can be attributed to the social and economic position of Māori in current New Zealand society. This position has been constructed by the shared histories of a predominantly British immigrant population and the indigenous Māori. As with other indigenous people throughout the world, Māori have been negatively impacted by colonisation. Māori have also been negatively impacted by the neo-liberal economic reforms that New Zealand experienced starting in the 1980s.

3/ Section three provides an overview of the position of Māori in contemporary New Zealand. The impacts of the processes of colonisation and neo-liberalism are clearly seen in the disparity between Māori and non-Māori in New Zealand’s current economic, health and social statistics, including that Māori have differential exposure to the risk factors for stomach cancer. This differential exposure leads to a vastly greater incidence rate for Māori which is then potentially exacerbated by differential access to the health care system and differential quality of care, or treatment, once
within the system – which is discussed in a later chapter.

4/ Section four provides an overview of the health care system in New Zealand, reviewing the funding and delivery of care including that of cancer treatment services. The chapter closes by summarising recent Government policy on both health inequity and cancer control.
**What is Stomach Cancer?**

Stomach cancer, also called gastric cancer, is a cancer that usually arises in the cells that form the innermost lining of the stomach (American Cancer Society, 2013). The majority of stomach cancers, around 90%, are adenocarcinomas (Kelley and Duggan, 2003; Mercer and Robinson, 2008). The remaining 10% of stomach cancers are composed primarily of non-Hodgkin’s lymphomas, gastrointestinal stromal tumours (GIST) and leiomyosarcomas (Kelley and Duggan, 2003).

The development of stomach cancer in an individual is thought to be slow, potentially taking several decades and following a number of intermediate or pre-cancerous stages: chronic gastritis, gastric atrophy, intestinal metaplasia and dysplasia (Ferlay et al., 2010). If investigated, these precursor states are able to be detected and treated, preventing progression into cancer (Abrams and Wang, 2010). Once stomach cancer has developed there is often a significant time period where it remains localised to the stomach and is potentially curable (Mann and Thomas, 2001). This is true for both adenocarcinoma and GIST (Zhao and Yue, 2012).

**Anatomy of the Stomach**

The stomach is divided into four regions (Figure 1): the *cardia* sits next to the junction of the oesophagus and stomach (the oesophagogastric (OG) junction), the *fundus* projects upward above the cardia and OG junction, the *body* is the largest portion of the stomach and located immediately below the fundus, the *antrum* extends from the body of the stomach to its junction with the duodenum (Mercer and Robinson, 2008; Semrin and Russo, 2010). Proximal to the stomach, the mucosal cells lining the OG junction change from the stratified squamous epithelium of the oesophagus to the simple columnar epithelium of the stomach (Maish, 2008). Collectively tumours arising in the cardia, fundus or body of the stomach can be referred to as proximal
tumours while those arising in the antrum or pyloric region can be referred to as distal tumours (American Cancer Society, 2013). This is the distinction made in this study.

**Figure 1: Divisions of the stomach**

![Diagram of the stomach](image-url)


The stomach wall is made up of four layers: the mucosa, submucosa, muscularis propria, and serosa and has an extensive lymphatic system that drains to four main groups of lymph nodes surrounding the stomach (Semrin and Russo, 2010; Mercer and Robinson, 2008).

### Risk Factors

Stomach cancer (adenocarcinoma) has a number of risk factors. However infection with helicobacter pylori (H. pylori) is the single most important modifiable risk factor; H. pylori and its related risk factors are discussed first below. The remaining risk factors for stomach cancer are then discussed, grouped into unmodifiable and potentially modifiable risk factors.
Helicobacter Pylori Infection and Related Risk Factors

In 1994, the World Health Organisation declared H. pylori to be a human carcinogen (International Agency for Research on Cancer, 1994). Infection with H. pylori has a known strong association with the development of stomach cancer (Crew and Neugut, 2006; Blair et al., 2012; Kato and Asaka, 2010). It is proposed to be an almost necessary causal factor for stomach cancer which arises distally (Brenner et al., 2004; Kato and Asaka, 2010; Talley et al., 2008). The World Health Organisation estimates that at least 63% of all cases of non-cardia stomach cancer are due to infection with the bacterium (World Health Organisation, 2008). However, systematic reviews of case–control studies report a much higher percentage, with up to 80% of non-cardia stomach cancer reported as attributable to H. pylori infection (Talley et al., 2008). Additionally much of the variation of stomach cancer incidence observed worldwide can be explained by differences in infection rates of H. pylori between populations, and over time (Kelley and Duggan, 2003).

Helicobacter pylori is a Gram-negative, microaerophilic bacterium found in the stomach (Herrera and Parsonnet, 2009) which passes from person to person via the gastro/faecal oral route (McLoughlin, 2004; Talley, 1996). Infection with H. pylori is in turn associated with poverty, overcrowding and poor sanitary conditions, particularly those experienced in childhood (Crew and Neugut, 2006; Blair et al., 2012; Talley, 1996; Herrera and Parsonnet, 2009). It is thought that infection in childhood, unless treated, sets up a lifelong infection with H. pylori (McLoughlin, 2004; Crew and Neugut, 2006).

Infection with H. pylori causes gastritis, a precursor to adenocarcinoma, and accounts for nearly all cases of chronic gastritis (Kelley and Duggan, 2003). Chronic gastritis in turn increases the risk of developing stomach cancer and is present in many patients diagnosed with the disease (Kelley and Duggan, 2003; Herrera and Parsonnet, 2009). Differing strains of H. pylori are shown to be more likely to be associated with increased risk of stomach cancer, with cagA-positive strains increasing the risk of

In New Zealand the likelihood of being infected with H. pylori varies by ethnicity, with prevalence rates being consistently higher for Māori (and Pacific peoples) than New Zealand Europeans (Fraser et al., 1996; Fraser et al., 2010; McDonald et al., 2015). Increased rates of H. pylori are linked to household crowding with those living in conditions with the greatest household crowding having 1.82 (95% CI, 1.55-2.14) times increased risk of infection with H. pylori, compared to those experiencing the least crowding, independent of age and socioeconomic status (Baker et al., 2013). H. pylori is also shown to be the major contributor to the excess stomach cancer incidence among Māori in New Zealand (MacDonald, 2013).

It is debated whether H. pylori infection alone can be responsible for the development of stomach cancer (World Health Organisation, 2008; Forman and Burley, 2006) or whether other cofactors need also be present (Brenner et al., 2004; Crew and Neugut, 2006). However, it is true that the vast majority of people infected with H. pylori do not go on to develop stomach cancer (Crew and Neugut, 2006). It is also thought that infection with the bacterium creates an internal environment that when combined with one or more other risk factors creates a much higher risk of stomach cancer than that seen by any one risk factor alone; H. pylori is thus considered an effect modifier of the other risk factors (Blair et al., 2012; World Health Organisation, 2008; Crew and Neugut, 2006; Gonzalez and Lopez-Carrillo, 2010; Brenner et al., 2002).

There is evidence of a strong deprivation gradient, in both incidence and mortality, for stomach cancer overall (Soeberg et al., 2012; Blakely et al., 2010) with consistent evidence of increased risk within lower socio-economic groups within any given population (Kelley and Duggan, 2003; Forman and Burley, 2006); this excess incidence mirrors a similar excess of infection with H. pylori in these populations (Kelley and Duggan, 2003; MacDonald, 2013). In New Zealand the higher proportion of Māori living in more deprived regions accounts for up to 14% of the differences in both incidence of, and mortality from, stomach cancer seen between Māori and non-Māori (Robson et al., 2010).
BACKGROUND

An association between previous stomach surgery and subsequent development of stomach cancer was first reported in 1922 (Kelley and Duggan, 2003). Infection with H. pylori is now hypothesised as the underlying cause as H. pylori causes gastritis, which in turn leads to stomach ulcers necessitating surgery (Abrams and Wang, 2010). Likewise, the 20% excess risk of stomach cancer in people with Type A blood group, in comparison to other blood groups (World Health Organisation, 2008) is now thought to be linked to infection with H. pylori. The bacterium adheres to a surface antigen of the blood cell, facilitating chronic infection with H. pylori (Dicken et al., 2005).

Non-Helicobacter Pylori Unmodifiable Risk Factors

Ethnicity

Ethnicity is important to stomach cancer: differential rates by ethnicity within countries are common (Dicken et al., 2005; Crew and Neugut, 2006). Indigenous people in the United States of America (USA) (Dicken et al., 2005), Australia (Zhang et al., 2011) and New Zealand (New Zealand Health Information Service, 2012; Arnold et al., 2014) all have higher incidence rates than do their non-indigenous counterparts. These differing rates by ethnicity are largely due to different patterns and prevalence of risk factors among ethnic groups, especially H. pylori (MacDonald, 2013). Of importance, ethnicity matters to cancer sub-site. Incidence of non-cardia stomach cancer is high among African-Americans (Crew and Neugut, 2006; Forman and Burley, 2006) and American Indians and Alaskan Natives (Arnold et al., 2014). Whereas white Americans are twice as likely as African-Americans (Crew and Neugut, 2006; Forman and Burley, 2006) or American Indians and Alaskan Natives (Arnold et al., 2014) to present with tumours located in the cardia region of the stomach. In New Zealand Māori have higher proportions of distally located tumours in comparison to New Zealand Europeans who have higher proportions of proximal or cardia tumours (Arnold et al., 2014; Biggar et al., 2011).
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**Gender**

While incidence of stomach adenocarcinoma has been declining in both sexes for several decades, worldwide it has a higher incidence in males than females (McLoughlin, 2004; World Health Organisation, 2008). The magnitude of this difference overall is in the ratio of 1.5–2.5 for males to 1 for females (Crew and Neugut, 2006; Ferlay et al., 2010). However, this ratio varies depending on tumour sub-site. Non-cardia stomach cancer has a male-to-female ratio of approximately 2:1 whereas cancer located in the cardia of the stomach has a much higher male to female ratio (Crew and Neugut, 2006; Kelley and Duggan, 2003).

**Age**

Stomach cancer is rare in people under 30 years of age, thereafter its incidence rises progressively to reach its highest rates in older populations (Kelley and Duggan, 2003; McLoughlin, 2004; Mercer and Robinson, 2008) with the majority of patients between 60 and 80 years of age at diagnosis (Forman and Burley, 2006).

**Potentially Modifiable Risk Factors**

**Tobacco**

The use of tobacco is shown to be linked to stomach cancer (Kelley and Duggan, 2003; Forman and Burley, 2006). While there has been some international disagreement, studies have shown an important relationship between smoking and stomach cancer (Chao et al., 2002; Tredaniel et al., 1997; Nomura et al., 2012). Notably, the International Agency on Research in Cancer concluded in 2004 that tobacco plays a causal role in stomach cancer, attributing between 11% and 18% of cases of stomach cancer worldwide to smoking (Forman and Burley, 2006). This relationship has been shown to be stronger for tumours located distally (Crew and Neugut, 2006; Brenner et al., 2002) and for males (Forman and Burley, 2006). There is a dose-response
relationship with a higher risk shown the more cigarettes smoked per day and the longer duration (years) of smoking (Nomura et al., 2012).

Additionally there appears to be a positive interaction between infection with H. pylori and tobacco smoking on the subsequent development of stomach cancer (Gonzalez and Lopez-Carrillo, 2010), especially those located distally (Gonzalez and Lopez-Carrillo, 2010; Brenner et al., 2002). This effect is reported to be 17-fold in smokers also infected with CagA-positive H. pylori compared with uninfected nonsmokers (Brenner et al., 2002). Thus, smoking is considered to be an effect modifier in the relationship between H. pylori infection and the development of stomach cancer.

**Alcohol**

The association between the use of alcohol and stomach cancer has been extensively studied with a meta-analysis reporting a pooled relative risk of 1.3 for a high alcohol intake (100 g/day) compared to a non-drinker (Forman and Burley, 2006). Despite this, the causal link between alcohol and stomach cancer has not been conclusively established (Forman and Burley, 2006; Kelley and Duggan, 2003).

**Obesity**

In comparison to alcohol use, the evidence linking obesity and adenocarcinoma of the cardia and proximal stomach is stronger (Forman and Burley, 2006). Obesity can cause gastro-oesophageal reflux that in turn can cause Barrett’s oesophagus, a cellular change and precursor for adenocarcinoma of the distal oesophagus or OG junction (Crew and Neugut, 2006; Koppert et al., 2004).

**Dietary Factors**

A number of dietary factors are thought to increase stomach adenocarcinoma risk, particularly of cancers located in the distal stomach. These factors primarily include diets high in nitrates, found in dried, smoked and salted or pickled foods, and low in fruits and vegetables (McLoughlin, 2004; Abrams and Wang, 2010; Mercer and
Background

Robinson, 2008). Conversely, diets high in fruit and vegetables have been shown to have a protective effect for stomach cancer perhaps due to the micronutrients and antioxidants contained within them (Mercer and Robinson, 2008; Kelley and Duggan, 2003).

Pernicious Anemia

Pernicious anemia, an autoimmune disease, results in a chronic gastritis in those with it and increases their risk of developing stomach cancer (Mercer and Robinson, 2008) by up to three times in comparison to patients without pernicious anemia (Kelley and Duggan, 2003).

Genetics

Familial Clustering

Stomach cancer shows familial clustering in around 5-10% of cases (Abrams and Wang, 2010; McLoughlin, 2004; Lynch et al., 2005; Hu et al., 2012; Vogelaar et al., 2012). While familial clustering might well be due to non-hereditary factors, such as exposure to H. pylori, higher prevalence of smoking within a family or a common diet, having a first-degree relative with stomach cancer is shown to be a consistent risk factor for stomach cancer (Yaghoobi et al., 2009).

Familial Stomach Cancer

Only 1-3% of confirmed stomach cancers arise from known inherited cancer predisposition disorders (Lynch et al., 2005; Hu et al., 2012), including syndromes such as Lynch syndrome, Peutz-Jeghers syndrome (PJS), Cowden syndrome, Li-Fraumeni syndrome, familial adenomatous polyposis (FAP), and hereditary diffuse gastric cancer (HDGC) (Lynch et al., 2005). The latter of these, HDGC, is the best described form of hereditary stomach cancer and is well known in New Zealand (Abrams and Wang, 2010; Blair et al., 2012) due to a large Māori family, who in collaboration with
BACKGROUND

researchers, published seminal work describing a molecular basis for familial stomach cancer (Guilford et al., 1998).

In the 30 years prior to Guilford et al’s study being published, 25 members of the family had died of stomach cancer, with an average age of 33 years (Guilford et al., 1998; Blair et al., 2012). It was the family’s search to uncover the reasons behind this high incidence of early-onset stomach cancer that led to the discovery of a mutation in the CDH1 gene, which carries a code for E-cadherin molecule (Blair et al., 2012). A person in a HDGC family who carries the gene mutation has an estimated 70% lifetime risk of developing stomach cancer; however since gene testing began only two members of the original family discussed above have died (Abrams and Wang, 2010; Blair et al., 2012; Framp, 2006). Subsequent to this research CDH1 mutations have been identified in two other unrelated Māori families and in a number of families with a high incidence of diffuse stomach cancer worldwide (Blair et al., 2012; Yu and Li, 2011).

However studies show that at a population level, hereditary risk is much less important to stomach cancer; the environmental risk factors already discussed play a more important role (Blair et al., 2012). Certainly the development of stomach cancer in 25 members of one Māori family over a 30 year time period, while important, is not enough to create the three to five-fold increased incidence seen within the New Zealand Māori population, nor would this impact noticeably on age at diagnosis at a population level.

Risk Factors for Gastrointestinal Stromal Tumors

Currently, there are very few known risk factors for gastrointestinal stromal tumors (GIST) with age, being older than 50, the primary known risk factor. In rare cases GIST can be due to inherited familial gastrointestinal stromal tumor syndrome (Zhao and Yue, 2012; Tarn and Godwin, 2012).
International Epidemiology

Stomach cancer is one of the most common malignancies worldwide. In 2008 it was the fourth most commonly diagnosed cancer, behind lung, breast and colorectal cancer and represented 7.8% of the total new incident cases worldwide. It is also one of the most common causes of cancer mortality worldwide (9.7% of the total number of deaths), with a death rate second only to that attributable to lung cancer (Ferlay et al., 2010).

There is wide geographical variation in both incidence and mortality worldwide (Crew and Neugut, 2006; Dicken et al., 2005; Forman and Burley, 2006). Nearly three-quarters of all cases of stomach cancer (70%) occur in developing countries with half of all cases in Eastern Asia (Ferlay et al., 2010; Crew and Neugut, 2006). It is thought that most of the geographic variation worldwide is due to cancers that arise in the distal region of the stomach (Kelley and Duggan, 2003).

There has been a steady decrease globally in overall stomach cancer incidence during the last 50 years (McLoughlin, 2004). There has also been a notable change in the site of stomach cancer - a ‘proximal migration’ - over the last few decades (World Health Organisation, 2008; McLoughlin, 2004; Forman and Burley, 2006). In comparison to the steady global decrease overall, cancer of the cardia region of the stomach has shown a rapid increase in incidence, especially in the developed countries of the West (Kelley and Duggan, 2003; McLoughlin, 2004; World Health Organisation, 2008; Crew and Neugut, 2006). The rate at which the incidence of proximally located stomach cancers has risen is said to exceed the rate of increase of any other cancer (Alberts et al., 2003). This rise is thought to be primarily due to an increased prevalence of obesity and its associated gastro-oesophageal reflux (Forman and Burley, 2006; Crew and Neugut, 2006; McLoughlin, 2004). Many studies over the last 20 years have identified similar epidemiological patterns for proximal stomach cancer and distal oesophageal cancer suggesting these cancers share the same risk factors of obesity and gastric reflux disease (Forman and Burley, 2006; McLoughlin, 2004; Crew and Neugut, 2006). Of note, proximally located stomach cancer predominates in white
males of more affluent societies (Kelley and Duggan, 2003). In comparison, as previously discussed tumours of the distal stomach are shown to have a strong negative socioeconomic gradient and are linked to infection with H. pylori (Kelley and Duggan, 2003; Kamangar et al., 2006; World Health Organisation, 2008; Crew and Neugut, 2006; Huang et al., 1998).

The decline in stomach cancer incidence over the last 50 years is primarily due to decreased rates of distally located tumours and has corresponded with increasing global affluence and better living conditions (Mcloughlin, 2004). Two factors are thought to be important. The widespread introduction of refrigeration has led to a decrease in the intake of preserved or salted foods and a higher intake of fresh fruits and vegetables (Crew and Neugut, 2006; Abrams and Wang, 2010), while improvements in sanitation and less household overcrowding have led to an overall decline in the prevalence of H. pylori infection (Crew and Neugut, 2006). Additionally, efforts of tobacco control leading to reduced smoking, especially among males, may have contributed to declining stomach cancer incidence over the last 50 years in some countries (Crew and Neugut, 2006). The prevalence of, or decline in, these risk factors is not however equally distributed between, or within countries, thus differing epidemiological patterns remain evident (World Health Organisation, 2008).

Characteristics and Classification

Stomach cancer can be classified in a number of ways: 1/ histologically depending on major morphological features, 2/ by grade according to how aggressive the cells look under a microscope, 3/ according to the site, or region, within the stomach from which the tumour arises and 4/ by stage at diagnosis. These four characteristics play important roles in clinical decision making and prognosis of patients diagnosed with stomach cancer.
Histopathology

The histologic classification of stomach cancer has historically been based on Lauren's criteria, developed in 1965, in which adenocarcinomas are subdivided into two major subtypes: intestinal type and diffuse type adenocarcinoma (Mcloughlin, 2004; Kelley and Duggan, 2003; Hu et al., 2012). These two subtypes have differing risk factors and thus differing epidemiological profiles, often requiring different clinical decision making and have differing prognostic outlooks (Lynch et al., 2005; Hu et al., 2012; Mercer and Robinson, 2008). Generally the prognosis for the intestinal subtype is better than that of the diffuse subtype (Mercer and Robinson, 2008).

Grade

Tumour grading aims to predict how a cancer will behave depending on the degree of cellular differentiation. Those that look the most like the normal tissue from which they originated are classified as well differentiated while those that look least like the original tissue are classified as poorly differentiated (National Cancer Institute, 2013a). Well differentiated tumour cells tend to grow more slowly and in a more orderly pattern and thus these cancers have a better prognosis compared with moderately or poorly differentiated tumour cells which tend to indicate a faster growing and more aggressive cancer (Burton, 2001; National Cancer Institute, 2013a).

Anatomic Site

Adenocarcinoma can occur anywhere within the stomach. The anatomic sub-site, or region, of the stomach that a tumour develops in impacts both treatment options and prognosis (Mann and Thomas, 2001; Abrams and Wang, 2010). Proximally located tumours are often larger in size and more advanced in stage at diagnosis than distal tumours (Dicken et al., 2005). Consequently proximal tumours tend to have higher incidence of operative associated mortality and morbidity (Crew and Neugut, 2006),
and a poorer prognosis than more distally located tumours (Mercer and Robinson, 2008; McLoughlin, 2004; Dicken et al., 2005).

**Stage**

Cancer stage describes how much cancer there is in the body and where it is located. It is important in determining treatment options and patient prognosis (Abrams and Wang, 2010; Mercer and Robinson, 2008). A number of systems have been used to classify stomach stage however the most commonly used system is the TNM (tumour, node, metastasis) system (Edge et al., 2010; Sobin et al., 1997). In the TNM system, cancer stage can be based on the results of physical examination, clinical or imaging results as well as histo-pathological findings (Abrams and Wang, 2010). The TNM system for staging contains 3 key pieces of information: T (tumour) indicates the depth of penetration into the stomach, N (nodes) indicates the amount of lymph node invasion, and M (metastasis) indicates the presence, or not, of distant metastases (American Joint Committee on Cancer (AJCC), 2012; Abrams and Wang, 2010). After the TNM categories have been determined they are combined and grouped to assign a stage denoted by a roman numeral I – IV, with Stage I having the best prognosis and Stage IV the worst (American Joint Committee on Cancer (AJCC), 2012).

**Prognosis**

Stomach cancer has a poor prognosis, with many patients diagnosed at an advanced stage (Abrams and Wang, 2010; Dicken et al., 2005; Allum et al., 2011). Data from the USA show that 65% of patients are diagnosed with locally invasive tumours (T3 or 4, as explained above) and 85% of patients are diagnosed with accompanying lymph node metastases (N as explained above) (Dicken et al., 2005). In the United Kingdom around 50% of patients are diagnosed with distant metastases (Allum et al., 2011). Most countries report overall five-year survival rates between 10% and 30% (Mercer and Robinson, 2008; Crew and Neugut, 2006; Dicken et al., 2005; Forman and Burley, 2006).
Prognosis differs when stratified for stage at diagnosis. Early stomach cancers, those confined to the mucosa or submucosa, have a five-year survival rate of 90% or greater (McLoughlin, 2004; Crew and Neugut, 2006; Yada et al., 2013). Whereas patients diagnosed with Stage IV metastatic disease have a five-year survival between 5% and 16% (Abrams and Wang, 2010). These stage-stratified prognosis rates emphasise how important it is to detect stomach cancer at the earliest possible stage.

**The Stomach Cancer Pathway**

The stomach cancer pathway extends from interventions that aim to prevent the disease, to those aimed at early detection, staging, treatment and ultimately, palliative care. Given that stomach cancer has known risk factors and a long latency period it is potentially amenable to both prevention and early detection through screening. It is also treatable, and potentially curable if diagnosed at an early stage, with the mainstay of curative treatment being surgical intervention. Stomach cancer though has a poor prognosis with many patients diagnosed at an advanced stage of disease. Palliative care consequently plays an important role in the treatment pathway for those diagnosed with stomach cancer.

**Primary Prevention**

At a population level, preventing new H. pylori infections is likely to be the most effective long-term primary prevention strategy for reducing stomach cancer. As infection with H. pylori is primarily associated with household crowding (Baker et al., 2013) addressing household overcrowding is fundamental (Baker et al., 2013; McDonald et al., 2015) and could also have the advantage of reducing other infections associated with poverty (McDonald et al., 2015).

Reducing the prevalence of H. pylori infection through measures to detect, and eradicate, H. pylori could also contribute to reducing incidence of stomach cancer in the future. Meta-analysis supports this position. In one instance meta-analysis
showed that H. pylori eradication resulted in much lower rates of stomach cancer (OR: 0.56; 95%CI 0.4–0.8) (Fock and Ang, 2010). In another meta-analysis a relative risk of 0.66 (95%CI 0.46 to 0.95) was reported (Ford et al., 2014). The Asia-Pacific Gastric Cancer Consensus meeting has recommended such a strategy in high-risk populations, those with high prevalence of both H. pylori infection and stomach cancer, since 2008 (Fock et al., 2008; Talley et al., 2008).

Other primary prevention measures of particular import to stomach cancer consist of dietary measures, such as reducing salt or nitrite intake, reducing levels of obesity and tobacco control (Talley et al., 2008; Pasechnikov et al., 2014; Allum et al., 2011). All of these measures would have broad population health benefit, although evidence is limited regarding their impact on future rates of stomach cancer (Talley et al., 2008; Pasechnikov et al., 2014).

Screening

Population-based screening is not cost-effective in countries where incidence is not high (Mann and Thomas, 2001; Pasechnikov et al., 2014) and so screening to detect stomach cancer early has not been routinely implemented in most countries except for people at high-risk (Pasechnikov et al., 2014). In contrast, because of its high incidence of stomach cancer, Japan has been carrying out population based screening since 1983, using double-contrast barium swallow (photofluography) followed by endoscopy in patients with abnormal results (Guillou, 2005; Hamashima et al., 2008). As a consequence Japan has shifted its stage at diagnosis profile with 50% of cancers diagnosed at a localised stage (Mann and Thomas, 2001; Inoue and Tsugane, 2005; Layke and Lopez, 2004), a high percentage compared to countries without population screening programmes. Japan and other countries with population-based screening programmes also have better five-year survival rates than counties without (Maduekwe and Yoon, 2011; Forman and Burley, 2006). These improved survival rates may reflect a true improved survival rate through more cancers being diagnosed at an early, and thus curable, stage. They may also be in part due to artefacts such as lead-time bias, whereby the diagnosis is brought forward but there is no difference to
the outcome. There is however evidence that the Japanese screening programme is effective in reducing mortality, with case control studies showing a 40–60% reduction in mortality (Hamashima et al., 2008; Tsubono and Hisamichi, 2000), suggesting a real improvement in survival.

Screening for stomach cancer in New Zealand is limited to high risk populations with known heredity disease (New Zealand Familial Gastrointestinal Cancer Service, 2009).

**The Stomach Cancer Treatment Pathway**

Adenocarcinoma of the stomach is a treatable disease; especially if it is diagnosed at an early stage (Crew and Neugut, 2006; McLoughlin, 2004). However, as the epidemiology of stomach cancer has been changing over the last decades so too has its management and treatment (Palser et al., 2009; Martin, 2002; Okines et al., 2010; Nakajima, 2002; Allum et al., 2002; Allum et al., 2011; NHS Executive, 2001).

A similar diagnostic and treatment pathway is recommended for gastrointestinal stromal tumors (GIST) (Tarn and Godwin, 2012; Zhao and Yue, 2012; Casali and Blay, 2010; Zalcberg et al., 2008), although lymph node resection is not recommended as GIST does not commonly metastasise via the lymphatic system (Casali and Blay, 2010). Targeted adjuvant chemotherapy has survival benefit in both first-line (initial treatment) and relapse GIST settings (Zalcberg et al., 2008).

**Detection of Signs and Symptoms**

In the absence of screening most stomach cancers are diagnosed after investigation for suspicious signs and symptoms. As both the stomach and the abdominal cavity in which it resides are large, and able to distend, early signs and symptoms are often absent, or non-specific and vague (Mercer and Robinson, 2008; Abrams and Wang, 2010; Dicken et al., 2005). The most common symptoms of stomach cancer are epigastric discomfort or abdominal pain and weight loss (Abrams and Wang, 2010; McLoughlin, 2004). Other symptoms tend to vary according to the location of the
cancer. Dysphagia (difficulty swallowing) occurs more commonly in patients with proximal cancers; in contrast, symptoms of gastric outlet obstruction such as nausea, vomiting, and early satiety occur more often among patients with distal cancers (Abrams and Wang, 2010; Mann and Thomas, 2001). Physical findings, if present, tend to indicate locally advanced or metastatic disease (Guillou, 2005; Mercer and Robinson, 2008; McLoughlin, 2004; Dicken et al., 2005).

**Investigations: Diagnosis and Staging**

Flexible endoscopy is the diagnostic tool of choice for stomach cancer, with definitive diagnosis confirmed via endoscopic biopsy in the majority of cases (Dicken et al., 2005; Mercer and Robinson, 2008; Allum et al., 2011). As with all tests, endoscopy can fail to diagnose with a failure rate of approximately 10%, primarily due to too few biopsy samples being taken (Allum et al., 2011). The upper gastrointestinal barium study while still sometimes ordered in the primary care setting as part of the diagnostic workup has been superseded by endoscopy.

Computed topography (CT) of the abdomen and chest is useful to determine if regional lymph node or distant metastases are present (Abrams and Wang, 2010). It can also identify malignant ascites, an accumulation of fluid in the peritoneal cavity which indicates metastatic disease (Mercer and Robinson, 2008). Computed topography is unable to accurately evaluate early stomach cancer, nor can CT accurately detect lymph node metastases less than 5mm in size or peritoneal or hepatic carcinomatosis (seeding) (Mercer and Robinson, 2008; Abrams and Wang, 2010). Endoscopic ultrasound (EUS) on the other hand is considered to be one of the most valuable tools for preoperative staging of stomach cancer (Dicken et al., 2005). It is particularly useful in providing accurate assessment of the depth of tumour invasion through the stomach wall (T stage) and thus tumour resectability and in local (perigastric) lymph node involvement (Dicken et al., 2005; Abrams and Wang, 2010). The use of EUS, in combination with endoscopy and CT, greatly increases the information gained in the staging of stomach cancer (Abrams and Wang, 2010; Allum et al., 2011).
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Staging laparoscopy is often the final staging procedure performed. Laparoscopic, or keyhole, surgery is minimally invasive surgery where an operation is performed through small incisions using a laparoscope (Sotiropoulos et al., 2005). It is employed for patients with cancers shown to be surgically resectable (those with Stage II and III disease) by the previous clinical staging examinations, providing additional treatment (Allum et al., 2011; Abrams and Wang, 2010). Importantly, with this additional information patients can avoid non-therapeutic (‘open and close’) surgery if their cancer is presumed to be localised but is in fact inoperable (Sotiropoulos et al., 2005).

Pathology

Pathological examination of any initial biopsy and subsequent surgical specimen is an important part of the stomach cancer staging process (Allum et al., 2011; Mercer and Robinson, 2008; Dicken et al., 2005). A pathologist can determine the tumour type, grade and thus the aggressiveness of the tumour cells and often the level of invasion into the stomach wall from initial biopsy. These factors and others such as site and size of the tumour, lympho-vascular spread, whether surgical margins are disease-free and whether tumour cells are present in local or regional lymph nodes can be determined from a surgical resection specimen (Allum et al., 2011).

Surgical Treatment

Surgery is the mainstay of treatment for stomach cancer (Maduekwe and Yoon, 2011) and is the only therapy that is potentially curative (Okines et al., 2010; Allum et al., 2011). However there are a number of controversies in surgical management of adenocarcinoma of the stomach. A particular controversy is the optimal extent of both resection of the stomach and regional lymph node dissection.

The type of surgery performed is tailored to the extent and location of the tumour and dictated by the need to obtain resection margins free of disease (Mercer and Robinson, 2008; Allum et al., 2011; Dicken et al., 2005). Very early stomach cancer, that is T1, N0, M0 (stage IA), can be treated endoscopically however gastrectomy
(removal of the stomach) is recommended for tumours of stage IB - III (Okines et al., 2010). For tumours located distally or in the mid-stomach a partial, or sub-total, gastrectomy is recommended (Maduekwe and Yoon, 2011; Mercer and Robinson, 2008; Palser et al., 2009) as long as a margin of at least 5cm is obtainable between the tumour and remaining stomach.

There has been significant debate regarding the extent of resection for proximally located tumours with both total gastrectomy and proximal gastrectomy advocated (Palser et al., 2009; Mercer and Robinson, 2008). While there appears to be little difference in tumour resectability between the two surgical options there is evidence of greater post-operative complication, morbidity and mortality when proximal gastrectomy is performed (Mercer and Robinson, 2008; Maduekwe and Yoon, 2011). Thus for tumours located proximally, in the cardia and proximal stomach, total gastrectomy may be the operation of choice (Mercer and Robinson, 2008). Total gastrectomy is often also employed for tumours of the diffuse morphology subtype, irrespective of original tumour location due to their pattern of diffuse intramucosal spread (Dicken et al., 2005). If the tumour is also extending into the lower third of the oesophagus an oesophagogastrectomy or removal of a portion of the lower esophagus and proximal stomach is indicated. These latter two operations necessitate using both thoracic (via the chest wall) and abdominal surgical approaches greatly complicating the surgery and post-operative recovery (Mann and Thomas, 2001; Mercer and Robinson, 2008; Abrams and Wang, 2010).

The extent of lymphadenectomy during surgical resection has been the most notable topic of ongoing debate in the treatment of adenocarcinoma of the stomach (Maduekwe and Yoon, 2011; Dicken et al., 2005). The extent of lymphadenectomy can impact on local recurrence and survival and improves staging accuracy due to more lymph nodes being pathologically examined (Maduekwe and Yoon, 2011). There is however common agreement in the West that at least 15 lymph nodes should be resected and pathologically examined in order to gain adequate staging information (Allum et al., 2011; Dicken et al., 2005; Mercer and Robinson, 2008; Mann, 2004). There is evidence however that 15 or more nodes are not routinely being resected, at
least in North American and European surgical centres; with a facility based study in the USA showed around 27% of its patients had 15 or more lymph nodes resected while a national study in the USA showed as few as 18% of patients nationwide had this recommended number resected (Dicken et al., 2005). It is important to stress that the total lymph node harvest identified following surgery is a function of both the extent of the surgical resection and the thoroughness with which the histological specimen is examined by the pathologist (Allum et al., 2011). This supports the importance of treating stomach cancer patients in a facility with a commitment to, and expertise in, their management and a multidisciplinary team approach (Allum et al., 2011; National Health Service Scotland, 2006; Cancer Services Coordinating Group, 2005; Department of Health, 2009; Okines et al., 2010).

**Adjuvant Treatment**

Stomach cancer has a high incidence of recurrence even after ‘curative’ surgery (Dicken et al., 2005; Mercer and Robinson, 2008; Maduekwe and Yoon, 2011) hence there has been increasing interest in adjuvant therapies over the last decades to improve patient outcomes (Dicken et al., 2005; Allum et al., 2002; Allum et al., 2011). Current practice in the West supports the use of neo-adjuvant (pre-surgery) chemotherapy followed by surgical resection and adjuvant (post-surgery) chemotherapy with evidence of significant survival benefit using this treatment approach (Okines et al., 2010; Allum et al., 2011; Abrams and Wang, 2010; Dicle et al., 2005). Adjuvant chemotherapy or adjuvant chemo-radiation is recommended for patients at high risk of recurrence and who did not receive chemotherapy prior to surgery (Allum et al., 2011). Adjuvant chemo-radiation appears to have better acceptance within the treatment pathway in the USA (Allum et al., 2011; Layke and Lopez, 2004).

Preoperative chemotherapy has also been shown to be useful in down-staging patients with locally advanced cancer, thus offering the possibility of a curative resection if the tumour responds well to chemotherapy (Okines et al., 2010). Intra-peritoneal chemotherapy (chemotherapy instilled into the abdominal cavity) for the
treatment or prevention of peritoneal metastases remains experimental (Allum et al., 2011).

**Palliative Care**

With large numbers of patients diagnosed with unresectable or metastatic disease, and a high chance of recurrence after curative treatment, symptom palliation is an important aspect of the overall management of adenocarcinoma of the stomach (Dicken et al., 2005; Mercer and Robinson, 2008). Surgical resection or bypass and external beam radiation can control bleeding, obstruction or pain while radiation can also be used to relieve dysphagia of oesophageal involvement. Endoscopic procedures, such as dilation or stent placement can palliate symptoms of either oesophageal or gastric outlet obstruction (Mercer and Robinson, 2008; Allum et al., 2011; Okines et al., 2010). There is also a role for systemic chemotherapy in the palliation of stomach cancer, with studies showing improved patient quality of life and median survival benefits of up to 10 months over supportive care alone (Dicken et al., 2005; Allum et al., 2011; Okines et al., 2010). There is however no international consensus on which chemotherapy protocol to use as first-line palliation (Allum et al., 2011).

**Comorbidity**

In part due to the combination of risk factors for stomach cancer, such as tobacco use and obesity, along with stomach cancer being a disease predominantly of an older age group, many patients have high levels of comorbid conditions (other conditions as well as the disease of interest) when diagnosed (Koppert et al., 2004; Palser et al., 2009; Sarfati et al., 2014b). Comorbidity is known to impact on the quality of care received by patients and on the likelihood of survival from cancer (Hill et al., 2010a; Lemmens et al., 2005; Sarfati et al., 2009; Sarfati et al., 2014a; Sogaard et al., 2013). As Māori are more likely to have comorbid conditions alongside their cancer than non-Māori (Hill et al., 2010a; Brewer et al., 2011; Swart et al., 2013; Sarfati et al., 2014b) in New
Zealand comorbidity impacts on Māori/non-Māori cancer survival equity (Brewer et al., 2011; Hill et al., 2010a).

Patient comorbidity can either affect cancer survival directly, whereby certain conditions directly impact on prognosis through sheer physiological burden of disease, or indirectly through limiting treatment options or decisions (Brewer et al., 2011; Sarfati et al., 2009; Sogaard et al., 2013). The use of different treatment options due to comorbidity can be clinically indicated; in particular comorbidity limits the ability of many patients with stomach cancer to be treated aggressively with surgery or chemotherapy. Age greater than 75 years and the presence of obesity or heart disease have been significantly associated with post-operative complications after surgery for stomach cancer (Kim et al., 2012; Park et al.; Kubota et al.). Comorbidity and advanced age are also associated with early postoperative mortality after surgical resection of stomach cancer, with some association found up to 90 days post-operatively (van Gestel et al., 2012).

However while a less aggressive treatment approach is often considered in the elderly or comorbid with stomach cancer, a less aggressive approach is not always indicated and may represent under-treatment (Saif et al., 2010). Chemotherapy, for example, is shown to be reasonably well tolerated and effective in controlling disease in the elderly (Kim et al., 2012). A study of 1135 patients, of whom 5% were older than 70 years of age, receiving chemotherapy at one Korean hospital aimed to investigate outcomes associated with receipt of chemotherapy. The study found that, neither age nor level of comorbidity (defined by the Charlson index - mild comorbidity vs. moderate/severe comorbidity) was a significant independent prognostic factor for survival. Rather receipt of surgery, tumour grade and response to first-line chemotherapy were associated with survival (Kim et al., 2012). Thus while each patient should be individually assessed, and treatment decisions and possible complications adequately discussed, neither chronological age alone, nor the presence of comorbidity, is necessarily sufficient reason to withhold treatment (Saif et al., 2010; Park et al., 2013; Kim et al., 2012).
Management and Treatment Guidelines

Up until December 2013 New Zealand did not have guidelines to inform clinical practice or the level of service provided to patients with cancer. However recognising the need for nationally coordinated and consistent care for cancer, the Ministry of Health (through working groups and expert advisors) developed national service provision standards for a number of key cancers, including for upper GI and hepatobiliary cancers (National HBP/Upper GI Tumour Standards Working Group, 2013). These are however management, rather than clinical, guidelines (National HBP/Upper GI Tumour Standards Working Group, 2013).

A number of countries do have clinical guidelines, principally countries of the West and those Asian countries with particularly high incidence of the disease. The key guidelines are listed in the table below (Table 1). As discussed earlier there are controversies in the treatment and management of stomach cancer which tend to differ primarily between Asian and Western countries. For example there are significant differences in the management and treatment of stomach cancer in Japan, the country with the highest incidence rates worldwide, over that of Western countries. Controversy surrounds indications for treatment of early stomach cancer, the surgical approach taken and the extent of lymph node dissection. Also, until recently the Japanese Gastric Cancer Association had its own staging system for stomach cancer preventing accurate comparison between studies carried out in Japan to those carried out in the West (Dicken et al., 2005).

Table 1: International stomach cancer treatment or management guidelines

<table>
<thead>
<tr>
<th>Country</th>
<th>Year</th>
<th>Guideline name</th>
<th>Guideline focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>2009</td>
<td>South Australia Upper Gastrointestinal Cancer Care Pathway (Department of Health, 2009)</td>
<td>Clinical and Service Guidelines for oesophageal and stomach cancer, includes consideration of Aboriginal and Torres Strait Islanders</td>
</tr>
</tbody>
</table>
Commonalities seen in Guidelines

As already mentioned there are significant differences in the management and treatment of stomach cancer in Japan when compared to Western countries. The following section highlights the commonalities regarding the management of stomach cancer in guidelines from the West only.

| United Kingdom | 2002, 2011 | Guidelines for the management of oesophageal and gastric cancer (Allum et al., 2002; Allum et al., 2011) | Clinical Guidelines for oesophageal and stomach cancer |
| Wales          | 2005       | National Standards for Upper Gastro-intestinal Cancer Services (Cancer Services Coordinating Group, 2005) | Service Standards for oesophageal, stomach pancreatic and hepatobiliary cancers |
| Europe         | 2010       | Gastric cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up (Okines et al., 2010) | A shorter clinical guideline on stomach cancer aimed at the medical oncology community |
| USA            | 2006, 2010 | Gastric Cancer Clinical Practice Guidelines in Oncology (TM) (Ajani et al., 2010) | Clinical Guidelines for stomach cancer only |
| Japan          | 2001, 2010 | Japan Gastric Cancer Association: Gastric cancer treatment guidelines (Japanese Gastric Cancer Association, 2011) | Clinical Guidelines for stomach cancer, not originally published in English |
| Japan          | 2008       | The Japanese guidelines for gastric cancer screening (Hamashima et al., 2008) | Screening guidelines for stomach cancer |
**Diagnosis, Staging and Treatment**

In all Western guidelines, upper GI endoscopy is the procedure of choice to diagnose cancer of the stomach, while CT, endoscopic ultrasound and laparoscopy, used in combination, are recommended to provide the most accurate pre-operative staging information (Allum et al., 2011; National Health Service Scotland, 2006).

Surgical resection is regarded as the mainstay of treatment in all countries. All resections are recommended to be carried out in high volume specialized units by experienced Upper GI surgeons (Allum et al., 2011; National Health Service Scotland, 2006; Cancer Services Coordinating Group, 2005; Department of Health, 2009). The UK also recommends that surgeons and surgical units should be audited against national standards (Allum et al., 2011).

The use of Upper GI Cancer Nurse Specialists is commonplace within the management of patients with stomach cancer in some countries (Allum et al., 2011; Department of Health, 2009).

**Multidisciplinary Teams**

The guidelines of the West have advised that treatment decisions for patients with stomach cancer should be carried out in the context of multi-disciplinary team meetings (MDM) since at least 2002 (Allum et al., 2002). It is proposed that MDM comprise endoscopists, surgeons, medical and radiation oncologists, gastroenterologists, radiologists, pathologists and upper GI nurse specialists and that the team takes note of all available clinical information, the patients co-morbid conditions and general nutritional status, along with patient preference in their decision making. The MDM should also have access to supporting services such as the primary health care team, psycho-oncology, social work and allied health professionals (Allum et al., 2011; National Health Service Scotland, 2006; Cancer Services Coordinating Group, 2005; Department of Health, 2009; Okines et al., 2010).
**Timeliness of Treatment**

Timeliness of treatment, where discussed, focuses more strongly on the initial phase of the patient journey. Both the UK and Australia recommend that patients at high risk of upper GI malignancy should have fast-tracked access to endoscopy investigation; this should be carried out within two weeks from initial presentation (Department of Health, 2009; Allum et al., 2011). Once diagnosed, Australian guidelines recommend that staging investigations be completed within two weeks and initial consultation with a cancer specialist should also occur within two weeks (Department of Health, 2009). Following the initial consultation discussion regarding the patient at MDM should take place no later than 42 days after initial presentation (Department of Health, 2009). Wales recommends that definitive treatment should start within two months from receipt of referral at the hospital (Cancer Services Coordinating Group, 2005).

**Summary of Stomach Cancer**

Stomach cancer, is a cancer that arises in the cells that form the innermost lining of the stomach. It is the fourth most commonly diagnosed cancer worldwide and one of the most common causes of cancer mortality. There is wide geographical variation in both incidence and mortality rates, with ten-fold difference between high-risk and low-risk populations noted, primarily due to different prevalence rates of infection with H. pylori and associated incidence of distally located tumours. Stomach cancer rates worldwide have declined over the last 50 years but there has been a notable change in tumour site (a ‘proximal migration’) over recent decades, due to different risk factors for tumours located within different sub-sites of the stomach.

Adenocarcinoma of the stomach is curable, if it is diagnosed at an early stage. However, many patients are diagnosed at an advanced stage and most countries report overall five-year survival rates between 10% and 30%. Surgery is the mainstay of curative treatment but there remains ongoing debate regarding overall surgical management. This debate is especially centered on the extent of lymph node
dissection to be carried out, with general consensus in the West being that at least 15 nodes should be resected. There has been a growing role for chemotherapy with curative intent, with and without radiotherapy, over the last few decades. Palliative care is an important part of overall patient management for stomach cancer.

At the time that patients involved in this study were diagnosed and treated, New Zealand had no guidelines to inform clinical practice. Service delivery standards intended to enable nationally coordinated, and consistent care, have been developed during the time of writing (National HBP/Upper GI Tumour Standards Working Group, 2013).
The Structural and Institutional Mechanisms of Inequity

In order to minimise inequities we must first have insight into the mechanisms by which they arise and are perpetuated. Rather than blame Māori for their disadvantaged health status this thesis focuses attention on the structural and institutional mechanisms that drive the disadvantage. Much of the stomach cancer inequity seen in New Zealand today can be attributed to the social and economic position of Māori in current New Zealand society. This position has been constructed by the shared histories of a predominantly British immigrant population and the indigenous Māori. As with other indigenous people throughout the world, Māori have borne the brunt of colonisation.

In essence, colonisation permits the (mis)appropriation and transfer of power and resources from indigenous peoples to the newcomers. This process of transfer is enabled by layer upon layer of new systems established to determine how resources will be obtained and how they will be redistributed and to whom. These systems, therefore, construct who will benefit and be privileged (Robson and Harris, 2007a).

The Treaty of Waitangi

The Treaty of Waitangi is recognised as New Zealand’s founding document (Boulton et al., 2004; Orange, 2011). The Treaty was an agreement between the Crown and Māori, offering peaceful settlement rights to the British in return for the Crown’s protection. When the Treaty was signed in 1840 Māori had a strong tribal identity and communal economy, reliant on the land on which they lived with sophisticated public health and law and order systems (Durie, 1998; Orange, 2011). Life expectancy for Māori was estimated to be about the same as that of their European equivalents, around 30 years (Reid, 1999b).
For the British, the Treaty was to serve three primary needs: legal (to prove New Zealand's changed status to that of a British colony), diplomatic (to give British subjects entitlement to settle peacefully in New Zealand), and humanitarian (appeasing groups in Britain who were becoming increasingly concerned about the treatment of indigenous people worldwide) (Orange, 2011).

The motivation for Māori to sign the Treaty is less clear. What is clear is that the Māori response was not universal, with some Chiefs refusing to sign the Treaty at all. It appears though that Māori hoped to gain British protection of their country against claims by other nations. Māori were especially distrustful of the French due to a previous massacre in 1772 (Orange, 2011). They also wanted some control of British settler’s land purchases and Pākehā lawlessness; now British law would govern the British people. Māori expected an increase in trade, Māori were already proficient traders and though collective efforts dominated key sectors of New Zealand economy for some time after signing the Treaty. They wanted protection of, but control over, their lands, mana and customs. They saw shared authority, a partnership and participation by Māori and the British. They did not intend to hand over all rights of sovereignty to the British people or British Crown (Orange, 2011).

The Treaty was written by a Crown representative with no formal legal training and translated into Māori by missionaries. Unfortunately there were substantial differences between the English and Māori texts (Orange, 2011). These differences remain the focus of much debate today (Boulton et al., 2004). The Treaty allowed for British governance, provided guarantees to Māori relating to property rights, conferred citizenship rights on individual Māori people and, in the Māori version at least, allowed for continued tribal authority (Durie, 2005). Central to the Treaty was the establishment of government, a government that looked after and protected all of its citizens (Reid, 1999a). Initially the aims of the Treaty were heeded by the Crown. Yet the Treaty was increasingly marginalised as the years went on and in 1877 the Treaty was declared ‘a simple nullity’ in a court of law and abandoned by the Crown and its entities (Durie, 2005; Orange, 2011). It was to be another 100 years before the
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Treaty would be written into New Zealand legislation and again formally considered by the Crown (Orange, 2011).

Colonisation

The signing of the Treaty of Waitangi marked the beginning of a formal relationship between Māori and their British colonisers. In reality, it was through a combination of this Treaty along with processes of colonisation that the sovereignty of New Zealand moved from the hands of Māori into the British Empire (later Commonwealth) (Orange, 2011; Durie, 1998). These processes of colonisation included: settler occupation, depopulation of Māori via the introduction of firearms and diseases, policies of assimilation, land acquisition, the use (or misuse) of parliamentary representation to ensure Māori had no voice in the making or administration of law and organised military suppression of Māori resistance (Orange, 2011; Durie, 1998; Koea, 2008). Throughout this time new systems and institutions were established, based on British models, which determined how the resources of Aotearoa New Zealand were obtained and distributed and in which Māori interests were often excluded or marginalised (Sinclair, 2000; Orange, 2011; Ministry for Culture and Heritage, 2014; Pihama et al., 2004).

The consequences of the processes of colonisation left Māori as the minority population, displaced from their land, their culture and their language and with little sway over how colonial New Zealand was administered (Orange, 2011; Durie, 1998). Unsurprisingly inequities existed between Māori and non-Māori and Māori health suffered (Durie, 1998).

The Modern Welfare State

New Zealand's welfare state was introduced in the 1930s, partly in response to the ‘great depression’ of previous years (Belich, 2001). It provided tax funded income support for those unable to support themselves, subsidised housing to those in need
and free education and health systems, although secondary not primary care (O’Brien, 2008). Modern New Zealand society, at least Pākehā society, was built on values of democracy, equality, full employment and an interventionist state with universal state assistance for those in need. In fact, until the neoliberal reforms of the 1980s and 90s markedly changed New Zealand society, the government intervened in nearly all aspects of New Zealanders’ lives: housing, health, education, finance, transport, telecommunications, forestry, farming and more (Bassett, 1998; Boston, 1999; O’Brien, 2008).

While not targeted toward Māori this state intervention was generally good for all New Zealanders, including Māori. Mortality trends, including infant mortality and life expectancy are useful ways of measuring the health status of a population overall and in determining equity between groups within that population. Between the 1940s and 60s the life expectancy of the New Zealand population overall rose steadily and a sharp reduction in the difference between Māori and non-Māori mortality occurred (Woodward and Kawachi, 2000). Life expectancy for Māori increased so rapidly over this time that up until the early 1980s the gap between Māori/non-Māori life expectancy was closing (Ajwani et al., 2003). Infant mortality rates dropped markedly for Māori from 94 per 1000 live births in 1929 (Durie, 2001) to 18.4 per 1000 in the early 1980s (Pōmare et al., 1995). Despite this dramatic reduction, Māori infant mortality remained high compared to the non-Māori rate of 11.4 per 1000 in the early 1980s (Pōmare et al., 1995).

**Urbanisation**

Urbanisation, following the World Wars, created immense social dislocation among Māori. Whānau ties were broken and many Māori became further alienated from their land and culture (Durie, 1998). Before World War II, over 80% of Māori were living in rural areas, primarily within their own tribal districts; however following World War II Māori migrated to the cities in large numbers. With little Māori-owned land left Māori were increasingly reliant on wage-based labour to survive, at the same
time employment opportunities were becoming centralised in major cities (Te Ahu Poata-Smith, 2013). This relocation was though also due to explicit government policy; after the 1961 Hunn Report made recommendations on social reforms for Māori the relocation of Māori in cities became official policy (Durie, 1998; Orange, 2011). However, employment opportunities for Māori were often limited to low-paying blue-collar jobs and they lived in poor quality overcrowded houses in communities often separate from those in which Pākehā lived. Although the prevailing view by Pākehā was one of a class-less New Zealand, compared to non-Māori Māori occupied a relatively impoverished and peripheral place in New Zealand society (Te Ahu Poata-Smith, 2013).

Māori Resurgence

During the 1970s and 80s Māori development was gaining momentum and the Treaty of Waitangi was elevated in New Zealanders thinking (Reid, 1999b). Māori women and health workers were becoming better organised. Holistic Māori models of health were being developed by Māori, moreover they were acknowledged in mainstream services (Durie, 1998). Māori language nests or Kohanga Reo were established helping to not only improve participation rates of Māori in early childhood education but also to revive the Māori language (Durie, 2001). Although initially established with ‘limited power’ the Waitangi Tribunal was set up in response to Māori demands for reparation for land-loss and began to restore resource to Māori communities (Orange, 2011). Māori protests were heard throughout the country; most notably the 1975 Hikoi or Land-March and the 1977 occupation of Bastion Point. Gone were the ‘Pākehā’ perceptions of harmonious race relations and an absence of class based inequity. Mainstream New Zealand was at last beginning to hear Māori dissent about the Treaty of Waitangi and its broken promises (Orange, 2011).
Neo-Liberalism and Market-based Reforms

It is said that "the fourth Labour Government came into office in 1984 with a greater commitment to the Treaty of Waitangi than any Government previously" (Durie, 1998: 88). The Waitangi Tribunal was given the power to consider historical claims, those going back until 1840, not only contemporary claims as originally directed to do (Orange, 2011). State departments were required to consult with Māori and consider applications for the Treaty in all legislation (Durie, 1998). The Department of Health was one of the first to respond by establishing Māori health as a priority, including Māori viewpoints in its policy and by forming Māori specific teams and committees. The 1988 Treaty principles recommended by the Royal Commission on Social Policy, those of partnership, participation and protection, better enabled the application of the Treaty in practice. Still, a gap persisted between recognition of the Treaty and its translation into performance indicators, outputs and Māori health gain (Durie, 1998).

Structural Readjustment

The fourth Labour Government also inherited a country that had long been living beyond its means (Kelsey, 1995). So in 1984 an exercise began to change the involvement of the state in most aspects of New Zealand life, "one hundred and forty-four years of interventionism had run its course"(Bassett, 1998: 14).

Informed by the Washington consensus for structural adjustment and driven by neoliberal ideology, New Zealand went from being one of the most regulated and interventionist countries within the 34 Organisation for Economic Cooperation and Development countries (OECD) to one of the most deregulated and privatised, all within a timeframe of less than two decades (Kelsey, 1995). Control of inflation was given priority over all policy decisions; the finance sector was deregulated, the New Zealand dollar floated, tariffs on imports reduced and subsidies to domestic industries removed. State owned enterprises were downsized or turned into commercial ventures. Foreign investment was encouraged with many former state owned
enterprises and existing companies bought by international enterprises. The labour market was restricted. The vision of creating economic growth and employment in fact brought restructuring, loss of jobs and services and profits leaving the country. Compounding this, the income tax system was flattened, a regressive consumption tax (GST) introduced, user charges introduced for health and education, government benefits cut and more strictly targeted and market rentals introduced for state housing (Kelsey, 1995; Belich, 2001).

The impacts of these free-market policies were not however evenly distributed throughout New Zealand society. In response to the changes so rapidly imposed upon New Zealand, Māori leaders at Hui Taumata (Māori Economic Summit) in 1984 predicted that “Māori will be the shock absorbers of the economy” (Blakely et al., 2004). These fears were borne out.

**Māori Inequity**

In conjunction with these economic and social reforms throughout the 1980s and 90s, New Zealand also experienced the fastest increase in income inequity of any OECD country (Woodward and Kawachi, 2000). While income inequities were seen, up until 1984 the divide between rich and poor was not conspicuous. That situation changed markedly under neoliberal ideology though, impacting most heavily on Māori. Māori were overrepresented in the job sectors where most job losses occurred (Kelsey, 1995). Between 1986 and 1990 the unemployment rate for Māori increased from 8.5% to 20.6%. The corresponding rate from non-Māori rose from 3 to 6.5% (Reid, 1999a).

Employment did not necessarily provide a buffer though with the spending power for the wealthiest 20% of New Zealand’s employed rising by 7% between 1987 and 1992. At the same time it fell by 2.9% for the poorest 20%, the section of society where Māori were more highly concentrated (Kelsey, 1995). By 1996 Māori were much more likely to be economically deprived with an average income less than 80% of the New Zealand average. Household income was also affected with Māori more likely to
be living in a household whose income was within the lowest 20% (28% Māori versus 17% European) and less likely to be living in households in the top 20% (9% Māori versus 21% European) (Howden-Chapman and Tobias, 2000). Moreover, during this time inequity between Māori and non-Māori widened in all areas that are considered to be key underlying determinants of health; not only employment and income but also indicators of educational attainment and healthy housing (Howden-Chapman and Tobias, 2000).

Māori Health Inequity

Not surprisingly Māori health was also affected over this time. Māori life expectancy, which had been rising rapidly and converging with the non-Māori rate up until the 1980s, began to plateau while non-Māori continued to experience increases in life expectancy (Ajwani et al., 2003). From the 1980s the gap between Māori and non-Māori for this important population health indicator began to widen as did inequities in mortality from ischaemic heart disease, diabetes, chronic lung diseases and a number of cancers (Ajwani et al., 2003). In a telling indicator of increasing ‘social disease’, suicide rates rose markedly over the 1980s and 90s, especially among young Māori men. Where previously 25 – 44 year old Māori men were 22% less likely than non-Māori to commit suicide, by 1996 – 99 they were 70% more likely to (Ajwani et al., 2003). In fact suicide rates rose so much that by the 1990s New Zealand was experiencing some of the highest rates in the OECD (Kelsey, 1995). As summed up by Reid (Reid, 1999a: 93) “Premature death is the ultimate cost for being on the losing side of social change”.

Restructuring the Health System

The health system was also significantly restructured during this period of economic and social reform. It underwent four major changes within 20 years. The health reforms of 1993 outlined in the Health and Disability Services Act, were “.... One of
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the most radical health sector restructurings witnessed anywhere in the world” (Gauld, 2001: 79). The system from 1993 until 1996 was characterised by a purchaser and provider split. There were expectations on the health system to run as a business and return profits to the Government. Government appointed boards replaced formerly elected ones. Board members and Chief Executive positions were populated by businessmen, often with little health sector experience (Gauld, 2001; Cumming and Mays, 2002). The education and social housing systems underwent similar commercialisation reforms (Te Ahu Poata-Smith, 2013).

While the focus of the health reforms was on fiscal restraint rather than improved health outcomes, one arena where Māori were able to gain traction over the time of the purchaser/provider split and contestable contracts was that of primary health care delivery (Reid, 1999b; Cunningham and Durie, 1999). The number of Māori providers increased quickly from just 30 in 1993 to over 200 in 1997 (Cunningham and Durie, 1999). Although limited by issues such as instability of contracts, lack of consistent policy, changing personnel in government agencies, varying approaches to Māori health around the country and still receiving a very small amount of the health budget, the growth of ‘by Māori for Māori’ providers offered a real opportunity to address Māori health issues in ways likely to be acceptable to many Māori (Cunningham and Durie, 1999).

Personal Responsibility

Another feature of this era of neo-liberalism was the moving of political attention from population health to individual health, from public health to private medicine. Health in effect became an individual responsibility where people were blamed for their ill-health. Differences in health were attributed to ‘self-inflicted lifestyle choices’ (Durie, 1998). Mainstream media supported the view “… with an editorial that described the first cause of poverty as ‘a culture of personal irresponsibility’” (Kelsey, 1995: 380). The 2003 report Decades of Disparity (Ajwani et al., 2003) clearly outlined health inequity between Māori and non-Māori and highlighted a widening gap in life
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expectancy over the time of significant social and economic reform in New Zealand. Media coverage however framed the reasons as poor choices and behaviours by Māori, portraying Māori as responsible for their own ill-health (Hodgetts et al., 2004). Public discourse largely concurred, and continues to concur with this view, ignoring the histories of Māori and non-Māori in New Zealand and the influence of these histories on Māori and their access to the underlying determinants of health (Nairn, 2011; Nairn et al., 2014; Rankine et al., 2014). And despite stark evidence of Māori/non-Māori inequity public discourse also often expounded the view that Māori are ‘privileged’ and that they ‘benefit’ from Treaty settlements and targeted initiatives intended to close gaps between Māori and non-Māori (Te Ahu Poata-Smith, 2013).

Summary of the Mechanisms of Inequity

Māori have suffered greatly through the impacts of colonisation. Deliberate policy decisions leading to loss of Māori control and authority, loss of language, loss of identity as Māori and cultural breakdown, social dislocation from loss of land and urbanisation, alienation from physical resources, limited access to society’s wealth and organised oppression all combined to make Māori vulnerable (Orange, 2011; Durie, 1998). The position of Māori was then compounded through neoliberal policies applied by successive governments from 1984 through the 1990s (Te Ahu Poata-Smith, 2013; Kelsey, 1995). Widening inequities between Māori and non-Māori were a predictable outcome of the neoliberal reforms initiated in New Zealand from 1984. Inequity between Māori and non-Māori widened in all areas considered to be underlying determinants of health as a consequence of the reforms of the 1980s and 1990s (Kelsey, 1995; Reid, 1999a). Not surprisingly Māori health also suffered (Blakely et al., 2004).
The Position of Māori and non-Māori in Current Society

According to the 2013 census (Statistics New Zealand, 2014) the total population of New Zealand has surpassed 4.5 million, with Māori comprising 598,602 or 14.9 percent. New Zealand Europeans remain the majority population at 68 percent although there are sizeable Asian (12%) and Pacific Island (7%) populations. Māori are a youthful population; their median age at 23.9 is significantly lower than that of New Zealand Europeans at 41 years, or the total non-Māori population at 38 years. Most New Zealanders live in urban centres with over 65 percent of both Māori and non-Māori living in urban areas (Statistics New Zealand, 2014). Māori are more likely to live in minor urban or rural areas (Robson and Harris, 2007a), especially in Northland or the east coast of the North Island. English is the most commonly spoken language but over 20 percent of Māori also speak Te Reo (the Māori language) (Statistics New Zealand, 2014).

However Māori today continue to be significantly disadvantaged in New Zealand society – a pattern which holds true in educational attainment, employment, income and housing, all of which are considered underlying determinants of health (Craig et al., 2014; Commission on Social Determinants of Health, 2008; National Health Committee, 1998). In turn, Māori are ultimately disadvantaged in most indicators of health (Robson and Harris, 2007a; Durie, 2001).

Educational Attainment

Māori are now more likely to participate in education at all levels (Robson and Harris, 2007a). Through the development of Kohanga Reo, Kura Kaupapa and Wānanga a Māori-focussed total immersion education is possible, from early childhood through to tertiary level. Despite the achievements of Māori-based education the majority of Māori continue to access their education through mainstream services which fails to
achieve equitable results for Māori (Robson and Harris, 2007a). The 2013 census showed that 66.7% of Māori (aged 15 years and over) had some sort of a formal qualification. While this was an increase from previous years it remains lower than the 78.7% of New Zealand Europeans who had a formal qualification. At a higher level, 10% of Māori had a Bachelor’s degree or higher compared to 20% of the total population (Statistics New Zealand, 2014). In other indicators such as school retention rates, unjustified absences, and numbers of suspensions or expulsions Māori do poorly compared to non-Māori. Clearly the education system does not meet the needs of Māori (Craig et al., 2014). Level of educational attainment is an important determinant of health as it is a critical precursor to future employment and occupational status and thus to level of income. Evidence suggests that people with university qualifications earn 62% more over their lifetime than those who don’t have university qualifications (Robson and Harris, 2007a).

**Employment and Income**

Māori are much more likely to be unemployed with an unemployment rate of 15.6% compared to 5.4% of New Zealand Europeans. Māori youth are particularly burdened with less than half of 15 – 29 year old Māori employed (Statistics New Zealand, 2014). Uptakes of the domestic purposes, sickness and invalids benefits are all higher for young Māori relative to non-Māori (Craig et al., 2014). When employed Māori remain more likely to be in low-paid occupations and experience discrimination in the labour market in a number of ways: getting a job, the type of job gained and in wages paid (Robson and Harris, 2007a).

Correspondingly the income gap between Māori and non-Māori remains sizable. The median income for Māori adults (15 years and older) in 2013 was $22,500 compared to $30,600 for New Zealand Europeans (Statistics New Zealand, 2014). Māori are much more likely to live in a household in the lowest income quintile (25% compared to 12% of non-Māori). Children are particularly affected. In 2004, 27% of Māori children were living in poverty (defined as a household income below 60% of the
median, after housing costs) compared to 16% of European children (Robson and Harris, 2007a). Child poverty appears to be worsening, especially for Māori. By 2010 – 2012 (using the same measure as above) 34% of Māori and 17% of European children were living in poverty (Craig et al., 2014).

Although income inequity between Māori and non-Māori in New Zealand fell between 2004 – 2007, in part due to the ‘Working for Families’ tax credits, it has begun to increase again since (Craig et al., 2014). The Working for Families package has however been criticised for disadvantaging Māori children. Working for Families is a ‘Welfare to Work’ policy which excludes beneficiary families, yet in today’s unstable job market Māori are more likely to be beneficiaries (Robson and Harris, 2007a). In another area of disparity, as Māori have lower levels of asset wealth than non-Māori they are more reliant on wage income for financial security and thus are doubly disadvantaged by differential employment and income (Robson, 2008).

Māori figure highly in criminal justice statistics. There is however also evidence of discrimination in the justice system. For example more Māori are referred to the youth court rather than for family intervention for minor offences and have higher rates of conviction than non-Māori despite similar offending records and socioeconomic backgrounds (Robson and Harris, 2007a).

**Housing**

Housing is also an important determinant of health with household crowding, poor housing conditions and insecure tenure all shown to impact on one’s level of wellbeing (Robson and Harris, 2007a). In 2013 only 28.2% of Māori stated that they owned or partly owned the home that they lived in. Fifty-three percent of Māori lived in rental accommodation with a significant proportion of them (20%) having the government as their landlord through Housing New Zealand (a Crown agency that provides housing for New Zealanders in need). In comparison 57.4% of New Zealand Europeans owned their own home and of those that rented only 7.5% had Housing New Zealand as their landlord (Statistics New Zealand, 2014). Māori face
discrimination in the housing market, both when renting and when buying houses (Harris et al., 2006a).

Household crowding is also unevenly distributed in New Zealand with children and Māori much more likely to live in crowded housing than adults or non-Māori (Baker et al., 2012). 2006 Census data shows that 22.8% of Māori lived in crowded conditions compared to just 4.7% of European/Other. Māori children are further exposed, with 10.1% Māori children younger than five years living in extremely crowded conditions versus only 1.9% of European/Other. In other words Māori children are five times more likely to be living in conditions that contribute to poor health, not only in childhood but throughout their lifetime (Baker et al., 2012). Māori children are doubly impacted by socioeconomic status as the proportion of children living in crowded households increases as each level of deprivation increases, with the highest rates in the most deprived households (Craig et al., 2014). Additionally, the relative differences in household crowding between Māori and European New Zealanders have increased over time (Baker et al., 2012).

Health

As shown above the social and economic position of Māori in today’s society is different to that of non-Māori. Māori are predominantly disadvantaged, non-Māori are advantaged. Given the unequal exposure between Māori and non-Māori to the upstream determinants of health the most pronounced inequities in health and health outcomes seen in New Zealand today are those between Māori and non-Māori. According to Durie (Durie, 2005) there is considerable evidence that structural causes account for health inequities. Furthermore much of the burden of ill health experienced by Māori is not only preventable; it breaches the human right to good health. It is also costly; not only to the health system, but to society as a whole (Craig et al., 2014).

Māori are more likely to be obese than their non-Māori counterparts. In 2011 – 2013 one in five Māori children and two in five Māori adults were obese, twice as many as
non-Māori despite similar levels of physical activity (Ministry of Health, 2013c). Food security (having enough nutritionally adequate food for a healthy life at all times) is much poorer for Māori with only 34.8% of Māori identified as being of fully or almost fully food secure compared with 64.2% of New Zealand Europeans (Stevenson, 2012). In keeping with the finding that Māori have poorer food security they are less likely than non-Māori to eat the Ministry of Health recommended three serves of vegetable or two serves of fruit a day (Ministry of Health, 2013c).

Māori adults are twice as likely to smoke relative to non-Māori (Ministry of Health, 2013c). Findings of the 2013 census showed 32.7% of Māori 15 years and over were regular smokers versus 14.1% of New Zealand Europeans. Māori women continue to have the highest rates of smoking at 34.7% (Statistics New Zealand, 2014). Unsurprisingly second-hand smoke and maternal exposure is also higher for Māori children (Craig et al., 2014).

Immunisation coverage rates for Māori children are lower than those of non-Māori. Well child visits (Government funded home visits by registered nurses for babies in the early weeks, and then clinic or further home visits for children up to 5 years old) for Māori babies are less than those of non-Māori (Craig et al., 2014). Admissions for injuries arising from assault in Māori infants 0 – 4 years old and Māori young people are significantly higher when compared to non-Māori. Alcohol related hospital admissions are significantly higher for young Māori than young non-Māori. Both self-harm and suicide mortality rates are also significantly higher in Māori youth compared to non-Māori (Craig et al., 2014).

Currently Māori have an 8-9 year lower life expectancy than non-Māori and experience differential incidence and outcomes across most major chronic diseases, cancers, infectious diseases, and injuries (Harris et al., 2006b; Robson and Harris, 2007a). Many of these gaps exist even after controlling for factors such as level of deprivation and health care access, so no matter their occupation, level of income or education Māori have poorer health status than non-Māori. What is more, not only is Māori health worse than that of non-Māori at all levels of deprivation, the inequities
between Māori and non-Māori increase as level of deprivation increases (Ajwani et al., 2003; Jansen et al., 2008).

One consequence of the unequal distribution of the determinants of health is that Māori today have much higher exposure to the risk factors for developing stomach cancer, key of which are poverty and subsequent household crowding leading to an increased prevalence of H. pylori infection, tobacco smoking and poor diet. It follows then that Māori also have a much higher incidence of stomach cancer than their non-Māori counterparts. Māori are also less likely to survive their stomach cancer once diagnosed (Soeberg et al., 2012) with evidence of poorer access to and through health and cancer services (Cormack et al., 2005). Cancer survival and health care access are discussed in the following chapters.

The Role and Significance of the Treaty of Waitangi for Current Māori Health

Although it was written and signed in 1840 the Treaty of Waitangi has considerable relevance in today's society. While it is a product of British ideology regarding ‘aboriginals’ of its time (Reid, 1999a), it is also referred to as an agreement written for the future (Durie, 1998). The Treaty speaks to the rights and responsibilities of the New Zealand government (as the successor to the Crown). It has implications for health and health policy today, especially policies regarding access to the underlying determinants of health, the role and accessibility of health services and health equity between Māori and non-Māori.

In 1998 a key government report identified social, cultural and economic factors as the main underlying determinants of health for New Zealanders (National Health Committee, 1998). These factors, most important of which are income and poverty, also include employment, education, housing, access to culture and social cohesion. These social, cultural and economic factors have a causal relationship to health by influencing exposure and vulnerability to health risks (Commission on Social Determinants of Health, 2008; Craig et al., 2014). For example health-damaging
behaviours such as tobacco smoking are more common among low socioeconomic groups as is a higher likelihood of working within unsafe working conditions or living within unhealthy housing (National Health Committee, 1998). As previously outlined, through breaches of the Treaty and the process of colonisation Māori were left with uneven access to the resources and opportunities of New Zealand society. This differential access was then compounded by the market-based reforms of the 1980s and 90s which disproportionately affected Māori communities in further breach of the Treaty’s promises.

Just as the determinants of health can be negatively impacted on by policy decisions they can also be positively impacted on by government policy. The New Zealand government has an obligation to address historical Treaty breaches and to ensure current policy enables Māori to participate equally in the benefits of New Zealand society and so reduce health inequity (Baragwanath, 2006). Today the Treaty is recognised within New Zealand legislation (New Zealand Parliament, 2000; New Zealand Government, 1988; New Zealand Government, 1987). The Waitangi Tribunal (a permanent commission of inquiry) is helping to redress current and historic Treaty breaches (Stokes, 1992; Shoebridge and Tribunal, 2012) and the Treaty been interpreted and applied within key government policy (King, 2000; King, 2001; Ministry of Health, 2002b), in particular social and health policy (Barrett and Connolly-Stone, 1998; Pōmare et al., 1995; Oda and Rameka, 2012).

The Treaty also has relevance for the accessibility of health services and their role in addressing the health needs of Māori (Pōmare et al., 1995). In keeping with the principle of tino rangatiratanga (or self-governance) Māori governed health services have improved access to services for many Māori, particularly in the primary health setting (Cunningham and Durie, 1999). Still the majority of Māori access their health services through mainstream providers (governed by New Zealand government and its entities) (French et al., 2001), this is especially so for cancer treatment services which are primarily delivered through mainstream hospitals and clinics. In order to address the health needs of Māori these services need to ensure they are accessible and culturally safe for all New Zealanders - not just the dominant Pākehā population.
Despite a higher awareness of the Treaty in contemporary New Zealand its place in society has remained contentious since its signing, at times many Pākehā (including judicial courts and the New Zealand Government) have ignored the Treaty or breached its guarantees (Orange, 2011). Māori however see the Treaty of Waitangi as the basis of their partnership with the State; a binding agreement between tangata whenua and the Crown (Reid, 1999b; Durie, 1998; Orange, 2011). Article Three of the Treaty guarantees Māori equity with British subjects. That equity has been interpreted as equity of resource control, equity of representation and participation in society and equity of health outcomes (Reid, 1999b; Pōmare et al., 1995; Barrett and Connolly-Stone, 1998). Quite clearly Māori have not shared equitably in New Zealand society over the years since signing the Treaty. Nor do they now.

**Summary the Position of Māori in Current Society**

Māori today comprise nearly 15% of New Zealand’s population with Europeans the majority ethnic group. Māori are on average younger (Statistics New Zealand, 2014) and are more likely to live in minor urban or rural areas (Robson and Harris, 2007a) than New Zealand Europeans. The Treaty of Waitangi remains the founding document of New Zealand and while article three guarantees that Māori will share equally in society quite clearly Māori do not share equally, or equitably, in current New Zealand society. Māori today live in social disadvantage with differential access to the underlying determinants of health. Māori are more likely to face discrimination in the labour (Robson and Harris, 2007a) and housing markets (Harris et al., 2006a). They experience differential outcomes in education (Statistics New Zealand, 2014; Craig et al., 2014), employment (Statistics New Zealand, 2014; Craig et al., 2014), justice (Robson and Harris, 2007a) and housing (Statistics New Zealand, 2014; Baker et al., 2012). Māori also have poor health relative to non-Māori New Zealanders (Robson and Harris, 2007a; Ministry of Health, 2013c; Harris et al., 2006b). They are disproportionately impacted on by a large number of diseases, including stomach cancer.
The New Zealand Health Care System

New Zealand’s political, economic and social systems, including its health care system, were built on a British model (French et al., 2001) that mainstreams Pākehā and requires non-Pākehā to adapt to its language, culture and protocols. New Zealand’s health care system is primarily one of universal access. However it is characterised by a publicly funded hospital sector with a government subsidised but private fee-for-service primary health care sector (French et al., 2001). This structure can lead to low use of primary health services and a correspondingly high use of secondary services, especially for Māori (Durie, 1998). Additionally there is much evidence outlining differential access to, and quality of care for, Māori across all parts of the health system, including cancer care - which will be discussed in a later chapter. The section below provides a brief overview of the current structure of the health care system in New Zealand and outlines the key strategies relevant to Māori health and cancer control.

The Funding and Delivery of Care

Health care in New Zealand is funded and organised by an interrelated network of organisations. Nationally the Ministry of Health provides advice to the Minister of Health on health issues, develops policy and works with other government agencies to implement those policies (Ministry of Health, 2013d). Recently a National Health Board has been established as an independent body, although sited within the Ministry of Health, to monitor, fund and organise New Zealand’s 20 district health boards (DHB) and to service a National Health IT Board and Health Workforce New Zealand (Gauld, 2012; Ministry of Health, 2013d). Other national organisations include PHARMAC, a national drug purchasing agency, a Health Quality and Safety Commission and an independent National Health Committee that carries out comparative-effectiveness research (Gauld, 2012).
Health care delivery in New Zealand is primarily a mix of publicly and privately funded mainstream providers, along with non-government organisations (NGOs). Around 81% of health services are publicly funded with general taxes contributing around 88% of this cost with New Zealand’s accident compensation scheme (ACC) and local government comprising the remainder. Private co-payments are required for primary care services and pharmaceuticals while patients bear the full-cost of privately provided dentistry, elective surgical and allied services. Private health insurance tends to provide supplementary rather than comprehensive cover and is held by 35% of the population (Gauld, 2012). The proportion of New Zealanders holding private health insurance differs by ethnicity with coverage in Māori about half of that of non-Māori (Ministry of Health, 2008). Medical insurance cover also decreases with increasing deprivation (Ministry of Health, 2008). New Zealand spends (USD) $2983.00 per capita per annum on health well below the OECD average of (USD) $3233 (Gauld, 2012).

The 20 regional DHBs plan, manage, purchase and provide health services for their populations. They are responsible for primary care, hospital services, public health services, aged care services, and services delivered by non-governmental health providers, including Māori and Pacific providers within their geographical boundaries (Ministry of Health, 2013d; Cumming et al., 2014). Despite this publicly funded health system, not all hospitals can offer the same level of services as each DHB manages its own budget and has differing financial thresholds for services (McLeod et al., 2004). Performance indicators are used to assess the performance of each DHB against set targets with significant differences in performance between DHBs evident (Cumming et al., 2014).

Māori representation in health governance is increasing with DHB boards now comprised of a mix of elected members and members appointed by the Minister of Health and a requirement to have at least two Māori representatives. DHBs are also required to involve Māori in service delivery, and to build Māori capacity in the health sector (New Zealand Parliament, 2000).
Primary Health Care

Thirty six primary health care organisations (PHOs) and a number of newly developed Integrated Family Care Centres provide the bulk of primary care services with General Practitioners (GPs) acting as a first point of contact with the health system and as gatekeepers to secondary and tertiary services. The move to organise primary care providers into PHOs in the early 2000’s was intended to make primary care more accessible and less costly (King, 2001; Cumming et al., 2014). Capitated funding of PHOs based on an enrolled population replaced the former fee-for-service government subsidy. As with DHBs, PHOs are required to include Māori representation on their boards of governance. They must also develop services that reflect the priorities and needs of their enrolled population and pay particular attention to health outcomes for Māori within the populations they serve (Ashton, 2005; King, 2001; Cumming et al., 2014).

Māori Health Providers

Most health care in New Zealand is delivered through mainstream or Pākehā-centred services (French et al., 2001). Until recent decades there has been almost no Māori involvement in decision making within the health sector. Māori input within mainstream has improved recently though with changes such as the requirements for Māori representation on DHB boards. In conjunction with these changes in mainstream the development of Māori health providers since the 1980s has enabled many iwi (tribe or tribal organisation) to attend to their own health needs and participate in the planning of future development of Māori health (Durie, 2001).

There are now a large number of Māori health providers contracted to DHBs throughout New Zealand. These organisations are unique in that they are Māori-led and operate from a kaupapa Māori framework; their services are integrated with Māori culture and are based on Māori aspirations and thus are more likely to be utilised by Māori (Durie, 2001; Boulton et al., 2004). Māori providers predominantly
deliver primary health care services only with secondary and tertiary care remaining the domain of mainstream organisations. Māori providers also tend to deliver health and disability services to a largely Māori client base, although access is not limited solely to Māori clients. There is evidence that Māori health providers have increased access to care for many Māori however the majority of Māori continue to access health care through mainstream organisations (Robson and Harris, 2007a). Thus it is imperative that mainstream providers ensure their services are accessible and acceptable to all New Zealanders.

Māori Health Workforce

Even with advances in bringing health into a Māori context, which has included an emphasis on Māori health workforce development, Māori remain significantly underrepresented in all parts of the health workforce (Durie, 1998). Despite a population comprising nearly 15% of the total New Zealand population, Māori make up 5% of the national health workforce overall (Durie, 2005). Within the regulated health professions, Māori comprise only 7% of all active registered nurses, 3.1% of dieticians, 2.9% of medical radiation technologists, 2.6% of medical practitioners and 2.1% of dentists (Ministry of Health, 2007). The more a health worker is able to appreciate the cultural needs of clients the greater the opportunity is for effective health care (Boulton et al., 2004; Durie, 1998), thus having proportionately too few Māori in the health workforce can exacerbate health inequity (Boulton et al., 2004).

Cancer Treatment Services

Detection of cancer is often initiated within the primary health care sector in New Zealand. Some cancer support and navigation services are provided by Māori health providers but cancer treatment is provided solely through mainstream secondary or tertiary health services. District Health Boards are the major funder of cancer services, particularly cancer diagnosis and treatment and are required to report on
cancer related activity within their District Annual Plans (Cancer Control Taskforce, 2005). Diagnostic and surgical treatment services are provided by DHBs throughout the country. Medical and radiation oncology are provided through six regional cancer treatment services sited in Auckland, Hamilton, Palmerton North, Wellington, Christchurch and Dunedin. These six regional cancer treatment services also offer specialist appointments and medical oncology services through peripheral clinics in a number of smaller centres.

Private health services in New Zealand deliver specialist secondary health care, concentrating mainly on elective surgical services (French et al., 2001; Cumming et al., 2014). Many surgeons and specialists in New Zealand practice in both the public and private health systems (Cumming et al., 2014). The delivery of cancer treatment within the private sector has increased over the last decade. It is now possible to receive not only cancer related surgery but also medical and radiation oncology treatment privately, although the latter is limited to a small number of providers. Of note the majority of treatment for stomach cancer is provided by publicly funded health services rather than within the private sector.

Recent Government Policy on Health Inequity and Cancer Control

Health Inequity

Although New Zealand health legislation began to recognise the Treaty of Waitangi and the need to reduce inequities within policy in the 1990s, the New Zealand Public Health and Disability Act of 2000 (New Zealand Parliament, 2000) is particularly significant. The passing of the Act saw the Treaty of Waitangi incorporated within national legislation for the first time. The Public Health and Disability Act provided mechanisms for Māori participation in decision making around resource allocation and delivery of health and disability services. It also placed onus on DHBs to take
responsibility for improving Māori health and reducing inequities (Boulton et al., 2004; New Zealand Parliament, 2000).

A number of key strategies followed the New Zealand Public Health and Disability Act. All to some degree outline a commitment to ensuring equitable access to health services, to reducing inequities in the health of different population groups, and specifically to improving the health of Māori. The partnership relationship between Māori and the Crown established under the Treaty of Waitangi is also recognised in these strategies.

*The New Zealand Health Strategy* (King, 2000) and *Primary Health Care Strategy* (King, 2001) both outline actions and priorities to improve the health of all New Zealanders including that of Māori. The key strategy document for Māori health *He Korowai Oranga* (Ministry of Health, 2002b) built on these previous two strategies. For the first time the health system was required to consider individual patients as part of a whānau (extended family, recognised as a foundation of Māori society), to attend to whānau ora (families supported to achieve health and wellbeing) and to take a multidisciplinary and wider social approach in their care (Boulton et al., 2004; Ministry of Health, 2002b).

Whānau Ora has since been developed as a key government initiative, launched in 2010 (Office of the Auditor-General, 2015). Whānau Ora is not only a health initiative, rather it is a key cross-government work programme involving the Ministry of Health, Te Puni Kōkiri (Ministry of Māori Development) the Ministry of Social Development and other agencies. The programme has defined whānau ora in a number of ways, as a philosophy, a model of practice, an outcome goal and a mechanism for funders (Taskforce on whānau-centred initiatives, 2010). Essentially it is an approach that places families or whānau at the centre of service delivery requiring the integration of health, education and social services to improve outcomes for whānau (Office of the Auditor-General, 2015). DHBs have been required to report on Whānau Ora activities within DHB Annual Plans since 2012 (Ministry of Health, 2015a).
Cancer Control

The New Zealand Cancer Control Strategy (Minister of Health, 2003) and its accompanying Cancer Control Action Plan (Cancer Control Taskforce, 2005) were the first comprehensive Government policy documents on cancer control in New Zealand. These documents outline the dual purposes of reducing the incidence and impact of cancer and reducing inequities with respect to cancer. They include specific reference to the Treaty of Waitangi and offer a framework to address New Zealand cancer statistics and inequities, especially those between Māori and non-Māori.

One objective of the Action Plan (Cancer Control Taskforce, 2005) is to ensure appropriate programmes and services are accessible to Māori across the cancer control continuum, from prevention through to palliative care. This accessibility is stated to also include policy, planning and funding, research and monitoring. Outside of health, the Action Plan discusses addressing the underlying economic and social inequalities between Māori and non-Māori in New Zealanders.

The Action Plan (Cancer Control Taskforce, 2005) also identifies the need to develop formal structures to enhance cooperation and collaboration for cancer control. From this, four Regional Cancer Networks were developed in 2008 to work with the Ministry of Health and DHBs to facilitate and coordinate cancer services at all levels. All Regional Cancer Networks have a stated and explicit commitment to improving Māori cancer outcomes and improving equity.

The Ministry of Health leads the work within cancer control through a national work programme, which is guided by the New Zealand Cancer Plan: Better, faster cancer care 2015-2018 (Ministry of Health, 2014b). The programme aims to reduce waiting times for cancer related appointments, investigations and treatment, to improve support for patients and their families and to standardise care pathways for cancer patients. This work programme has an explicit focus on equity, stating that it aims to:

improve cancer outcomes for all New Zealanders. This means that people, irrespective of their ethnicity, gender, locality or socio-economic status, must be able to have every opportunity to access
services that will reduce their risk of developing cancer, enable their cancer to be detected earlier as well as getting high-quality cancer treatment quickly (Ministry of Health, 2014b: 2).

The work programme involves DHBs and the regional cancer networks and includes a number of key initiatives:

- The ongoing development of, and service review against, national tumour standards for ten tumour types describing the level of service that a person with cancer should have access to, promoting nationally coordinated and consistent levels of service provision across the country.

- A service improvement fund, with funding of $11.2 million over four years made available to support DHBs to deliver faster cancer treatment.

- Improving the coverage and functionality of multidisciplinary meetings so that more patients benefit from a range of expert opinion and there is better continuity of care with less duplication of services.

- Implementing the Cancer Nurse Coordinator Initiative so that patients who need more personalised support have access to a specialist nurse (Ministry of Health, 2014b: 6).

**Stomach Cancer Control**

New Zealand has two guidelines related to stomach cancer, one focuses on the primary care sector and the other on secondary and tertiary services. In addition, surgeons performing surgery for stomach cancer in New Zealand have the option of joining the Australian and New Zealand Gastric and Oesophageal Surgical Association.

**Suspected Cancer in Primary Care**

*Suspected Cancer in Primary Care* released in 2009, advise primary care practitioners about the detection, investigation and referral pathways for a number of important cancers, including stomach cancer (New Zealand Guidelines Group, 2009). In keeping with the younger age profile of the Māori population (Robson and Harris, 2007a), the
guideline specifically advises the consideration of stomach cancer at a younger age (suggesting ten years earlier) when treating Māori patients compared to the general population.

**Service Provision Standards**

The *Standards of Service Provision for Upper Gastrointestinal Cancer Patients in New Zealand – Provisional* (National HBP/Upper GI Tumour Standards Working Group, 2013) was released in 2013 as part of the better, faster cancer care 2015-2018 work programme. The Standards provide advice to DHBs about the expected level of service delivery to patients with upper GI cancers (including stomach cancer) aiming to promote nationally coordinated and consistent standards of service provision across New Zealand, with a focus on equity. The standards are outlined in ten separate areas:

- Prevention and early identification.
- Timely access to services.
- Referral and communication.
- Investigation, diagnosis and staging.
- Multidisciplinary care.
- Supportive care.
- Care coordination.
- Treatment.
- Follow-up and surveillance.
- Clinical performance monitoring and research.

They are currently deemed to be provisional standards only and not mandatory for DHBs. The expectation is that all DHBs will work with their respective Regional Cancer Network to review the delivery of services and outcomes against the level expected within the Standards. The Standards will be reviewed and finalised by 2018.
Australian and New Zealand Gastric and Oesophageal Surgery Association

In 2006 the Australian and New Zealand Gastric and Oesophageal Surgical Association (ANZGOSA) was formed as a mechanism for improving the surgical management of diseases of the upper GI tract through: peer networking and support, fellowships and training opportunities, coordination of clinical research/audit and the development of clinical guidelines (Australian and New Zealand Gastric and Oesophageal Surgical Association, 2006).

The ANZGOSA manages a clinical audit database which aims to evaluate, improve and maintain the quality of care provided by upper GI surgeons. Participating surgeons are able to enter pathological, clinical and surgical outcome data of patients undergoing resection for upper gastrointestinal cancer and gastrointestinal stromal tumour (GIST). Surgeons can then self-assess their performance and compare their performance against that of peers. New Zealand surgeons began contributing data to the audit in 2010. As of 31 July, 2014 the database contained a total of 1469 cases of which 69 were from surgeries performed in New Zealand (Royal Australasian College of Surgeons, 2014).

Guidelines were published in 2013 for hospitals and health services to assist in the assessment of surgeons performing stomach cancer surgery (Australian and New Zealand Gastric and Oesophageal Surgery Association (ANZGOSA), 2013). The guidelines include direction on credentialing of, and expected training for, surgeons. Direction is also given on the levels of services, including MDT requirements, required by hospitals along with surgical audit outcomes. Of note, membership and participation in any ANZGOSA activity is voluntary.

Summary of the New Zealand Health Care Sector

Health care in New Zealand is characterised by publicly funded and delivered care, with free, albeit secondary and tertiary only, services. Primary health care is provided on a fee for service basis with GPs acting as gatekeepers to the rest of the health system. Twenty DHBs plan, manage and provide health care services for the
population within their geographical boundary. However DHBs provide different levels of service to their respective population with differences also evident in performance indicators by DHB.

Most health care in New Zealand is delivered through public (or mainstream) organisations. The development of Māori health providers since the 1980s has increasingly enabled Māori to attend to their own health care needs, although Māori providers predominantly deliver primary care-based health care services only. The majority of cancer services are delivered through the public system, with cancer treatment services delivered solely by mainstream organisations. Six regional cancer treatment services spread across New Zealand provide the bulk of medical and radiation oncology services. Diagnostic and surgical oncology services are provided by DHBs throughout the country although private facilities provide some specialist outpatient and surgical care to patients (French et al., 2001). The majority of treatment services for stomach cancer are provided by publicly funded services rather than the private sector.

A number of recent government policies include a stated commitment to reducing health inequities and the burden of cancer. As well guidelines, albeit non-mandatory, specifically address the diagnosis and treatment of stomach cancer for the primary, secondary and surgical sectors.
Chapter 3: Indigenous Cancer Inequities

This chapter outlines the evidence regarding inequities in stomach cancer for indigenous people both in New Zealand and internationally. While there are well documented inequities in stomach cancer incidence, mortality and survival among ethnic minority groups, especially African Americans in America, this study is primarily interested in whether there are disparities between indigenous Māori of New Zealand and their majority non-Māori counterparts. Thus indigenous inequity forms the main focus of this chapter.

This chapter opens with a brief overview of cancer in New Zealand, it then focuses on the most obvious and sustained example of cancer related inequity in New Zealand, that seen between Māori and non-Māori. The chapter highlights the evidence of differential cancer and stomach cancer incidence and mortality seen within Māori. Incidence and mortality inequities, those of both cancer and stomach cancer, are then examined for other indigenous peoples.

Finally the focus of this chapter is turned to survival from cancer once diagnosed. Cancer survival is determined by a number of factors. However survival is a useful way to gauge the overall effectiveness of a country’s cancer screening, diagnostic, treatment and management services, and so differences in cancer survival between ethnic groups within a country provides important background to this thesis. Thus cancer and stomach cancer survival inequities evidenced in indigenous people internationally and for New Zealand Māori are discussed.
Cancer in New Zealand

Cancer is a significant public health issue in New Zealand (Minister of Health, 2003; Ministry of Health, 2002a; Blakely et al., 2010). Currently cancer is the leading cause of death in New Zealand, accounting for nearly a third (28.9%) of all deaths in 2009 (New Zealand Health Information Service, 2012). Incidence and mortality rates are projected to stop increasing over the coming decades, although it is predicted that the overall burden of cancer will still increase due to the increasing size and aging of New Zealand’s population (Ministry of Health, 2010a).

Compared with other countries New Zealand has high incidence and mortality from a number of cancers (Jemal et al., 2011; Minister of Health, 2003). New Zealand also has well documented inequities in both cancer incidence and mortality (Blakely et al., 2010; Robson et al., 2006; Soeberg et al., 2012).

Cancer incidence and mortality inequities in New Zealand exist along a number of axes: socio-economic, gender, geographic and ethnic (Minister of Health, 2003; Blakely et al., 2010; Robson et al., 2010). These inequities do not happen by chance but rather are due to a complex mix of factors, including differential access to the underlying determinants of health and differential access to, and through, health services including cancer services (Robson and Harris, 2007a).

Socioeconomic position plays a large role in a person’s risk of developing and dying of cancer (Blakely et al., 2011; Blakely et al., 2005). Inequities in cancer mortality by socioeconomic position are widening in New Zealand (Blakely et al., 2005; Soeberg et al., 2012) with increases seen in both relative and absolute socioeconomic cancer mortality in New Zealand between 1981 and 1999 (Blakely et al., 2005). Ethnicity also plays a large role in a person’s risk of developing and dying of cancer. Pacific Island New Zealanders are differentially impacted by number of key, and often preventable, cancers (Tukuitonga et al., 1992; Foliaki et al., 2004; Blakely et al., 2004; Meredith et al., 2012); however, one
of the most stark and sustained examples of cancer related inequity in New Zealand is that seen between the indigenous Māori population and non-Māori.

Māori/non-Māori Cancer Incidence and Mortality

It is well documented that the burden of cancer disproportionately impacts Māori in New Zealand (Minister of Health, 2003; Blakely et al., 2004; Jefferys et al., 2005; Robson et al., 2006; Blakely et al., 2010). Overall between 1996 and 2001 Māori were 18% more likely to be diagnosed with cancer but 93% more likely to die from it compared with non-Māori (Robson et al., 2006). Not only do Māori and non-Māori rates differ for all cancers combined, Māori have been shown to have significantly higher incidence of a number of specific cancer sites; namely the preventable and poorly prognostic cancers of the lung, cervix, liver and stomach along with breast cancer (Robson et al., 2006; Moore et al., 2015). Māori also have somewhat higher rates of cancers of the oesophagus, pancreas, uterus, testis and thyroid than non-Māori (Robson et al., 2006). Māori are also more likely than non-Māori to die from the majority of cancers, even many cancer sites where their incidence rate is similar or lower than that of non-Māori (Robson et al., 2006).

Furthermore, for many cancers inequities between Māori and non-Māori are widening (Blakely et al., 2004; Ajwani et al., 2003; Blakely et al., 2007; Blakely et al., 2010). During the period from 1981 to 2004 wide and increasing Māori/non-Māori inequities in tobacco-related cancer incidence were reported; inequities in non-tobacco-related cancer incidence were smaller though, and trends varied (Blakely et al., 2010).

In addition, while it is true that increasing deprivation is associated with increased cancer incidence and mortality for both Māori and non-Māori the association is stronger for Māori (Robson and Harris, 2007a; Robson et al., 2010). These disparities also hold true
for stomach cancer (Blakely et al., 2011; Dockerty et al., 1991; Thompson, 2002; New Zealand Health Information Service, 2012).

**Māori/non-Māori Stomach Cancer Incidence and Mortality**

New Zealand does not have a high incidence of stomach cancer on an international scale; the combined world age-standardised rate for cancer incidence is 14.1 per 100,000 (Ferlay et al., 2010) while the overall rate for New Zealand males is 8.2 per 100,000 and females is 3.8 per 100,000 (New Zealand Health Information Service, 2012). However in 2009 the age-standardised rate of stomach cancer for Māori males was two and a half times that of non-Māori males (19.3 vs 7.3 per 100,000 respectively); the rate for Māori females five times that of non-Māori females (15.2 vs 2.8 per 100,000 respectively) (New Zealand Health Information Service, 2012). These findings are consistent with a number of individual studies which all find at least a two-fold increase in stomach cancer incidence for Māori when compared to non-Māori (Blakely et al., 2011; Dockerty et al., 1991; Thompson, 2002). Mortality rates mirror this pattern of inequity (New Zealand Health Information Service, 2012).

Incidence trends show decreasing rates of stomach cancer in New Zealand over the time period from 1981 to 2004 (Blakely et al., 2010). This is true at least for non-Māori/non-Pacific New Zealanders, whose rates fell by 33% for men and 42% for women. With a smaller number of incident cases over this time the rates for Māori were not stable but appeared to decrease, albeit to a lesser degree. What is clear is that the disparity between Māori and non-Māori remains, with Māori having two to three times the incidence of non-Māori over this time period (Figure 2 and Figure 3). Furthermore a widening relative incidence between Māori and non-Māori women was observed (Blakely et al., 2010).
Figure 2: Male stomach cancer registration rate, by ethnicity, 1999–2009

Age-standardised rate per 100,000 population; standardised to the WHO world standard population.

Figure 3: Female stomach cancer registration rate, by ethnicity, 1999–2009

Age-standardised rate per 100,000 population; standardised to the WHO world standard population.
Differences in Stage at Diagnosis

There are high numbers of stomach cancer registrations on the New Zealand Cancer Registry that do not have extent of disease at diagnosis recorded, with ‘unknown’ recorded for a third of all registrations (Robson et al., 2006). In a population-based study using Cancer Registry data, linked to mortality data, that accounted for all registrations between 1996 and 2001, Māori were less likely than non-Māori to have extent of disease at diagnosis recorded (Robson et al., 2006). Of those people for whom extent at diagnosis was recorded, Māori were more likely to be diagnosed with localised disease however Māori were 50% more likely than non-Māori to die of their disease no matter their extent at diagnosis (Robson et al., 2006). In contrast another smaller institution-based study that was able to ascertain stage at diagnosis for its total cohort (n=133) through clinical notes review found no significant difference in stage at diagnosis between Māori and non-Māori (Biggar et al., 2011). Importantly to this thesis, no previous New Zealand study has investigated stomach cancer at a population level based on complete data on staging.

Differences in Tumour Site

Two New Zealand studies point to differential distribution of tumour site between Māori and non-Māori (Biggar et al., 2011; Armstrong and Borman, 1996). Notably, it appears that the tumour sub-site in Māori with stomach cancer defies international trends of increasing proportions of tumours located in the proximal stomach, and corresponding lower proportions of tumours located distally (McLoughlin, 2004; Forman and Burley, 2006; World Health Organisation, 2008).

An older study (1978 – 1992) using New Zealand Cancer Registry data reported an average annual incidence of adenocarcinoma of the cardia among non-Māori men over twice the rate in Māori men (0.9 per 100,000 in Māori men vs 2.2 per 100,000 in non-Māori men), while the converse was shown for adenocarcinoma elsewhere in the
stomach (9.7 per 100,000 in Māori men vs 3.7 per 100,000 in non-Māori men) (Armstrong and Borman, 1996). Among Māori women the average annual incidence of non-cardia (distal stomach) adenocarcinoma was over four times that of non-Māori women (7.9 vs 1.9 per 100,000 respectively). There was however also a high percentage of stomach cancers overall (41%) with unspecified sub-site (Armstrong and Borman, 1996). The more recent single institution-based study of Biggar et al (Biggar et al., 2011) which was able to ascertain tumour sub-site for all 3% of patients supported the findings of Armstrong and Borman. Biggar et al reported that New Zealand European patients were more likely to be diagnosed with proximal (47%) than distal tumours (16%). Again the converse was true for Māori patients (proximal 12% vs distal 44%).

It has been suggested that the higher prevalence of distally located tumours for Māori is linked to their much higher rates of infection H. pylori compared to non-Māori New Zealanders (Fraser et al., 1996; McDonald et al., 2015). Importantly, except for the one institution-based study above there has been little recent work investigating stomach cancer tumour sub-site in New Zealand.

**Gender**

Stomach cancer incidence rates in men are around double those of women in most population groups worldwide (Ferlay et al., 2010), including most indigenous groups (Arnold et al., 2014). In Māori however, women appear nearly as likely to develop stomach cancer as men. In 1996-1997 Māori men had an incidence of 26.5 per 100,000 while the corresponding rate for Māori women was 24.0 per 100,000 (Skegg and McCredie, 2002). The data of the New Zealand Health Information Service supports this finding; in 2009 the age-standardised rate of stomach cancer for Māori women at 15.2 per 100,000 was 80% of that of Māori men at 19.3 per 100,000 (New Zealand Health Information Service, 2012). In addition, proportionately more Māori women were diagnosed than non-Māori women when compared to their male groups (New Zealand Health Information Service, 2012).
Stomach Cancer and Socioeconomic Status

As with cancer overall, stomach cancer incidence and mortality are linked to socioeconomic status. While this is true for both Māori and non-Māori, the association is stronger for Māori. The higher proportion of Māori living in more deprived regions accounted for up to 14% of the differences in both incidence and mortality seen between Māori and non-Māori. Socioeconomic status did not however explain the differential extent of disease at diagnosis for stomach cancer (Robson et al., 2010).

Indigenous/non-Indigenous Cancer Incidence and Mortality

There is a large international body of work supporting the existence of cancer disparities due to socioeconomic inequity. Literature on cancer disparity by indigeneity is more limited. In part this is due to ethnicity not being systematically and accurately recorded by cancer registries worldwide (Gordon-Dseagu, 2007; Zhang et al., 2011; Foote et al., 2007; Sarfati and Robson, 2015). There is however enough evidence to show a scenario similar to that seen in New Zealand, one of differential cancer incidence and mortality for indigenous people within a country when compared to the non-indigenous population. Often it is the preventable and poorly prognostic cancers, including stomach cancers, which are disproportionately borne by indigenous people (Roder, 2005; Moore et al., 2010; Condon et al., 2005; Zhang et al., 2011; Ward et al., 2004; Paltoo and Chu, 2004; Jemal et al., 2004; Friborg et al., 2003; Arnold et al., 2014; Moore et al., 2015).
Indigenous Cancer Incidence and Mortality in Australia

Significant differences have been found between Indigenous Australians and other Australians especially in potentially preventable and poorly prognostic cancers of the liver, head and neck, lung, oesophagus and cervix (Roder, 2005; Moore et al., 2010; Condon et al., 2005; Zhang et al., 2011; Moore et al., 2015). Additionally markedly higher incidence rates for Indigenous Australians have been shown for colorectal, breast, pancreatic and oropharynx cancers (Zhang et al., 2011; Condon et al., 2005).

Cancer mortality is also differential for Indigenous Australians compared to other Australians. Indigenous Queenslanders are 21% less likely to be diagnosed with cancer than the total Queensland population but 36% more likely to die from it (Moore et al., 2010) while Indigenous Australians in the Northern Territory and South Australia are 40% more likely to die from their cancer than their non-Indigenous counterparts (Roder, 2005; Condon et al., 2004).

Stomach Cancer

Stomach cancer appears to follow a similar pattern, that of higher incidence and mortality for Indigenous Australians when compared to non-Indigenous Australians. The numbers of Indigenous Australians diagnosed with stomach cancer is however low, thus firm conclusions cannot be reached and study results are varied.

One study showed an apparent lesser risk of developing and dying from stomach cancer for Indigenous Australians of the Northern Territory compared to non-Indigenous (Condon et al., 2005). However this finding was based on only 13 Indigenous cases.

In contrast, Indigenous Australian men in a Queensland study had an 80% higher risk of developing stomach cancer than non-Indigenous men (Moore et al., 2010), while in New South Wales Indigenous men had an 85% higher risk (Morrell et al., 2012). Reported
incidence in Indigenous Australian women varies from an apparent lower incidence (standardised incidence ratio 0.68; 95% CI, 0.32–1.24) (Moore et al., 2010) to a probable higher incidence (standardised incidence ratio 1.35; 95% CI, 0.73-1.98) (Morrell et al., 2012). Nationally, a larger cohort study (using data which covers 84% of the Indigenous Australian population) found a 30% higher risk of stomach cancer for Indigenous Australian compared with non-Indigenous men (incidence rate ratio 1.3; 95% CI, 1.0-1.7). Again the rate for Indigenous Australian women appears lower than non-Indigenous, although it was based on only 29 cases (Zhang et al., 2011).

Mortality for Indigenous Australian men has been shown to be greater than two-fold increased than that of the total New South Wales population (Supramaniam et al., 2006; Morrell et al., 2012). Despite their apparent lower incidence, mortality for Indigenous Australian women was higher when compared to non-Indigenous women (Moore et al., 2010), in one study reaching statistical significance (1.98; 95% CI, 1.15-3.16) (Morrell et al., 2012).

Despite the lack of power within most of these studies due to low numbers of Indigenous Australian cases, the magnitude and direction of these findings are consistent with higher stomach cancer incidence and worse mortality for the Indigenous Australian population. However the magnitude of difference may be greater than presented here as underestimation of Indigenous Australian cancer incidence is likely in these studies. None of these studies report stomach cancer by tumour sub-site, although there is documented evidence of a high prevalence of H. pylori in Indigenous Australians (Nogrady, 2005) with rates two to three times higher than that of the non-Indigenous Australian population (Windsor et al., 2005).

### Indigenous Cancer Incidence and Mortality in America

Historically studies have shown lower cancer incidence rates overall among the American Indian and Alaskan Native (AI/AN) population when compared to the majority white
population of North America (Paltoo and Chu, 2004). This lower incidence rate was thought to be due to lower rates than white Americans of the major cancers such as breast, prostate and colorectal. However there is mounting State-based evidence of significant undercounting of AI/AN ethnicity in cancer registries and thus in national SEER datasets from which many studies have drawn data (Partin et al., 1999; Foote et al., 2007; Wiggins et al., 2008).

In order to improve classification of American Indian cancer cases some States in America have linked State-based data to data of their Indian Health Service, which has more accurate ethnicity classification. After data linkage, American Indians were shown to have similar cancer incidence when compared to the total population, over twice that reported by SEER (Foote et al., 2007) while the risk of developing breast cancer was twice as high as previously estimated (Partin et al., 1999). Incidence rates of a number of other specific cancers were also higher in AI/AN groups compared to the total population; cancer of the gallbladder was up to 4 times higher, liver up to 2.3 times higher and kidney twice as high (Paltoo and Chu, 2004). A more recent study by Moore et al (Moore et al., 2015) which derived its data from population-based cancer registries, reported an overall standardised rate ratio between indigenous Alaskan Native women and white American women of 1.30 (95% CI, 1.21- 1.40) along with higher rates of breast, head and neck, colorectal, lung and liver cancers among Alaskan Natives.

Cancer mortality overall appears to be lower for AI/AN people but higher for certain cancer sites. Specifically cancer mortality was higher for AI/AN compared to white Americans for preventable cancers of the cervix, liver and stomach, although the study used SEER data so undercount is likely (Ward et al., 2004). Additionally, over the last decade cancer mortality remained stable for AI/AN while at the same time falling by more than 1% annually for every other racial/ethnic group in America (Siegel et al., 2012).
Stomach Cancer

Even in studies likely to have underestimated rates, AI/AN men have been up to 20% more likely to be diagnosed with stomach cancer than white American men. For women this differential was up to 50% (Ward et al., 2004; Paltoo and Chu, 2004; Jemal et al., 2004).

One study, which linked SEER data to Indian Health Service records, confirmed a substantially differential burden of stomach cancer in AI/AN’s populations across America for the period 1999 to 2004 (Wiggins et al., 2008). A stomach cancer rate of 14.7 was reported for AI/AN males compared to 8.5 for white males, a 30% greater risk; while for AI/AN females a rate of 7.9 was reported compared to 3.6 for white females, a risk greater than 50% (Wiggins et al., 2008). Wiggins et al also found that in many regions AI/ANs were diagnosed with higher proportions of tumours located in the central or distal stomach indicating a differential burden of H.pylori infection within the AI/AN population (Wiggins et al., 2008).

Two papers discuss stomach cancer trends over time for AI/ANs however they present contradictory results. Paltoo and Chu (Paltoo and Chu, 2004) reported increasing trends in AI/AN people between 1992 and 1999, significantly so for women. They also reported concurrent decreasing trends in white Americans. In comparison cancer of the oesophagus was reported to be increasing in white males while decreasing in AI/AN males (Paltoo and Chu, 2004). However a large study, using SEER data linked to Indian Health Records (Espey et al., 2005) reported declining incidence rates of stomach cancer for AN/AIs, men and women, from 1975 to 2004. However despite the contradictory results, both of these studies present consistently higher incidence rates of stomach cancer among AI/AN persons than in the non-indigenous comparison groups.

All of the above studies have aggregated data for AI/AN populations. American Indians and Alaskan Natives include many different tribal groups, who each have unique cultural and lifestyle practices and who live in diverse geographical regions. Cancer risk and
mortality in AI/ANs have been shown to be different dependent on geographical or tribal region (Espey et al., 2005). Kelly and colleagues (Kelly et al., 2006) aimed to address the limitation of aggregated data. They compared cancer incidence rates for the period 1993 to 2002 among Indians in Alaska and New Mexico—the most complete indigenous datasets—and white Americans. Overall stomach cancer was one and a half times higher in Alaska Indians than New Mexico Indians. It was twice as high in Alaska Indian men as in whites (Alaskan/White rate ratio 2.3; 95% CI, 1.5-3.6), while it was three times higher in Alaska Indian women than in whites (Alaskan/White rate ratio 3.0; 95% CI, 1.8-5.1). Differing prevalence of risk factors undoubtedly plays a role with Alaska Native people previously reported to have a high prevalence of H. pylori infection (Kelly et al., 2006). This finding of a threefold increase of stomach cancer risk among Alaskan Natives compared to American whites is supported by 1994–2008 data from the Alaska Native Tumor Registry (Kelly et al., 2012). In addition, the recent study by Moore et al (Moore et al., 2015) also supports this finding of threefold stomach cancer risk with an Alaskan Native/white American standardised rate ratio of 3.19 (95% CI, 1.95–5.20) reported for men. The corresponding ratio for women was 3.75 (95% CI, 1.92–7.36). However stomach cancer rate ratios between American Indians and white Americans were consistently lower in the indigenous people across all States of America.

While stomach cancer mortality rates overall are falling, mortality is up to four times worse for AI/ANs compared to white Americans (Kelly et al., 2012; Jemal et al., 2004). Additionally, stomach cancer mortality is decreasing at a much faster rate for white Americans (annual percentage change for white men -3.6 versus AI/AN men -1.2; white women -2.8 versus AI/AN women -1.4) (Jemal et al., 2004). These findings are likely to be more pronounced due to the aforementioned issues with misclassification of AI/AN leading to undercounting within SEER databases. Still the findings indicate not only a higher likelihood of dying of stomach cancer for AI/AN peoples but an increasing mortality gap between AI/ANs and white Americans.
Other Indigenous Groups

Stomach Cancer

Other than the indigenous peoples already discussed, elevated stomach cancer incidence and mortality rates are found in most other indigenous peoples globally. The highest rates are seen in indigenous Siberians (Tsukanov et al., 2011), the Mapuche people of Chile (Heise et al., 2009) and Inuit (Friborg et al., 2003; Arnold et al., 2014). Additionally there an increased risk of developing stomach cancer among the Sami of Sweden and Sami women of Norway and Finland (Hassler et al., 2008), while the Skolt Sami of Finland have particularly high stomach cancer mortality, which is reported to be four fold that of their non-indigenous countrymen (Soininen and Pukkola, 2008).

It is likely that infection with H. pylori drives these high rates for indigenous peoples. A higher proportion of distally located tumours was found among the total cohort in the Chilean study (1.0 distal tumour for each 0.7 proximal tumour) when compared to proportions seen in developed countries suggestive of H. pylori driven disease (Heise et al., 2009). Inuit in Nunangat Canada are more likely to live in crowded housing and have a lower median income than their non-indigenous countrymen both in Nunangat and the rest of Canada (Carriere et al., 2012). The combination of a high rate of H. Pylori infection along with the tobacco and dietary practices among indigenous Siberians are put forward by the authors as contributing factors to their extremely high rates of stomach cancer (Tsukanov et al., 2011). Furthermore the high risk of stomach cancer within the Inuit population of Greenland remains once they migrate to the lower risk Denmark region (Boysen et al., 2008) indicating that long term or early risk factors, most probably infection with H. pylori, play a role in the high observed incidence.
Summary of Indigenous Stomach Cancer Incidence and Mortality

Differential incidence and mortality rates have been noted in most indigenous peoples for a number of cancers, including stomach cancer (Blakely et al., 2010; Condon et al., 2004; Moore et al., 2015; Condon et al., 2005; Zhang et al., 2011; Paltoo and Chu, 2004; Ward et al., 2004; Wiggins et al., 2008; Heise et al., 2009; Friborg et al., 2003).

The differential stomach cancer rates most probably point to a disproportionate burden of H. pylori-associated disease for indigenous peoples (Paltoo and Chu, 2004; Ward et al., 2004; Wiggins et al., 2008; Arnold et al., 2014). One study reported on increased household crowding for the indigenous people of investigation (Carriere et al., 2012) and while most of the studies do not investigate tumour site, those that do, reported higher proportions of distally located tumours (Biggar et al., 2011; Armstrong and Borman, 1996; Heise et al., 2009) – adding weight to the H. pylori hypothesis of disease.
Cancer Survival Inequities

Cancer survival is a useful indicator of the overall effectiveness of a country’s cancer screening, diagnostic and treatment services. Survival is positively associated with a country’s gross domestic product and level of spending on health (Coleman et al., 2008). The five-year relative survival ratio for all cancers combined in New Zealand over the ten years from 1994 to 2003 was 0.605; thus around 60% of New Zealanders diagnosed with cancer lived at least five years after diagnosis (New Zealand Health Information Service, 2006). This combined survival ratio and the survival ratio of individual cancers in New Zealand was similar to those seen in other developed countries (Coleman et al., 2008; Soeberg et al., 2012). Poorer survival overall from cancer is usually seen in less developed countries, in part due to a higher prevalence of cancers with worse prognosis such as stomach and liver cancers but also due to issues of health system access and quality (Ferlay et al., 2010; Coleman et al., 2008).

The existence of cancer survival inequities by ethnicity is well evidenced in a number of countries and across a number of cancer sites (Soeberg et al., 2012; Ferlay et al., 2010; Coleman et al., 2008; Walters et al., 2011). Survival once diagnosed is determined by patient, tumour and treatment related factors and survival inequities are thought to be due to a combination of these factors rather than one factor alone. More specifically survival inequities are potentially explained by differences in: cancer incidence rates of rapidly fatal or poorly prognostic cancers (for all cancers combined), tumour morphology, access to cancer screening or primary health care, stage at diagnosis and level of comorbidity as well as access to cancer treatment and the quality and timeliness of that treatment (Coleman et al., 2008; Ferlay et al., 2010; Soeberg et al., 2012; Jemal et al., 2004). Ethnic differences in cancer survival within a country can then provide an indirect marker of the equity of health care delivery.
In New Zealand a 2012 population-based study highlighted significant and sustained ethnic survival disparities across a number of cancers (Soeberg et al., 2012). This study’s findings are supported by a large body of work evidencing ethnic survival disparities for a variety of cancers in New Zealand (Alexander et al., 2010; Brewer et al., 2012b; Dachs et al., 2008; Gill and Martin, 2002; Haynes et al., 2008; Hill et al., 2010a; Jeffreys et al., 2009; New Zealand Health Information Service, 2006). There are also gaps in cancer survival by socioeconomic position both internationally (Baastrup et al., 2008; Kuwahara et al., 2010; Woods et al., 2006; Yu et al., 2008) and in New Zealand (Soeberg et al., 2012; Robson et al., 2010; Jefferys et al., 2005).

However in keeping with cancer incidence and mortality the most stark and sustained survival inequities in New Zealand are those seen between Māori and non-Māori. This survival inequity for New Zealand Māori is outlined below, but firstly it is placed in relation to survival inequity seen within the indigenous people of Australia and North America.

**Indigenous/non-Indigenous Cancer Survival**

There is much evidence showing worse survival from cancer for indigenous people internationally. However few international studies include, or individually report on, data regarding stomach cancer survival disparities.

**Survival Inequities in Australia**

Overall cancer survival is worse in Indigenous Australians compared with other Australians. In part this poorer survival is due to Indigenous Australians being more likely to be diagnosed with rapidly fatal and poorly prognostic cancers, such as oropharynx, lung and liver cancers (Morrell et al., 2012; Moore et al., 2010; Chong and Roder, 2010;
Condon et al., 2005; Moore et al., 2015). At the same time they are less likely to be diagnosed with cancers that have better survival, such as melanoma or breast cancer (Chong and Roder, 2010; Moore et al., 2010). One national multi-cancer study and a number of state-based multi-cancer studies provide comprehensive evidence of Indigenous/non-Indigenous survival disparity across Australia. These studies are reviewed below.

The national study reported an overall (all cancers combined) poorer survival for Indigenous than non-Indigenous Australians (age adjusted one year survival 63.8% Indigenous vs 83.4% non-Indigenous) and poorer survival for most individual cancer sites (Condon et al., 2014). This study used national cancer registration data between 1991 and 2005 to calculate relative survival for Indigenous Australians compared with non-Indigenous Australians. It was unable to account for stage at diagnosis as this information was not available, nor does the study attempt to investigate clinical explanations for differential survival, it does however report on geographical remoteness as a possible explanatory factor. At five year post-diagnosis age adjusted likelihood of survival for Indigenous Australians was 46.7% and 70% for non-Indigenous, thus the majority of the disparity arose within the first year post-diagnosis. Survival was also lower for rural and remote residents than those residing in urban areas; this disparity was much greater for Indigenous Australians (Condon et al., 2014). These results, the first at a national level, are supported by those of a number of individual states.

Marked survival disparities were found between Indigenous and non-Indigenous Queenslanders in the first year after cancer diagnosis (HR 1.50; 95% CI, 1.38 – 1.63) (McCramb et al., 2012). However these disparities nearly disappeared after two years (HR 1.03; 95% CI, 0.78 – 1.35), so that Indigenous Australians who survived the first two years after diagnosis experienced similar on-going survival as their non-Indigenous counterparts (McCramb et al., 2012). This study linked data of the Queensland cancer registry for all Queenslanders diagnosed with cancer from 1997 to 2006 (of which 1.2% were Indigenous) to a national death index register and investigated possible
explanations for differential survival. One limitation of the study is the inability to account for stage at diagnosis as stage data were not collected by the registry during the study period. The fact that Indigenous Australians have a much higher risk of developing cancers of poorer prognosis is accounted for through adjusting for broad prognostic stage groupings; however Indigenous survival remains worse than that of non-Indigenous up to two year post diagnosis even after adjustment for this factor. The study is limited by the comparatively small Indigenous Australian cohort, meaning analyses for individual cancers could not be investigated with precision. Only 50% of the differential survival between the Indigenous and non-Indigenous Australian study cohorts in the first year post diagnosis was accounted for by geographical remoteness, socioeconomic factors, age, sex or cancer grouping by survival. The authors propose that comorbidity and differential access to, and through treatment, play a role in the remaining disparity (McCramb et al., 2012).

Two studies by Moore and colleagues both find poorer survival overall for Indigenous Australians in Queensland compared to that of non-Indigenous Queenslanders (Moore et al., 2010; Moore et al., 2014a). The first study reports a standardised Indigenous/non-Indigenous mortality ratio of 1.36 (95% CI 1.28 – 1.45) (Moore et al., 2010). This study, reporting on the years 1997–2006, was the first to report on cancer incidence and survival state-wide in Queensland. However as the study used both data from the Queensland Cancer Registry along with estimates of the Indigenous Australian and total populations of Queensland obtained from the census, a numerator-denominator bias was likely. This would have resulted in undercounting of the Indigenous Australian cohort within this study and an underestimation of the survival disparity (Moore et al., 2010). Work undertaken in New Zealand to link census data to that of the New Zealand Cancer Registry showed an underestimation of indigenous cancer incidence of up to 30% within the Cancer Registry (Shaw et al., 2009).

The second study by Moore and colleagues (Moore et al., 2014a) was a frequency-matched cohort study that investigated cancer survival and reasons for poorer survival of
Indigenous Australians from 1998 to 2004. The study found that Indigenous Australians were more likely to live remotely (27% vs 20%, p <0.001) and in the most deprived quintile (37% vs 25%, p <0.001) than non-Indigenous. Indigenous Australians also had more advanced cancer stage (p = 0.03), more comorbidities (p <0.001) received less cancer treatment (77% vs 86%, p = 0.001) and were less likely to survive their cancer (cancer specific unadjusted HR 1.30; 95% CI, 1.15-1.48). This study has a number of strengths. It is fairly large and utilises a number of data sources, including individual patient records, in order to ascertain more accurate ethnicity, stage and treatment data than would have been gained through the use of administrative level data alone. With the known misclassification of Indigenous Australian ethnicity in state-based cancer registries there is the possibility that some Indigenous Australian patients with cancer were not included in the study. However this is unlikely to be a major source of bias as, unlike the previous study, the numerator and denominator are obtained from the same data source. The reported 30% poorer survival of Indigenous Australians was largely explained by demographic and clinical factors (age, sex, stage, remoteness, deprivation and any treatment) with an adjusted hazard ratio of 1.10 (95% CI 0.96-1.27). Although with only the unadjusted and fully adjusted HRs reported the individual effect of these factors is unable to be assessed.

Valery and colleagues (Valery et al., 2006) also compared a matched sample of all Indigenous Australian Queenslanders diagnosed with cancer between 1997 and 2002 with an equal number of non-Indigenous cancer patients and also reported a 30% higher likelihood of dying from cancer for Indigenous Queenslanders (HR 1.3, 95% CI, 1.1 – 1.5). This hazard ratio was adjusted to account for differential stage, treatment and level of comorbidity between the Indigenous Australian and non-Indigenous cohorts. Like the study above, this study used cancer registry data and clinical data obtained from medical note review and so has similar strengths (Valery et al., 2006). Also like the study above, Indigenous Australian people were more likely to live remotely (20% vs 11%) and in the most deprived quintile (39% vs 28%), had less localized cancer stage (p = 0.007), more
comorbidity or multi-morbidity and were less likely to undergo cancer treatment. Stomach cancer was included in the study but hazard ratios were not reported for individual cancers. To reiterate, after accounting for differential stage, treatment and level of comorbidity, overall survival was 30% poorer for Indigenous Australian Queenslanders (Valery et al., 2006).

After adjusting for socioeconomic factors and time-period of diagnosis a relative risk of 2.0 for death from all cancers combined was reported for Indigenous Australians, when compared to non-Indigenous in a large South Australian study (Chong and Roder, 2010). The authors attribute much of the lower survival seen in the Indigenous South Australians to the fact that the cancers of poorer prognosis are more prevalent among them and thus, when all cancers are combined, Indigenous Australians are more likely to die. The study did though find poorer survival for Indigenous than non-Indigenous Australians for a number of specific cancers, namely breast, colorectal, cervical and unknown primary cancers. This study included all 671 Indigenous Australian people diagnosed with cancer in South Australia during the study period along with a random sample of non-Indigenous, matched only for year of diagnosis (n=15,799). Data were gained from the South Australian Cancer Registry and linked to the register of deaths. While this study does rely upon cancer registry data with a known Indigenous Australian ethnicity undercount it shows differential survival for Indigenous South Australian people (Chong and Roder, 2010).

An Indigenous Australian/total population hazard ratio of 1.9 (95% CI, 1.7 – 2.1) is reported in a Northern Territory study for thirteen major cancer sites combined (Condon et al., 2005). The study identified all new incident cases of cancer in the Northern Territory from 1991 to 2001 from the state cancer register and used Cox proportional hazard modelling to compare survival of Indigenous Australians of the Northern Territory to that of the Western Australia and Tasmania population diagnosed with cancer over the same time period. Eight of the individual cancer sites (oropharyngeal, pancreas, breast, uterus, cervix, vulva, lymphoma and leukaemia) had a statistically significant hazard ratio
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of 3.0 or greater, adjusted for age at diagnosis and (where applicable) for sex. This represents an over three times greater relative risk of dying of primarily preventable or treatable cancers than the non-Indigenous population. The study was not however able to take account of stage at diagnosis so it is possible that differential stage plays some role in this survival disparity (Condon et al., 2005).

Another Northern Territory study that was able to take account of stage, investigated 1197 people (of whom 242 were Indigenous Australians) diagnosed between 1991 and 2000 with colorectal, lung, breast and cervical cancers and non-Hodgkin lymphoma (Condon et al., 2006). The study found a higher risk of cancer death (adjusted for cancer type, age and stage) in Indigenous than in non-Indigenous Australians (relative risk 1.7; 95% CI, 1.4–2.1). This difference was greater still in Indigenous Australians with an Indigenous first language (relative risk 2.9; 95% CI, 2.2–3.8). For the Indigenous Australian cohort, being diagnosed with more advanced stage disease was more likely for four of the five cancers investigated. Lung cancer was the exception. Patients were identified from the Northern Territory Cancer Registry and stage and clinical data gathered through medical note review which was then linked to state and national death databases. Ethnicity was also confirmed by medical note review thus it is likely the study relied on accurate data for ethnicity and other key variables. Stage (and cancer type) accounted for over half of the differential survival noted in the study. The aforementioned 1.7 relative higher risk of cancer death for Indigenous Australians was 2.5 when adjusted for age only (95% CI 2.1–3.0) (Condon et al., 2006).

Likewise a New South Wales (NSW) multi-site study that was also able to account for stage reported significantly poorer survival for Indigenous Australians than that of their non-Indigenous counterparts (Morrell et al., 2012). In Indigenous Australian people 51% of men and 43% of women had died of their cancer by five years following diagnosis. This compared to 36% and 33% of non-Indigenous Australians men and women respectively. This study aimed to account for known undercounting of Indigenous Australians in the NSW cancer registry by using multiple imputation to assign ethnicity status where those
data were missing, reported at 12-18% over the time period of the study (1999 – 2007). Five year survival was reported and cox proportional hazard modelling used to produce cancer specific hazard ratios for 18 key cancer sites (including stomach cancer). However while hazard ratios were adjusted for age, year of diagnosis and stage at diagnosis only the final hazard ratio is reported thus it is impossible to assess the impact of these factors on survival based on their manuscript. Overall, for all cancer sites, Indigenous Australians were less likely to be diagnosed with localised disease and correspondingly more likely to be diagnosed with regional or distant disease than their non-Indigenous counterparts. However, they were significantly and substantially more likely to die at each stage grouping (including unknown stage) than non-Indigenous people, even when diagnosed at the potentially curable localised stage. Significantly poorer survival was also reported for a number of individual cancer sites; these were often preventable cancers, head and neck, lung, cervix, or amenable to early detection, bowel and breast, and include stomach cancer (Morrell et al., 2012).

Those studies above that investigated reasons for the differential survival observed provided evidence that Indigenous Australians were more likely to live in areas remote from cancer treatment facilities, came from more deprived quintiles in society, were more likely to have more advanced disease when diagnosed, were more likely to have comorbid conditions and were less likely to receive curative treatment for their cancer than non-Indigenous Australians (Condon et al., 2014; McCramb et al., 2012; Moore et al., 2014a; Moore et al., 2011; Condon et al., 2006; Valery et al., 2006; Chong and Roder, 2010). Furthermore higher levels of comorbidity, less favourable stage at diagnosis and differential receipt of treatment all played a role in the poorer survival outcomes seen within the Indigenous Australian peoples (Moore et al., 2014a; Condon et al., 2006; Valery et al., 2006; Chong and Roder, 2010). In addition, much of the survival disparity occurs in the first years after diagnosis when access to treatment is most likely to play a key role in subsequent survival (Condon et al., 2014; McCramb et al., 2012).
A number of individual cancer site studies add to the literature. Similar survival between Indigenous and non-Indigenous Australians was reported for colorectal (Moore et al., 2014b) and oral cancers (Frydrych et al., 2014). Poorer survival was reported for Indigenous Australian women with cervical (unadjusted HR 2.46; 95% CI, 1.03–5.90) (Diaz et al., 2015a) and breast cancers (age adjusted HR 1.88; 95% CI, 1.36–2.51) (Supramaniam et al., 2014), when compared to non-Indigenous women. As well poorer survival was reported for Indigenous Australians with lung (unadjusted HR 1.48; 95% CI 1.14–1.92) (Coory et al., 2008) and head and neck cancers (unadjusted HR 2.19; 95% CI, 1.36–3.53) (Moore et al., 2011), when compared to non-Indigenous Australians. Differences in stage, receipt of treatment and level of comorbidity accounted for some of the survival disparities between the ethnic groups for breast (Supramaniam et al., 2014) and head and neck cancers (Moore et al., 2011). Ethic differences in treatment and level of comorbidity accounted for most of the lung cancer survival disparities (Coory et al., 2008) while stage and treatment differences accounted for all the survival disparity in cervical cancer (Diaz et al., 2015a).

**Stomach Cancer Survival - Australia**

Only three Australian studies report on stomach cancer individually. These studies show that non-Indigenous Australians are twice as likely as Indigenous Australians to survive for five years once diagnosed with stomach cancer. Indigenous Australian women are particularly adversely affected. All three studies have been described in the section above.

Poorer stomach cancer survival for Indigenous Australians living in NSW compared to non-Indigenous was reported by Morrell and colleagues (HR 1.36, 95% CI 1.01–1.82, adjusted for age and stage at diagnosis) (Morrell et al., 2012). Stage at diagnosis (extent of disease) was only reported on cumulatively for all cancer sites and only the adjusted hazard ratios were reported so it is impossible to determine the effect of stage specifically.
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on stomach cancer from their manuscript. The study found that for Indigenous men the likelihood of surviving five years was 19.9% compared to 29.6% for non-Indigenous. While in women these likelihoods were 11.4% compared with 29.5%. The female Indigenous Australian/non-Indigenous hazard ratio was 1.98 meaning that non-Indigenous women were nearly twice as likely to survive than Indigenous Australian women (Morrell et al., 2012).

The Queensland study by Moore and colleagues (Moore et al., 2010) reported Indigenous Australian/non-Indigenous mortality ratios of 1.57 (0.98–2.37) for men and 1.11 (0.53–2.04) for women. So despite the finding of a lesser incidence rate among Indigenous Australian women within this study (as previously outlined) it appears that Indigenous Australian women remained more likely to die from their stomach cancer than their non-Indigenous counterparts.

The national survival study (Condon et al., 2014) reported one year stomach cancer survival of 39.8% for Indigenous Australian people and 56.1% for non-Indigenous people. The corresponding five year survivals were 16.9% and 30.7%. These are age-adjusted to the age distribution of Indigenous Australians with stomach cancer, but stage was unable to be included.

Taken together, these studies point to much poorer survival from stomach cancer for Indigenous Australians compared to their non-Indigenous countrymen and women.

Survival Inequities in North America

A number of American studies have investigated indigenous inequities in cancer survival. They show a higher risk of dying from cancer, and poorer survival once diagnosed, for most indigenous peoples, relative to the majority white American population. Of all population groups in America, American Indian/Alaskan Natives (AI/AN) (and although not indigenous also African Americans) consistently fare worst in terms of survival.
American Indians and Alaskan Natives

Indigenous Americans have persistently poorer cancer survival relative to the non-indigenous American population with AI/AN men showing the poorest survival of any ethnic group in America (Gilliland et al., 1998). One State based study (Gilliland et al., 1998) and two large studies using Surveillance and End Results (SEER) population data (Clegg et al., 2002; Jemal et al., 2004) provide the most evidence of these survival disparities. As detailed below, all three studies report markedly poorer cancer survival for the AI/AN population compared with white Americans.

A large study looking at trends in cancer survival across 27 cancer sites in residents of New Mexico and Arizona not only found consistently poorer cancer survival among AI/AN peoples compared with non-Hispanic whites but also evidence of widening survival disparities (Gilliland et al., 1998). The study used data from the New Mexico Tumour Registry which has worked to ensure accurate ethnicity data for the indigenous populations it serves. Relative five year survival rates and death rates were calculated. In the first time period investigated 1969 – 1982 non-Hispanic whites had better survival than American Indians for all cancer sites combined and for the majority of individual sites. For all sites combined five year cancer survival probabilities were 53% for whites compared to 48% for American Indians. In the second time period 1983 – 1994, and again for all sites combined, five year cancer survival probabilities were 64% for whites compared to 53% for American Indians. Therefore while cancer survival improved for both ethnic groups over time, the survival improvement was greater for whites than for American Indians leading to widening survival disparities (Gilliland et al., 1998).

The first of the SEER studies by Clegg and colleagues (Clegg et al., 2002) focussed on ethnic disparity in cancer survival in four major cancers, breast, colorectal, lung and prostate. The study utilised data from nine of the SEER cancer registries, covering 9% of the total American population and 14% of AI/ANs for the years 1975 to 1997. While stage distributions were reported and stage was adjusted for in survival analyses, hazard ratios
adjusted for age only were not reported. Thus the effect of stage at diagnosis is unable to be assessed in the data presented within this manuscript. The study did however find that AI/ANs were more likely than non-Hispanic whites to be diagnosed with advanced stage at diagnosis for each of the four cancers. American Indians and Alaskan Natives also had the poorest survival overall of any ethnic group in the study compared with non-Hispanic whites. The male AI/AN to white hazard ratio for all four cancers combined was 1.7 (95% CI, 1.5 – 1.8) and female 1.8 (95% CI, 1.7 – 2.0). That AI/AN had the poorest survival of any ethnic group was also true for each of the individual cancers, except colorectal cancer in men where African American men presented with the highest relative risk of death. While the risk of dying decreased over time for all ethnic groups this improvement differed by ethnicity and cancer site and survival disparities persisted throughout the study period (Clegg et al., 2002).

The second of the SEER studies by Jemal and colleagues (Jemal et al., 2004) utilised data from 12 SEER cancer registries covering 14% of the US population and 21% of AI/ANs. While it was not solely focussed on survival it does include a comprehensive analysis of survival across five ethnic groups for 15 cancer sites, using Cox proportional hazard modelling. After adjusting for age and stage at diagnosis the AI/AN to white hazard ratio for all cancers combined was 1.69 (95% CI, 1.59 – 1.79) in men and 1.54 (95% CI, 1.45 – 1.64) in women. These represent the poorest relative risk of any of the ethnic groups included in the study.

**Stomach Cancer Survival**

A number of studies that specifically investigate or include stomach cancer with their analyses found both that indigenous people were more likely to be diagnosed with advanced stomach cancer and more likely to die of their stomach cancer, even when stage was taken into account (Young et al., 1984; Gilliland et al., 1998; Samet et al., 1987; Jemal et al., 2004).
In the same SEER based study by Jemal and colleagues as above (Jemal et al., 2004) five-year stomach cancer survival probabilities were 19% in AI/AN men and 35% in white men. For women these probabilities were 22% and 31% respectively. After adjustment for age and stage the AI/AN to white hazard ratio was 1.87 (95% CI, 1.52–2.30) for men and 1.53 (95% CI, 1.19–1.97) for women. While these confidence intervals are wide they remain statistically significant, suggesting substantially poorer survival among AI/ANs (Jemal et al., 2004).

Two studies investigated stomach cancer as an individual cancer. The studies by Samet and colleagues (Samet et al., 1987) and Gilliland and colleagues (Gilliland et al., 1998) in New Mexico and Arizona are also described above. The studies both found that the five year survival from stomach cancer was poor for both white Americans and American Indians (and Hispanics). However the survival probability for whites at 17% was better than that of American Indians at 14%. American Indians were reported to be less likely to be diagnosed with localised disease and less likely to receive treatment appropriate to their stage of disease compared to white Americans. These factors made some difference to their likelihood of survival but did not explain all of the disparity. The American Indian to white hazard ratio for 1969–1982 was 1.11 (95% CI, 0.95–1.29). This ratio decreased to 1.07 (95% CI, 0.92–1.25) once adjusted for stage and treatment receipt (Samet et al., 1987; Gilliland et al., 1998). In the time period 1983–1994 the same hazard ratio decreased from 1.21 (95% CI, 1.01–1.45) to 1.08 (95% CI, 0.91–1.30). These results suggest that most of the survival disparity between American Indian and white Americans with stomach cancer was due to a greater likelihood of being diagnosed with more advanced disease and a lesser quality of treatment received by indigenous Americans (Gilliland et al., 1998).

One further study investigated stomach cancer survival for eight ethnic groups in America, including whites and American Indians (Young et al., 1984). This study used SEER data from patients diagnosed 1973-79 who were then followed up until December 31, 1981 in order to assess their survival. American Indians had the poorest one, three
and five year survival of any of the ethnic groups looked at. With a relative five year survival of 7% for men and women combined the American Indians in the study were only half as likely to survive their disease as white Americans. The study merely investigated and compared cancer survival for the different population groups, it did not attempt to explain or account for these disparities.

Other Indigenous Groups

Stomach Cancer Survival

One final paper reported stomach cancer survival in an indigenous population. Along with their high incidence and mortality the indigenous Mapuche people of Chile also have poorer survival than their non-indigenous counterparts once diagnosed with the disease. This in a region where the probability of surviving stomach cancer is poor overall compared to international survival probabilities (Heise et al., 2009). In this study 79 Mapuche and 369 Hispanic/white people were eligible for survival analysis. Of these 392 people died of stomach cancer, 11 from other causes and only 42 people overall remained alive five years after diagnosis. This represents a 10.6% survival rate when survival rates in other countries are often around 20%. When compared to the majority Hispanic/white population of the region the indigenous Mapuche had even poorer survival still. Looking at three year survival 7.3% of the Mapuche cohort remained alive compared with 16.9% of the non-indigenous population, while only 4.4% of the Mapuche cohort were alive at five years compared to 11.9% of the non-Mapuche cohort (Heise et al., 2009).

Summary of Indigenous Stomach Cancer Survival

In each country reviewed above indigenous people are less likely than the non-indigenous population to survive their cancer once diagnosed. Where investigated, indigenous
people were more likely to live in geographically (in terms of cancer treatment) and socioeconomically disadvantaged areas, were more likely to be diagnosed with advanced disease and/or comorbidities and were less likely to receive curative treatment for their cancer than non-Indigenous. Furthermore these factors played a role in the poorer survival outcomes observed.

Poorer survival for indigenous people is especially true of stomach cancer. In Chile over twice as many non-indigenous people diagnosed with stomach cancer are alive five years after diagnosis than the indigenous Mapuche people. A similar pattern is seen in Indigenous Australians with stomach cancer whom were reported as half as likely to survive for five years after diagnosis than non-Indigenous Australians. Indigenous Australian women were particularly adversely affected. Likewise American Indians were only half as likely to survive their stomach cancer as white Americans. American Indians were also less likely to be diagnosed with localised disease and less likely to receive treatment appropriate to their stage of disease compared to white Americans and these factors appeared to account for most of the survival disparity observed.

Māori/non-Māori Cancer Survival

There is a growing body of work that describes differential cancer survival between Māori and non-Māori New Zealanders. Three large and two smaller studies that investigate survival across a number of key cancers all find significant survival disparities, with poorer survival for Māori when compared to non-Māori (Soeberg et al., 2012; Robson et al., 2006; Robson et al., 2010; Jefferys et al., 2005; Haynes et al., 2008). A number of cancer-site specific studies add to the literature (McLeod et al., 2010; Hill et al., 2010a; Brewer et al., 2012b; Alexander et al., 2010; Stevens et al., 2008b; McKenzie et al., 2011; Obertova et al., 2014b; Chamberlain et al., 2013; Swart et al., 2013; Campbell et al., 2015).
The first of the multi-cancer site studies by Jefferys et al. (Jefferys et al., 2005) found significantly poorer survival across a number of cancer sites for Māori when compared to non-Māori. The authors linked cancer registrations over an eight year period across 20 key cancer sites (n=124,599) to mortality data and compared survival for Māori, Pacific and non-Māori non-Pacific New Zealanders, using a prioritised ethnicity classification. They report a poorer five year survival for Māori than that of non-Māori non-Pacific New Zealanders for the majority of cancer sites, including breast (relative survival rate; Māori 0.74 vs non-Māori non-Pacific 0.81), cervix (RSR 0.63 vs 0.75), colorectal (RSR; 0.41 vs 0.60), lung (RSR; 0.06 vs 0.10), prostate (RSR; 0.69 vs 0.83) and uterus (RSR; 0.62 vs 0.75). Once age and stage were accounted for, five year survival continued to be poorer for Māori across the majority of the 20 cancers investigated. Additionally while stage at diagnosis explained much of the survival disparity for breast, ovarian and prostate cancers, very little of this differential survival was explained by stage for cancers of the bladder, cervix, colon/rectum, head/neck/larynx, lung or uterus. The authors point to differential socioeconomic position and differential health care access as possible contributors to this remaining disparity (Jefferys et al., 2005).

Likewise the reports Unequal Impact and its sequel Unequal Impact II both find significantly poorer cancer survival across most cancer sites for Māori when compared to non-Māori (Robson et al., 2006; Robson et al., 2010). Both of these reports are based on cancer registry data linked to mortality and census databases. In contrast to the previous study these reports use an ever-Māori method of ethnicity classification to minimize a known under-count of Māori in these databases, whereby if a person has ever been identified as Māori in any of the data sources they are assigned Māori ethnicity in the study. The reports also age-standardise to the average Māori population, to better reflect the relatively young Māori age structure. The first study Unequal Impact reports that Māori have a greater than two-fold increase in dying for cancers of the testis, cervix, prostate, bladder, rectum and mouth compared to non-Māori. The authors adjusted for stage (extent of disease) at diagnosis and found that for most cancers some of the
survival disparity could be explained by stage, however for other cancers Māori remained more likely to die from their cancer despite being diagnosed at the same stage as non-Māori (Robson et al., 2006). In the second report *Unequal Impact II* the authors attempt to explain this remaining disparity by looking at cancer survival between Māori and non-Māori accounting not only for stage at diagnosis but also socioeconomic position and rural-urban status; the latter as a proxy for health care access (Robson et al., 2010). They found that after adjusting for stage at diagnosis the risk of dying for Māori remained significantly higher for all the investigated cancers when compared to non-Māori (Figure 4). They also report that Māori living rurally have significantly lower survival from cervical, prostate and uterine cancer than those living in urban areas and Māori have a non-significant but steeper deprivation gradient than non-Māori for most cancers. They conclude that while stage at diagnosis, socioeconomic status and place of residence do play a role in differential survival between Māori and non-Māori New Zealanders, the gaps in survival from cancer remain even after accounting for these factors (Robson et al., 2010).
A further multi-cancer site survival study undertaken on New Zealand’s five most common cancers diagnosed between 1994 and 2004 (n=99,062) also found consistent gaps in survival between Māori and non-Māori non-Pacific New Zealanders (Haynes et al., 2008). This study utilised cancer registry and mortality data and then matched these data to New Zealand census data in order to determine if not only stage but also socioeconomic position and travel time to primary care or a cancer treatment centre impacted on survival. Gaps in survival were however still found between Māori and non-Māori non-Pacific New Zealanders across all five cancers. Prostate cancer showed the widest gap with Māori having nearly twice (93.5% higher) the likelihood of dying from their cancer once diagnosed compared to non-Māori non-Pacific New Zealanders. Once the authors controlled for extent of disease at diagnosis these ethnic inequities remained, albeit with somewhat smaller gaps. Breast cancer was the exception where, as in the
study by Jefferys et al, it appears that extent of disease at diagnosis explained all of the ethnic survival disparity. The authors also found that survival was negatively associated with increasing deprivation for colorectal, lung, and breast cancers along with melanoma but not for prostate cancer. Travel time was important to survival from colorectal and prostate cancers. The authors conclude that while extent of disease at diagnosis is the most important predictor of survival age, sex, socioeconomic position and especially ethnicity all play roles in the likelihood of survival from these five cancers. However, with the exception of breast cancer, the factors investigated did not explain all of the observed ethnic survival disparities; again these authors point to differential access to health care services as playing a role in the remaining disparity for Māori (Haynes et al., 2008).

The most recent multi-site study *Cancer Trends: trends in cancer survival by ethnic and socioeconomic group* report presented not only information on disparities in cancer survival for 21 cancers over a 13 year period - 1991 to 2004 - but also reported on trends over this time period in disparities for these cancers (Soeberg et al., 2012). *Cancer Trends* linked Cancer Registry registrations, mortality data and New Zealand Census records for around 145,000 patients; ethnicity was classified according to self-identification in the census dataset and assigned to either Māori or non-Māori. Excess mortality findings are reported for each cancer site, ethnic group and income group; these are adjusted for age, sex, ethnicity (for income analyses), time since cancer diagnosis, and calendar period of diagnosis. However, these findings were unable to be adjusted for stage due to poor data quality. Māori were shown to experience excess mortality, of 10% or more, in 17 of the 21 sites of cancer investigated. Averaged across the 21 cancer sites, Māori with cancer experienced excess mortality 29% higher than non-Māori with cancer (Soeberg et al., 2012). And while survival improved over this time period for all 21 cancer sites, this improvement was differential by ethnicity and by cancer site. Overall there was no increase in the survival gap between Māori and non-Māori but for some cancers a large survival gap remains. Cancers that already had a higher likelihood of cure, such as breast cancer, prostate and thyroid gland cancers show greater improvements in survival than
those with a poor prognosis, with the latter including stomach cancer (Soeberg et al., 2012).

A number of cancer specific studies all report poorer survival among Māori compared to non-Māori New Zealanders for cancers of the brain (Alexander et al., 2010), colon (Hill et al., 2010a), cervix (Brewer et al., 2012b; McLeod et al., 2010), breast (McKenzie et al., 2011; Campbell et al., 2015; Seneviratne et al., 2014a; Seneviratne et al., 2015), rectum (Swart et al., 2013), liver (Chamberlain et al., 2013), testis (Gurney et al., 2015) and prostate (Obertova et al., 2014b).

The studies above highlight sustained and, at times, unexplained disparities in cancer survival between Māori and non-Māori. Factors such as stage (or extent of disease) at diagnosis, age, sex, socioeconomic status and place of residence all appear to play a role in the differential survival seen between Māori and non-Māori New Zealanders. However these factors do not fully explain the disparity (with the exception of breast cancer). The authors of these studies point to the fact that differential health care access may be a contributor to the remaining disparity.

**Summary of Māori/non-Māori Cancer Survival**

The studies above highlight sustained and, at times, unexplained disparities in cancer survival between Māori and non-Māori. The five multi-cancer site studies all find significant survival disparities, with poorer survival for Māori when compared to non-Māori (Soeberg et al., 2012; Robson et al., 2006; Robson et al., 2010; Jefferys et al., 2005; Haynes et al., 2008). While survival improved over time for all cancer sites in the large study on survival trends, this improvement differed by ethnicity and cancer site. Furthermore a large survival gap, with poorer survival for Māori than that of non-Māori, remained for many cancers. Factors such as stage (or extent of disease) at diagnosis, age, sex, socioeconomic status and place of residence all appear to play a role in the differing survival seen between Māori and non-Māori New Zealanders. However these
factors do not fully explain the disparity (with the exception of breast cancer). The authors all point to the role that differences in health care access may play as a contributor to the remaining disparity.

**Māori/non-Māori Stomach Cancer Survival**

The prognosis for people diagnosed with stomach cancer in New Zealand is poor, with a five year survival rate for patients with stomach cancer of 20%, compared to a five year relative survival rate of 60% for all cancer sites combined (New Zealand Health Information Service, 2006). This poor prognosis is experienced by both Māori and non-Māori. Nevertheless results from the Cancer Trends study showed that from 1991 to 2004 Māori diagnosed with stomach cancer experienced poorer survival, with 25% greater excess mortality than that of non-Māori aggregated over these years (Soeberg et al., 2012). Additionally while overall survival for patients with stomach cancer in New Zealand improved over the time of the Cancer Trends study with a 14% decrease in excess mortality evident for each 10 year period of the study, there was no evidence of changes in the excess mortality experienced by Māori with stomach cancer when compared to non-Māori over this time (EMRR 0.84; 95% CI, 0.60 – 1.17) (Soeberg et al., 2012).

Jefferys et al (Jefferys et al., 2005) reported worse stomach cancer survival for Māori relative to non-Māori/non-Pacific people in their large multi-cancer site study. This study investigated stomach cancer survival in 259 Māori and 1543 non-Māori/non-Pacific people diagnosed between 1994 and 2002. The probability of being alive five years after diagnosis was similar for the two groups when the data were only age standardised with a relative survival rate of 0.20 for Māori versus 0.22 for non-Māori/non-Pacific. However, when stage was also accounted for, the likelihood of being alive at five years among Māori deceased to 0.15, whereas the non-Māori/non-Pacific likelihood remained the same at 0.22. This represents a rate ratio of 0.68 or, in other words, Māori in the study
were nearly a third less likely to survive their stomach cancer once diagnosed than the non-Māori/non-Pacific people in the study (Jefferys et al., 2005).

The Unequal Impact report found very poor prognosis overall from stomach cancer with around 20% survival at five years (Robson et al., 2006). However the study relied upon Cancer Registry data which has poor staging data for stomach cancer with over 33% of people recorded with unknown stage. While some caution should be taken when interpreting findings based on inadequate stage data, the report found poorer survival for Māori when compared to non-Māori, unexplained by stage. The Māori/non-Māori hazard ratio adjusted for age and sex was 1.57 (95% CI, 1.35 – 1.83), when further adjusted for stage (extent of disease at diagnosis) the hazard ratio rose to 1.73 (95% CI, 1.49 – 2.01).

Stomach cancer was one of the few cancers in Unequal Impact where Māori were more likely than non-Māori to be diagnosed at a localised stage yet Māori remain more likely to die from their disease. As shown in the table below, when stratified by stage groups the Māori/non-Māori hazard ratio was significantly higher for Māori within each stage group, including unknown stage (Table 2). In other words, Māori survival from stomach cancer remains poorer than non-Māori even when diagnosed at the same stage as non-Māori. However to reiterate, as this study was based on inadequate stage data caution should be taken when interpreting the findings.

Table 2: Māori/non-Māori hazard ratios for stomach cancer survival, by stage, 1996–2001

<table>
<thead>
<tr>
<th></th>
<th>Localised</th>
<th>Regional</th>
<th>Distant</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HR (95% CI)</td>
<td>p value</td>
<td>HR (95% CI)</td>
<td>p value</td>
</tr>
<tr>
<td>Total</td>
<td>1.98 (1.14–3.43)</td>
<td>0.015</td>
<td>1.70 (1.28–2.25)</td>
<td>0.0002</td>
</tr>
<tr>
<td>Female</td>
<td>2.17 (0.96–4.94)</td>
<td>0.064</td>
<td>1.54 (1.00–2.38)</td>
<td>0.052</td>
</tr>
<tr>
<td>Male</td>
<td>1.86 (0.89–3.90)</td>
<td>0.10</td>
<td>1.78 (1.24–2.57)</td>
<td>0.002</td>
</tr>
</tbody>
</table>

a) Age- and sex-standardised
b) Age standardised

Source: Robson et al, Unequal Impact (Robson et al., 2006)
Unequal Impact II demonstrated a 24% higher risk of dying from stomach cancer for Māori compared to non-Māori over the period 1996–2006 (Māori/non-Māori HR 1.24; 95% CI, 1.10 – 1.38, adjusted for age and sex) (Robson et al., 2010). As in the previous report, stage does not appear to play a role in this differential survival with the hazard ratio increasing once additionally adjusted for stage (extent of disease) at diagnosis (Māori/non-Māori HR 1.34; 95% CI, 1.20 – 1.49). This trend remained when the unstaged cancers were removed from analyses. However it appears that level of deprivation plays some role in the disparity seen in stomach cancer survival with the previously mentioned Māori/non-Māori hazard ratio decreasing from 1.24 to 1.20 (95% CI, 1.07–1.34) when adjusted for deprivation (Robson et al., 2010).

One further study adds to the pattern of stomach cancer survival disparity experienced by New Zealand Māori. This study found differential survival by ethnicity across all upper gastrointestinal (GI) cancers, including stomach (Gill and Martin, 2002). It used Cancer Registry data - assigning each of its key variables according to the Registry’s classification - to evaluate the effects of socioeconomic status, ethnicity, age, gender and distance from a cancer treatment centre on survival. It did not adjust for stage at diagnosis. The study found that across all upper GI cancers Māori have poorer survival than non-Māori (HR 1.28; 95% CI, 1.13 – 1.46). However for stomach cancer, age is the only independent predictor of survival. Younger Māori patients (< 50 years) with stomach cancer are shown to have significantly poorer survival when compared to non-Māori (p = <0.05) while there is no survival disparity in older patients. The study also found poorer survival for all patients with stomach cancer, regardless of ethnicity, living 51 – 100km from a cancer treatment centre, while those living closest and furthest distances fared better, although the study did not assess distance to specialized surgical treatment services. Given that surgery is the mainstay of curative treatment for stomach cancer this would have been a more interesting variable to assess. In this study level of deprivation did not impact on survival (Gill and Martin, 2002).
Summary of Māori/non-Māori Stomach Cancer Survival

While the studies discussed above may not be directly comparable to each other due to different methodologies (years of analysis, ethnicity classification, comparison groups and standardisation methods) they do provide evidence of survival disparities between Māori and non-Māori diagnosed with stomach cancer in New Zealand. However, the studies above all share similar limitations in that they are all based on routine level Cancer Registry data, which has poor staging data for stomach cancer, linked to the national mortality database. Thus they are unable to provide evidence based on accurate data on the most important prognostic factor, stage at diagnosis. Nor do the studies move beyond describing the ‘problem’ into assessing the impact of patient and treatment factors on subsequent survival. As summarised by Robson and colleagues ‘Stomach cancer is a high priority for Māori cancer control. Efforts to improve outcomes for Māori should be strengthened throughout the cancer continuum’ (Robson et al., 2006: 192). This includes investigating disparity and why it exists (and thus what can be done about it) based on good quality data, including accurate stage and clinical data.

Summary of Indigenous Cancer and Stomach Cancer Inequities

Cancer inequities exist internationally and in New Zealand across a number of axes. These inequities do not happen by chance but rather are due to a complex mix of factors, including differential access to the underlying determinants of health and differential access to, and through, health services including cancer services. The inequity observed between Māori and non-Māori is the most evident cancer-related inequity in New Zealand. Overall between 1996 and 2001 Māori were 18% more likely to be diagnosed
with cancer but 93% more likely to die from it compared with non-Māori (Robson et al., 2006).

Differences in stomach cancer incidence and mortality between non-indigenous and indigenous people are evidenced in New Zealand (Blakely et al., 2011; Dockerty et al., 1991; Thompson, 2002; New Zealand Health Information Service, 2012), Australia (Condon et al., 2005; Moore et al., 2010; Zhang et al., 2011; Supramaniam et al., 2006; Morrell et al., 2012), America (Ward et al., 2004; Paltto and Chu, 2004; Jemal et al., 2004; Wiggins et al., 2008; Espey et al., 2005), Siberia (Tsukanov et al., 2011), Chile (Heise et al., 2009), Canada and Greenland (Arnold et al., 2014; Friborg et al., 2003).

Ethnic differences in cancer survival within a country provide an indirect marker of the equity of that country's health care delivery. Poorer survival from stomach and other cancers is observed among indigenous people in a number of countries (Soeberg et al., 2012; Ferlay et al., 2010; Coleman et al., 2008; Walters et al., 2011). At times this poorer survival is explained by differential stage at diagnosis, higher levels of comorbidity and differential receipt of treatment (Moore et al., 2014a; Moore et al., 2011; Condon et al., 2006; Valery et al., 2006; Samet et al., 1987; Gilliland et al., 1998). The evidence of differential cancer treatment for New Zealand Māori is discussed in the following chapter.

However while a number of studies provide evidence of significant survival disparities between Māori and non-Māori diagnosed with stomach cancer in New Zealand (Jefferys et al., 2005; Soeberg, 2012 #66; Robson et al., 2006; Robson et al., 2010; Gill and Martin, 2002), the studies attempt to assess the impact of patient or treatment factors on subsequent survival. In addition, and importantly to this thesis, these studies all share a common limitation. These studies are all based on Cancer Registry data, and thus on poor stomach cancer staging data. Therefore, they are unable to provide the evidence of stomach cancer survival disparity based on accurate data on the most important prognostic factor, stage at diagnosis.
Chapter 4: Understanding Inequity and Interventions

This chapter provides further background and context to this thesis. There are a number of possible explanations for ethnic differences in cancer survival, many of these at an individual or patient level. Explanations such as patients’ socioeconomic status, level of comorbidity or stage at diagnosis while valid are, with a public health lens on, actually a reflection of differential access to the underlying determinants of health. As this thesis is positioned in the historical and contemporary contexts of Māori and non-Māori New Zealanders, it acknowledges the importance of processes such as colonisation and neoliberalism in shaping and perpetuating differential access to those determinants of health and so impacting on health equity.

As stated in the previous chapter cancer survival is a useful indicator of the overall effectiveness of a country’s cancer screening, diagnostic and treatment services; inequitable survival between population groups (as is seen for stomach cancer in New Zealand) then provides an indirect marker of the equity of access to, and quality of, those services. Thus the main focus of this thesis is on whether different ethnic groups in New Zealand (Māori and non-Māori) receive differential access to, and quality of care for stomach cancer, and if so, whether that contributes to differential survival. Māori with stomach cancer deserve excellence in cancer care, including equitable and timely access to high quality cancer services, thus the thesis also turns its focus to where we can intervene to minimise any disparities. If health disparities are said to arise from deliberate policy options then it follows that any disparities should be amenable to intervention, although the nature of institutionalised racism means that unequal treatment is entrenched in organisations, often not visible and difficult to change.

This chapter firstly outlines a theoretical model that helps to explain health disparity or inequity between ethnic groups. Secondly it focuses on whether Māori and non-
Māori in New Zealand are likely to receive differential cancer care once diagnosed with stomach cancer. It does this by examining the literature on whether Māori and non-Māori receive differential health care more generally, and cancer care (for cancers other than stomach cancer) more specifically. Finally the chapter outlines a framework for examining ethnic inequities in cancer care and looks to the literature to explore potential interventions to improve access to, and quality of, cancer services for Māori in New Zealand.
A Model to Understand Differential Access to, and Quality of, Health Care

Camara Jones, an American researcher, argues for three pathways through which health inequities occur (Jones et al., 2009). These are: differential access to the underlying determinants of health (discussed in relation to Māori and non-Māori in a previous chapter), differential access to health care and differential quality of health care received.

Jones also developed a theoretical model that helps to explain why differential access to, and quality of, health care may occur between ethnic groups (Jones, 2000; Jones, 2002; Jones et al., 2009). Jones’ model outlines three levels at which racism exists in society: that is, internalised, personally-mediated and institutionalised racism (Jones, 2000). With this model Jones describes the mechanisms by which racism produces and maintains ethnic health disparities within a population. In particular the model highlights the roles that historical injustices play in shaping patterns of disadvantage or privilege in current society. This disadvantage (or privilege) is then, according to Jones, perpetuated through contemporary structural factors (Jones, 2000).

Jones describes internalised racism as “acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth” (Jones, 2000: 1213). This acceptance is said by Jones to reflect the values within a society including those that privilege certain groups within that society.

Personally-mediated racism is the most explicit of the three levels of racism, whereby people behave in discriminatory ways toward members of different ethnic groups based on assumptions about their abilities or motives. Personally-mediated racism can be intentional or non-intentional and includes acts of commission and omission (Jones, 2000).

Institutionalised racism on the other hand is expressed as “differential access to the goods, services, and opportunities of society by race” (Jones, 2000: 1212). By this
definition institutionalised racism can mean differential access to physical conditions (or the underlying determinants of health) that impact on health as well as access to power and control. Institutionalised racism can also manifest as inaction in the face of need. While institutionalised racism can describe any system of inequity based on ethnicity, it occurs in the institutions of society such as media organisations and universities along with government and its entities, including health care organisations.

While all three levels play a part in creating health disparities between different ethnic groups, Jones places most emphasis on addressing institutionalised racism in interventions to address health disparities (Jones, 2000; Jones, 2002; Jones et al., 2009). That is, addressing the structural causes of inequity. This includes addressing the underlying determinants of health which cause certain groups to be sicker than others, as well as addressing access to, and quality of, care within the health system itself.

Other international researchers also examine and acknowledge the impact of racism on ethnic health inequities with increasing recognition internationally of the need to consider racism as an underlying determinant of health and a driver of health inequity (Feagin and Bennefield, 2014; Williams and Mohammed, 2009; Krieger, 2003). However Jones’ model has been described as it provides a useful framework for thinking about racism in the New Zealand context. Jones’ model resonates with the history of Māori and non-Māori which has been highlighted in an earlier chapter. Jones’ model has also been utilised to examine the relationship between ethnicity and cancer care, as well as to recommend interventions to address disparities, in New Zealand (Walker et al., 2008).

The nature of institutionalised racism means that it is a longstanding issue, deeply embedded in organisations, often not visible and difficult to change (Williams and Mohammed, 2009; Krieger, 2003; Feagin and Bennefield, 2014). It can exist, or persist, even when individuals within organisations are not prejudiced and do not behave in discriminatory ways (Williams and Mohammed, 2009; Krieger, 2003). Institutionalised racism within society can however be changed (Feagin and
Bennefield, 2014) and as argued by Jones ‘inaction in the face of need’ is a form of institutionalised racism (Jones, 2002).

There is a growing body of work in New Zealand explicitly recognising the impact of racism on health. This work provides evidence that Māori experience higher levels of racial discrimination and subsequently have poorer health outcomes. Two studies based on consecutive New Zealand Health Survey data (Harris et al., 2006a; Harris et al., 2012) found that of all the ethnic groups surveyed Māori reported experiencing the highest levels of discrimination and were ten times more likely to report multiple types of discrimination than non-Māori. These higher levels of reported discrimination were associated with poorer self-rated health for Māori compared to non-Māori. Further, although the Ministry of Health has recognised institutional racism as a determinant of health in policy documents since the 1990s, recent research indicates that institutional racism is common within health policy in New Zealand (Came, 2014). According to Came (2014), institutional racism is seen within decision-making practices with policy decisions primarily made by the dominant ethnic group, the use of evidence to favour the dominant ethnic group viewpoint, deficiencies in cultural competencies such as low levels of cultural competency training among senior management, flawed consultation processes, and ‘Crown filters’ that dilute Māori content in policy (Came, 2014).

There is also much evidence of inequitable access to, and quality of, health care and cancer care for Māori in New Zealand. In this thesis Māori/non-Māori differences in the treatment or management of stomach cancer are interpreted as reflecting institutionalised racism within New Zealand’s health care system.

**Māori/non-Māori Access to Health Services**

A body of health services research in New Zealand shows how racism might affect Māori health; how that Māori, who need healthcare the most, receive it the least or in lesser quality.
Racism manifests within the primary health care sector in Māori/non-Māori disparities in primary health care utilisation, poorer quality services and inferior patient-provider relationships (Crengle et al., 2005; Jansen et al., 2008; Ministry of Health, 2014a). This is important as the majority of cancer in New Zealand, including stomach cancer, is detected within the primary care setting. Māori (and low-income groups, in which Māori predominate) are more likely than non-Māori to report unmet primary health care need and are less likely to access general practitioner services than other groups, despite subsidies intended to raise Māori levels of engagement with primary health care (Scott et al., 2003; Crengle et al., 2005; Ministry of Health, 2014a). Cost, distance, transport and cultural differences between providers and patients are cited as barriers to utilisation of primary care services by Māori (Jansen et al., 2008).

Once Māori do access primary care services they can receive a differential quality of care. A nationally representative survey of primary medical care services, entailing data collected from 244 general practitioners (GPs) across New Zealand, found that when Māori did see a primary care provider their consultation was of shorter time than that of a non-Māori patient (mean length 13.7 minutes for Māori patients vs. 15.1 minutes for non-Māori patients) (Crengle et al., 2005). In the same study Māori were also less likely to be referred on for tests (Māori referred in 21.0% of visits compared to non-Māori in 25.4% of visits) or to a specialist service (Māori referred in 14.7% of visits compared to non-Māori in 16.2% of visits) (Crengle et al., 2005). Māori have also been shown to be less likely than non-Māori to collect a prescription due to cost, with Māori reported in the 2006/2007 New Zealand Health Survey as being 2.3 times less likely to have collected a prescription due to cost than non-Māori/non-Pacific people (Ministry of Health, 2008); using this same measure Māori were 2.4 times less likely in the 2013/2014 Health Survey (Ministry of Health, 2014a).

Furthermore the patient–provider relationship has been reported to be of lesser quality for Māori (Jansen et al., 2008; McCleanor and Naim, 2002; Crengle et al., 2005). Patient–provider communication is cited as a major barrier to Māori receiving quality healthcare (Jansen et al., 2008; McCleanor and Naim, 2002). Doctors in the nationally representative survey of primary medical care services described in the
paragraph above reported lower levels of rapport with Māori patients (Crengle et al., 2005). Furthermore discourse analysis has been used to analyse the way 25 non-Māori GPs talk about Māori health. The analysis showed that GPs largely spoke in a way that blamed Māori for their poor health status and supported the view of individual responsibility for health, while ignoring the advances made by Māori which described health in holistic ways (McCreanor and Naim, 2002). Moreover Māori patients have reported that they have been treated with disrespect by non-Māori health providers merely because they were Māori, based on the findings of ten focus groups across New Zealand (Jansen et al., 2008).

Likewise, specialist and hospital services show differential accessibility and quality of care for Māori and non-Māori. The 2006/07 New Zealand Health Survey (Ministry of Health, 2008) indicates that, despite high need for health care, Māori are less likely to see a specialist in an outpatient setting yet more likely than European/Other to access emergency department care or to be hospitalised. Māori also have substantially higher rates of amenable or avoidable mortality and avoidable hospitalisation than non-Māori. This suggests lesser access and uptake of primary prevention, primary health care and ambulatory treatment (Ministry of Health, 2010b).

A number of studies show a lesser quality of secondary or tertiary health care received by Māori (Davis et al., 2006; Wilson and Barton, 2012; Westbrooke et al., 2001; Tukuitonga and Bindman, 2002; Harris et al., 2007). One of the most extensively researched examples is from cardiac care.

Māori experience higher rates of, and mortality from, cardiovascular disease than do non-Māori (Curtis et al., 2007; Ministry of Health, 2013c) and so might also be expected to have higher rates of intervention cardiology (treatment to restore the heart’s blood supply that has been shown to reduce morbidity and mortality from cardiovascular disease). Yet two studies that analysed intervention rates for cardiovascular disease through the 1990’s (Westbrooke et al., 2001; Tukuitonga and Bindman, 2002) found that Māori, while more likely to be hospitalised for heart failure (Westbrooke et al., 2001), were less likely to undergo intervention cardiology for that heart failure (Westbrooke et al., 2001; Tukuitonga and Bindman, 2002). This disparity
remained after controlling for age, sex and deprivation level (Westbrooke et al., 2001), although the authors do not report adjusting for comorbidity which could have impacted results. The differences by ethnicity are described as “disturbing” (Westbrooke et al., 2001) and as a failure of the health system as a whole to provide quality care (Tukuitonga and Bindman, 2002).

Cardiac intervention rates have increased since the 1990’s, for both Māori and non-Māori. Yet, at least up until 2005, they remained lower for Māori despite much higher mortality (Curtis et al., 2007). In more recent research on cardiac care within one large New Zealand hospital, Māori who received a coronary bypass (CABG) were more likely to have died at both 30-days and 1-year after surgery than non-Māori (Wang et al., 2013). These differences remained after the authors adjusted for cardiac mortality risk factors such as smoking status, comorbidity and level of deprivation. A national level study supports these mortality findings with Māori having substantially higher risk of mortality at 28-days and one-year than Europeans/Others after hospitalisation for acute coronary syndrome (unstable angina and any myocardial infarction or heart attack) (Grey et al., 2014). Again the ethnic mortality disparity persisted after adjustment for socioeconomic status however treatment differences were not investigated. So despite higher levels of cardiovascular disease in Māori (Ministry of Health, 2013c; Chan et al., 2008) and it being over a decade since the work of Westbrooke et al. clearly identified differential treatment by ethnicity, it appears that Māori continue to receive suboptimal cardiac care; certainly Māori have worse outcomes after a cardiac event than their non-Māori counterparts providing indirect evidence of Māori/non-Māori treatment disparity.

Treatment disparity within cardiac care is likely in part to be related to access to and type of treatment facility. A series of national audits undertaken through the last decade looking at the management of patients with acute coronary syndrome found considerable differences according to treatment facility type (Ellis et al., 2013; Ellis et al., 2010; Ellis et al., 2004). In New Zealand a number of large tertiary public hospitals and three private hospitals, all sited in main centres, provide intervention cardiology services. Patients admitted to these intervention hospitals waited less time and were
more likely to receive comprehensive cardiac investigations than patients admitted to non-intervention hospitals. Intervention hospital patients were also more likely to receive state-of-the-art treatment than those admitted to non-intervention hospitals (Ellis et al., 2004; Ellis et al., 2010; Ellis et al., 2013). Māori were significantly more likely to be admitted to a non-intervention hospital (Ellis et al., 2004; Ellis et al., 2010) meaning they were less likely to receive timely and quality care. This provides an example of how structural issues, in this case the funding and location of health services, can in turn affect the accessibility of those services resulting in poorer care and poorer outcomes for certain groups in society.

One further study that highlights differential receipt of quality care between Māori and non-Māori used adverse events while hospitalised as an overall indicator of treatment quality (Davis et al., 2006). Adverse events can be a useful measure of quality as they reveal systematic failures to provide adequate staffing, training or policies and protocols resulting in undesirable health outcomes. In this study Māori were more likely than non-Māori to experience any adverse event while hospitalised. Moreover after controlling for age, other demographic factors, and reason for hospitalisation Māori were 47% more likely to experience a ‘preventable’ adverse event defined as an error in health-care management due to failure to follow accepted practice at an individual or system level. Furthermore the study showed that despite a higher likelihood of harm when hospitalised Māori had shorter hospital stays than non-Māori (Davis et al., 2006).

Summary: Māori/non-Māori Access to Health Services

The findings above indicate that New Zealand health services are more accessible for non-Māori compared with Māori. Māori are more likely to report unmet primary health care need; accordingly Māori are less likely to see a GP than non-Māori. When they do see a primary care provider Māori are less likely to be referred on, less likely to fill a prescription, their consultation time is shorter than that of non-Māori patients and the provider-patient relationship is reported to be of lesser quality.
Likewise specialist and hospital services show differential accessibility for Māori and non-Māori patients. Using cardiac care services as an example, while Māori have higher rates of, and mortality from, cardiovascular disease they also receive lesser rates of cardiac care, at lesser quality than non-Māori. Māori are less likely to undergo intervention cardiology and when they do, they are more likely to die post-surgery than non-Māori. These disparities are in part likely to be due to differences in access to intervention cardiology hospitals, with Māori significantly more likely to be admitted to a non-intervention hospital. Furthermore, when hospitalised, Māori are more likely to experience an adverse event than non-Māori.

These observations raise questions about why health services in New Zealand perform less well for Māori compared with non-Māori patients. They point to institutional factors that privilege non-Māori and discriminate against Māori within New Zealand’s health care system.

**Māori/non-Māori Access to Cancer Services**

The inequity in observed between Māori and non-Māori in the provision of health care extends to the cancer context. This section reviews recent studies, covering a number of cancers, which together provide compelling evidence of differential accessibility and quality of cancer care for Māori in New Zealand (Hill et al., 2010a; Hill et al., 2010b; Sarfati et al., 2009; Alexander et al., 2010; Lawrenson, 2014; Obertova et al., 2015; Stevens et al., 2008b; Seneviratne et al., 2014c; Seneviratne et al., 2014a; McLeod et al., 2010; Swart et al., 2013; Chamberlain et al., 2013; Seneviratne et al., 2015). None of these studies specifically examined Māori/non-Māori differences in treatment of stomach cancer.

**Colon Cancer**

Differences between Māori and non-Māori New Zealanders have been noted in the presentation and management of colon cancer. These differences impact on survival.
Māori within the study by Hill et al (Hill et al., 2010a) outlined in the previous chapter, had poorer survival with unadjusted hazard ratios showing that Māori were 33% more likely than non-Māori to die from their colon cancer (HR 1.33; 95% CI, 1.03 -1.71). Adjusting for demographic, disease and patient factors (particularly comorbidity) accounted for one-third of the disparity (HR 1.20; 95% CI, 0.89 – 1.63). While further adjusting for health care process and access factors (i.e. type of treatment received, timeliness to treatment, facility and surgeon type, deprivation and rurality) brought the hazard ratio close to null (HR 1.07; 95% CI, 0.77 – 1.47). Māori in this study were more likely to present acutely in a hospital emergency room rather than through a primary care referral, more likely to live in highly deprived and/or rural areas, and more likely to be treated within a smaller non-cancer centre public hospital than either a tertiary or private facility. These latter three factors were considered as markers of health service access. In the case of deprivation the authors argued that while a patient’s level of deprivation may impact on survival through later stage at diagnosis and differential treatment, both of these factors were adjusted for prior to adjusting for deprivation in multivariable modelling. This means that the remaining effect of deprivation was likely to have occurred primarily through its influence on access through health and cancer care services. The results suggest that the majority of the colorectal cancer survival disparity evident between Māori and non-Māori is explained by these latter factors, with factors associated with access to health care services, accounting for around one-third of the differential survival outcomes (Hill et al., 2010a).

In this study, Māori and non-Māori had similar rates of surgical resection however Māori patients were less likely to undergo extensive lymph node clearance and were more likely to die during the postoperative period, indicating receipt of a lesser quality surgical care than that received by non-Māori patients (Hill et al., 2010a). Furthermore most Māori patients who died post-operatively underwent their surgery in a smaller non-cancer centre public hospital (Hill et al., 2010b). In addition Māori with stage III disease were 20% less likely than non-Māori to be offered chemotherapy and 30% less likely to receive chemotherapy within 8 weeks of surgery, even after clinical factors were adjusted for (i.e. age, sex, year of diagnosis, tumour site, tumour
grade and comorbidity). Māori were also substantively more likely to experience a delay of at least 8 weeks before starting chemotherapy (RR, 1.98; 95%CI, 1.23-3.16). This is despite adjuvant chemotherapy within 8 weeks of surgery being the recommended treatment for stage III colon cancer patients at the time (Hill et al., 2010b).

Comorbidity was common among patients in this study overall but Māori patients were more likely than non-Māori to have each of the comorbidities that were recorded within the study, except neurological disorders (Hill et al., 2010b; Hill et al., 2010a). Further analysis from this study provided evidence of a pathway through which disparities in cancer care and outcomes could occur; the analysis suggested that comorbidity played a role in the differential receipt of chemotherapy and subsequently on survival (Sarfati et al., 2009). Both presence of comorbidity, and increasing age, were significantly associated with a lesser likelihood of being offered chemotherapy (16% of patients with a Charlson score of 3 or more were offered chemotherapy compared with 81% of patients with a score of 0). Not being offered chemotherapy was in turn associated with poorer survival (HR 2.32; 95% CI, 1.34 – 4.00, colon cancer specific survival, adjusted for age, sex and comorbidity). Those with higher levels of comorbidity had substantially poorer survival than those without, but those with comorbidity who were offered chemotherapy had 60% better survival than those with comorbidity who were not offered chemotherapy (Sarfati et al., 2009).

Overall this study showed that Māori with colon cancer are less likely to get high quality, and timely, cancer care and that this differential care impacts negatively on subsequent survival for Māori. In part, this poorer survival is due to higher levels of comorbidity among Māori. Further analyses by Sarfati et al (Sarfati et al., 2009) clearly shows that were those with comorbidity were substantially less likely to receive chemotherapy despite the fact that chemotherapy was found to reduce the mortality risk in patients with stage III disease, even in those with the highest levels of comorbidity. In other words this paper suggested that patients with comorbidity, of whom Māori comprise a higher proportion, might be undertreated with adjuvant therapy – and that if they were treated, their survival would likely improve. These
observations raise questions. Why are Māori with colon cancer less likely to receive chemotherapy than non-Māori, and when they do receive it why is its receipt more likely to be delayed? Why do Māori patients receive lesser quality surgical care than non-Māori? Is this a deficit on the part of Māori with colon cancer or could it be that the health system performs better for non-Māori New Zealanders and thus privileges them with better survival outcomes?

Breast Cancer

New Zealand has a publicly funded breast cancer screening programme (BreastScreen Aotearoa) which is open to all women aged 45 to 69 years. However, participation is known to differ by ethnic group with substantially lower participation for Māori women than non-Māori women (Page and Taylor, 2008; Sarfati et al., 2010b). In turn, Māori women with breast cancer have been shown to be more likely to be diagnosed with advanced cancer than non-Māori women, in part explained by their lower rate of screen detected cancer (Seneviratne et al., 2015a). Māori women also had higher rates of mastectomy for cancers potentially amenable to breast conserving surgery (Seneviratne et al., 2015b) and longer waiting times for both surgical care (Seneviratne et al., 2014c) and adjuvant therapy (Seneviratne et al., 2014a) when compared with non-Māori women. The waiting times experienced by Māori fall outside of current recommendations and in the case of adjuvant therapy impact negatively on survival (Seneviratne et al., 2015a). Survival was also significantly lower for Māori women, compared to NZ European women who were diagnosed symptomatically rather than through BreastScreen Aotearoa (Seneviratne et al., 2015a). Furthermore the age-adjusted risk of death from breast cancer for Māori women, which was more than twice that for NZ European women, was largely explained by differences in stage at diagnosis, screening, treatment and patient factors (comorbidity, obesity and smoking) (Seneviratne et al., 2015). The study on which these papers were based used Waikato (a region of New Zealand) breast cancer register data (WBCR) which is a comprehensive database of breast cancers diagnosed since 1999 within the Waikato region. The data held by WBCR has been shown to be more accurate than that of the
NZCR (Seneviratne et al., 2014b), including not only accurate staging data but also detailed presenting, diagnostic and treatment information from both public and private treatment facilities.

Several papers by Seneviratne and colleagues reported the analysis of the WBCR data. The first paper on 1846 women of screening age diagnosed with breast cancer between 1999 and 2012 (Seneviratne et al., 2015a) reported that Māori women were significantly more likely to be diagnosed with more advanced cancer compared with NZ European women (OR = 1.49, p < 0.05, adjusted for age). Half of this stage difference was explained by lower rate of screen detected cancer for Māori women (OR = 1.25, p = 0.101, adjusted for age, year of diagnosis and screening status). For those cancers detected symptomatically, Māori had significantly lower 5-year (64.2% vs. 83.2%, p < 0.001) and 10-year breast cancer survival compared with NZ European (46.5% vs. 73.2%, p < 0.001). No significant survival differences were observed for screen detected cancer by ethnicity or socioeconomic deprivation (Seneviratne et al., 2015a) which highlights the potential for organised screening to improve survival and reduce disparities in breast cancer outcomes in New Zealand.

Another paper by Seneviratne and colleagues investigated ethnic differences in the surgical management of breast cancer for 2848 women newly diagnosed between 1999 – 2012 (Seneviratne et al., 2015b). Māori were significantly more likely to undergo mastectomy for cancers, which were potentially amenable for breast conserving surgery (42% vs. 34%, P = < 0.05), but were significantly less likely to undergo post-mastectomy breast reconstruction (12% vs. 35%, P < 0.001), than NZ Europeans. While women treated within a public sector hospital also appeared more likely to undergo mastectomy (36% vs. 33%, p = <0.05) and less likely to undergo post-mastectomy breast reconstruction (23% vs. 42%, p = 0.002) than women treated within the private sector. No differences were observed in rates of sentinel node biopsy or local therapy for stage I – II cancers (Seneviratne et al., 2015b).

Of the 1264 women undergoing primary surgery for their breast cancer between 2005 and 2010 (Seneviratne et al., 2014c) Māori women were on average younger at diagnosis than NZ European women. As well a significantly higher proportion of Māori
lived in areas of higher deprivation and at a distance greater than 100kms from a treatment facility. Compared to NZ Europeans, Māori were also more likely to be diagnosed with later stage disease. In regards to treatment Māori women were less likely to receive surgery at a private facility than were NZ European women (8.1% vs. 32.5%, p= 0.001) and waited significantly longer for surgery than did NZ European women (mean = 37.1 days vs. mean 30.4 days, p = 0.005). In multivariable modelling a number of factors were associated with these longer wait times to receipt of surgical care. These factors included treatment within the public sector, stage at diagnosis, higher co-morbidity scores, having a mastectomy rather than breast conserving surgery and earlier year of diagnosis (after adjusting for age, socioeconomic status, mode of diagnosis and distance from hospital). Of note, nearly two-thirds of NZ European women (within the screening age) were diagnosed through Breast Screen Aotearoa (BSA), while less than half of the Māori women in the study were (63.7% vs. 49.7%, p = < 0.05). This is important as a much higher proportion of non-BSA diagnosed women compared to BSA diagnosed women - who were subsequently treated within the public sector - had a delay in treatment longer than 31 days (55.7% vs. 47.3%, p = <0.05). This difference was even greater for Māori women; 59.6% of Māori women who were diagnosed symptomatically and treated publicly had a delay in treatment longer than 31 days compared with 37.3% of Māori women who were diagnosed through BSA (p = <0.05). Thus the ethnic difference in BSA participation rates in effect meant that fewer Māori received the advantage that the quality standards and auditing of the programme confer on those diagnosed in this way (Seneviratne et al., 2014c). Thirty one days is the threshold for the longest acceptable delay in access to surgical treatment as set by the Ministry of Health in their Faster Cancer Treatment Indicators (Ministry of Health, 2014b).

Further analysis on the Waikato data by Seneviratne and colleagues (Seneviratne et al., 2014a) focussed on chemotherapy use in 1918 women with non-metastatic breast cancer. Factors associated with delay in adjuvant chemotherapy (using a 60-day threshold) and radiotherapy (using a 90-day threshold) for breast cancer were investigated and compared between Māori and NZ European women. As with surgical care, higher proportions of Māori women compared with NZ European women
experienced delays longer than thresholds for adjuvant chemotherapy (37.3% vs. 30.5%, \( p = 0.103 \)) and radiation therapy (39.8% vs. 30.6%, \( p = <0.05 \)), although in the former case \( p \) values do not denote statistical significance. In multivariate modelling being Māori, living rurally rather than in an urban area, requiring a surgical re-excision and receipt of surgical treatment in public compared with private hospitals were all associated with longer delays for first adjuvant therapy \( (p = <0.05) \), although being of Māori ethnicity was only statistically significant for delay to radiation therapy. Delay in receiving first adjuvant therapy also appeared to impact on mortality with a hazard ratio of 1.45 (95% CI, 1.05-2.01) and non-significant hazard ratios for delay in chemotherapy and radiotherapy, 1.34 and 1.28 respectively (adjusted for a large number of patient and tumour factors) (Seneviratne et al., 2014a).

A final paper by Seneviratne and colleagues (Seneviratne et al., 2015), which included 2,679 women, attempted to explain the survival disparity between observed Māori and non-Māori women. It reports significantly lower 5 year (86.8 vs. 76.1 %, \( p < 0.001 \)) and 10 year (79.9 vs. 66.9 %, \( p < 0.001 \)) crude cancer-specific survivals for Māori compared with NZ European women. Māori women also had significantly higher age-adjusted cancer-specific mortality (HR 2.02; 95 % CI, 1.59-2.58). When this was incrementally adjusted for various explanatory factors, stage at diagnosis explained 25-40 % of the survival disparity, while screening, treatment and patient factors (comorbidity, obesity and smoking) contributed approximately 15% each toward the observed survival disparity with almost all of the cancer survival disparity accounted for within the final model (HR 1.07; 95 % CI, 0.80-1.44) (Seneviratne et al., 2015).

Taken as a whole these papers by Seneviratne and colleagues are consistent with non-Māori women receiving care that could be conducive with a survival advantage over their Māori peers through a number of mechanisms; they were less likely to live rurally further from a cancer treatment centre, less likely to live in a socioeconomically deprived area, less likely to have comorbidity, more likely to be diagnosed early, more likely to be diagnosed through the national screening programme BSA and thus privileged by the programmes quality standards, more likely to be treated privately.
with less lengthy waiting times and when treated within the public system waited less time for surgical and adjuvant care than did Māori women. Furthermore non-Māori women were more likely to undergo breast conserving surgery and when they did have a total mastectomy were more likely to undergo breast reconstruction post-mastectomy. These differences appear to impact on survival. Women whose first adjuvant therapy was delayed, of which a higher proportion were Māori, had a 45% higher likelihood of dying than women whose therapy was not delayed (95% CI, 1.05-2.01). Additionally in women whose breast cancer was diagnosed symptomatically both 5-year and 10-year survival was poorer for Māori women compared with NZ European women, while no significant ethnic difference in survival was observed for women whose breast cancer was screen-detected. This latter finding highlights the potential for organised screening, with agreed and monitored pathways of care, to not only improve survival overall but to also reduce survival disparities between Māori and non-Māori women.

**Prostate Cancer**

Despite having lower incidence rates Māori men are nearly twice as likely to die of prostate cancer as non-Māori men (Obertova et al., 2014b). In part this differential survival is shown to be due to higher rates of prostate specific androgen (PSA) screening in non-Māori men which results in over-diagnosis of cancers with questionable clinical significance and thus very high survival rates (Obertova et al., 2014a). In addition, Māori had higher Gleason scores (extent of disease) at diagnosis and greater likelihood of being diagnosed with stage IV metastatic disease (Obertova et al., 2015). However two studies suggest that differential treatment contributes to the poorer prostate cancer survival profile seen in Māori men.

The first of the two studies that investigated prostate cancer treatment patterns examined the use of surgery (orchidectomy), androgen deprivation therapy (ADT) and chemotherapeutic agents in 15,947 New Zealand men diagnosed between 2006 and 2011 (Lawrenson, 2014). The study identified men from the NZCR and linked data with the Pharmaceutical Collection and the National Minimum Dataset to identify
receipt of treatment in the first year post-diagnosis. Māori, Pacific and non-Māori/non-Pacific men were compared. Chemotherapy and ADT was received by few patients overall (0.2% and 31.2% respectively). Māori men were more likely to receive ADT and be treated with orchidectomy than non-Māori/non-Pacific men. In regression modelling Māori men with advanced disease (regional or metastatic) were twice as likely to receive ADT as non-Māori/non-Pacific men with advanced disease, adjusted for age and combinations of age, year of diagnosis and orchidectomy. One limitation of the study is that it relied on NZCR staging data, which has largely missing stage data for prostate cancer, thus 71.7% of patients in the study were recorded as having ‘unknown’ extent of disease and treatment by stage was unable to be accurately assessed. Despite this limitation it appears there is some treatment differential between Māori/non-Māori in this study, however the authors do not comment on this ethnic difference specifically, rather they conclude that overall ADT and chemotherapy are under-utilised in New Zealand patients with prostate cancer (Lawrenson, 2014).

The second study looking at prostate cancer treatment patterns investigated the disease in 136 Māori and 400 NZ European men (Obertova et al., 2015). The study identified patients through the NZCR but used data gathered through clinical note review to circumvent the largely missing stage data held by the NZCR. The authors reported stage and demographic data for the total cohort and went on to investigate treatment disparities for the 406 (76.1%) men with localised prostate disease only. Overall, Māori men in this study were more likely to have metastatic disease, more likely to live in the most deprived areas and more likely to have multiple comorbidities than non-Māori men. For those men that were diagnosed with localised prostate cancer, which is potentially highly curable with a fifteen-year survival rate of around 80%, Māori men were 34% less likely to be treated with surgery (radical prostatectomy) and 73% less likely to be treated with low-dose brachytherapy. Māori men were substantially more likely (more than twice) to be treated with either high-dose brachytherapy or external beam radiation, both of which carry the risk of more severe side-effects than does low-dose brachytherapy. Māori men were also more likely to be treated conservatively with either active surveillance or watchful waiting,
than were non-Māori men in the study. Multivariate analysis showed that even once
adjusted for comorbidity, age, socioeconomic status and extent of disease factors
Māori men were in fact 74% more likely to be managed conservatively than non-Māori
men (Obertova et al., 2015).

While neither study investigated survival they show markedly differential treatment
for Māori and non-Māori males. In the case of localised prostate cancer these
treatment differentials are not explained by patient characteristics, such as
comorbidities or extent of disease factors at diagnosis. So while poorer survival
outcomes for Māori men may be related to later stage at diagnosis, which most
probably reflects differential access within the primary care setting, differences in
treatment once diagnosed with prostate cancer may also be a factor.

**Brain Cancer**

A study on high grade glioma, also reviewed in the previous chapter, investigated both
receipt of treatment and survival by ethnicity. It reported differential treatment
between Māori and non-Māori (Alexander et al., 2010). Although with only 19 Māori
(6.3%) within the study the findings must be interpreted with caution. In this case,
Māori were more likely than non-Māori to have their tumour completely resected (OR
3.59, 95% CI 1.01-12.76). However Māori were also more likely to not have extent of
surgery recorded (16% Māori vs. 5% non-Māori, p= 0.048). Waiting times for
radiotherapy are an important predictor of survival for patients with high grade glioma
and this study provided some evidence that Māori patients waited longer than non-
Māori for radiotherapy (median 47 days vs. 34 days, p = 0.065). Hazard ratios failed to
reach statistical significance, however they did suggest survival disparity for Māori (HR
adjusted for age, grade, performance status at presentation and extent of surgery
1.55; 95% CI, 0.95 – 2.55, p = 0.082) (Alexander et al., 2010).
In a study that investigated the management of lung cancer comparing (n=565) Māori, Pacific peoples and New Zealand (NZ) Europeans, Stevens et al highlight lower rates of curative treatment for Māori (Stevens et al., 2008b). As the study was based on data from a clinical note review it utilised detailed information on patient, tumour and clinical management factors. Māori within the study were on average 10 years younger at diagnosis than NZ Europeans; they were also more likely to be a current or past smoker, to live in the most deprived communities and more likely to have COPD or diabetes. As with prostate cancer Māori were diagnosed with poorer stage disease. Māori were half as likely to be diagnosed with localised disease (Māori/NZ European Odds Ratio 0.5, 95% CI, 0.3 – 1.00) and 2.5 times more likely to be diagnosed with locally advanced disease than NZ Europeans (Māori/NZ European Odds Ratio 2.6, 95% CI, 1.3 – 5.3, p < 0.01). Both of these odds ratios were adjusted for age, gender, level of deprivation and comorbidity. In terms of receipt of treatment once diagnosed with lung cancer, treatment with curative intent was given to only 12% of Māori compared with 22% of NZ European patients; this difference was not accounted for by differences in either patient or disease factors (age, gender, level of deprivation, comorbidity, tumour type, stage, and the patient declining treatment). Māori also waited on average 44 more days from diagnosis until start of treatment than did NZ Europeans (Māori 43 days (25–62) vs. NZ European 29 days (12–52)). This delay until treatment remained statistically significant (p =<0.05) even after adjusting for documented patient-related delays such as deferring or missing appointments (Stevens et al., 2008b). This study identified substantial differences in management between Māori and non-Māori for lung cancer; including less curative treatment and longer waiting times for that treatment in the Māori patients. The authors concluded that, while later stage disease played a role, these treatment differences would likely impact on subsequent survival.
Other Cancers

Three further separate studies investigating cervical (McLeod et al., 2010), rectal (Swart et al., 2013) and hepatocellular (Chamberlain et al., 2013) cancers all found that Māori and non-Māori patients received similar levels of treatment for these cancers, although there were delays in referral for adjuvant treatments for Māori with rectal cancer (Swart et al., 2013). In each study however survival appeared to be poorer for Māori compared to non-Māori. With small numbers, the rectal and hepatocellular studies were underpowered to determine this definitively, however in the larger cervical cancer study the association was statistically significant (Māori/non-Māori HR 2.07; 95% CI, 1.63-2.62) (McLeod et al., 2010). Māori had higher prevalence of comorbidity in both the rectal and hepatocellular cancer studies which is likely to have impacted on their survival. Within the cervical cancer study Māori women were likely to be diagnosed with more advanced stage disease which is likely to be in part attributable to their documented lower enrolment and participation in New Zealand’s National Cervical Screening Programme than that of non-Māori women (Sadler et al., 2004; Independent Monitoring Group, 2008). Stage at diagnosis accounted for some but not all of the difference in cervical cancer specific survival between Māori and non-Māori in the study. Although this finding must be interpreted with some caution as the study used national level data in which 36.9% of Māori and 33.2% of non-Māori women were recorded as stage unknown (McLeod et al., 2010).

Summary: Māori/non-Māori Access to Cancer Services

As with the health system in general the findings above suggest that Māori and non-Māori New Zealanders diagnosed with cancer experience differential access to, and quality of, health care with Māori less likely to receive quality, and timely, care. Furthermore this differential care impacts negatively on subsequent survival for Māori.
In a number of cancers Māori were more likely than non-Māori to be diagnosed with later stage disease (Hill et al., 2010a; Obertova et al., 2015; Stevens et al., 2008b; McLeod et al., 2010). For women with breast cancer, this later stage was in part explained by a lower rate of screen detected cancer (Seneviratne et al., 2015a). Māori were also more likely than non-Māori to present acutely rather than through the primary care pathway (Hill et al., 2010a), to have comorbidity (Swart et al., 2013; Chamberlain et al., 2013; Hill et al., 2010a; Obertova et al., 2015; Stevens et al., 2008b) and to live in highly deprived (Hill et al., 2010a; Stevens et al., 2008b; Seneviratne et al., 2014c; Obertova et al., 2015), and/or rural areas (Hill et al., 2010a; Seneviratne et al., 2014c) further from cancer treatment centres.

In terms of treatment and management, Māori were more likely than non-Māori to be treated within a smaller non-cancer centre public hospital than either a tertiary or private facility (Hill et al., 2010a; Seneviratne et al., 2014c), were less likely to receive curative treatment for their cancer (Hill et al., 2010a; Stevens et al., 2008b; Obertova et al., 2015), were more likely to die post-operatively (Hill et al., 2010a) and were more likely to experience longer times through the treatment pathway (Swart et al., 2013; Hill et al., 2010b; Stevens et al., 2008b; Alexander et al., 2010; Obertova et al., 2015; Seneviratne et al., 2014a). In the case of breast cancer these waiting times were partly explained by lesser access to organised cancer screening and the benefits imparted through being involved in its standardised, and monitored, pathways of care (Seneviratne et al., 2015a), and partly explained by differences in the type of facility patients were treated in (Seneviratne et al., 2014a).

Delays in receiving adjuvant therapy impacted negatively on breast cancer survival (Seneviratne et al., 2014a). One third of the differential colon cancer survival outcomes observed between Māori and non-Māori were due to factors associated with access to health care services (Hill et al., 2010a). One third was also due to comorbidity (Hill et al., 2010a). Furthermore, when patients with the highest levels of comorbidity in this study did receive chemotherapy their mortality risk was substantially reduced. This suggests under-treatment of patients with comorbidity, of whom Māori comprised a higher proportion (Sarfati et al., 2009).
While survival differences are in part due to the lesser access to screening and later stage at diagnosis along with the higher levels of comorbidity observed in Māori compared with non-Māori, the poorer cancer survival seen within New Zealand’s indigenous Māori is also in part due to differential access to, and quality of, cancer treatment services (Hill et al., 2010a; Seneviratne et al., 2015). These differences reflect evidence of health system factors that privilege non-Māori and disadvantage Māori.

Taken together these studies raise the questions: why do Māori receive differential cancer care compared to the majority non-Māori population, especially in the New Zealand context of a publicly funded (and theoretically accessible) secondary and tertiary health care system? Does this reflect institutionalised racism within health care? Finally, what can be done to mitigate this?

**How and Where to Intervene**

With the known stomach cancer survival disparity between Māori and non-Māori in New Zealand, this thesis started with the premise that the different ethnic groups (Māori and non-Māori) may receive differential access to, and quality of, care for their stomach cancer. As a thesis in the discipline of Public Health it was also important to also explore how to intervene to better enable equitable access to, and through, treatment services. This approach is supported by leading researchers on racism in health care (Jones, 2002; Feagin and Bennefield, 2014; Krieger, 2003). Indeed Woodward and Kawachi (Woodward and Kawachi, 2000) argue that as health disparities arise from deliberate policy options of successive governments (such as the finance, health and welfare policies through eras of colonisation and neoliberalism outlined in Chapter 2) they should be amenable to intervention.

The following section firstly outlines a framework for thinking about strategies and actions to address cancer care disparities for Māori. The framework, by Mandelblatt and colleagues (Mandelblatt et al., 1999), has been used previously in New Zealand to
investigate Māori/non-Māori cancer care disparity and recommend interventions to improve access to care (Hill et al., 2013; Cormack et al., 2005; Walker et al., 2008). Importantly, the framework is also used to consider the qualitative results of this study in a following chapter and to organise this study’s discussion.

Secondly the following section goes on to review interventions that have the potential to improve access to, and through, cancer services for Māori in New Zealand. A search for literature on interventions specific to stomach cancer was undertaken however no previous studies were found that described interventions to improve minority group, indigenous or Māori access to stomach cancer services. Instead the section below draws on related literature which provides context to improving Māori access to, and through, cancer services more generally. The framework of Mandelblatt et al (Mandelblatt et al., 1999) is also used to consider this literature.

**Mandelblatt: A Framework to Guide Intervention Thinking**

According to Mandelblatt et al (Mandelblatt et al., 1999), inequities in accessing cancer care may arise at a number of levels. Inequities can stem from structural barriers, factors that influence physician recommendations and factors that affect patient choice. These levels have since been grouped into a three-tiered conceptual framework which considers barriers at: a) the level of the health system as a whole, b) the health care processes within that system or c) at the level of the individual or patient (Shavers and Brown, 2002; Cormack et al., 2005). Importantly while the framework does include a patient level, a key feature of the framework is that it looks beyond the individual (both the individual patient and the health care worker) to consider the role the health system as a whole plays, in access to cancer services (Hill et al., 2013).

*The health system level* includes factors related to the context of the health system and the environment in which it operates. Factors such as the funding, location and resourcing of cancer services each contribute to issues around accessing those
services (Mandelblatt et al., 1999). In the New Zealand context the universal (or monocultural) focus of the system and the cultural responsiveness of services have also been recognised as factors to do with the health system which impact on access to cancer services for Māori (Cormack et al., 2005; Hill et al., 2013).

In contrast the health care process level includes factors to do with the way in which services and providers of care work and communicate, both with each other and with patients and/or whānau, and how these impact on pathways through care. This level includes the predominantly non-Māori composition of the health workforce along with other characteristics of the workforce such as age, gender, cultural competence, bias and communication skills and the impact these characteristics have on the patient-provider relationship (Mandelblatt et al., 1999; Cormack et al., 2005; Hill et al., 2013).

Finally individual or patient level factors that have been shown to impact on access to, and through, cancer services include patient demographics such as age, ethnicity, sex, socio-economic position, level of education and/or income along with personal decision making or patient choice. Stage at diagnosis and level of comorbidity are also said to be patient level factors although both reflect in part access to and the distribution of underlying determinants of health and resultant disadvantage or privilege (Cormack et al., 2005; Mandelblatt et al., 1999; Hill et al., 2013).

Conventionally, when discussing access to cancer services, the focus has been on factors at an individual level such as patient socio-economic status although in reality access is likely to be multidimensional and multilevel with some factors fitting under more than one level (Cormack et al., 2005). For example one’s socio-economic status and concomitant level of ability to pay for costs associated with cancer care (i.e. travel to a regional cancer centre or time away from work) could be viewed either as an individual level factor or in another way as a health system factor where the focus is on the location and resourcing of cancer services (Hill et al., 2013).

Hill and colleagues (Hill et al., 2013) urge that focus is placed beyond the individual in order to improve the quality and equity of cancer services and impact on cancer survival in indigenous people. Indeed placing focus on the individual or patient plays
into the individual responsibility espoused within the era of neo-liberalism where in effect people are blamed for their ill-health. With this focus, interventions then target individual people or population groups to change their behaviour in order to receive ‘better’ health care. In comparison placing focus on the health care system and processes levels corresponds with Jones’ model of racism and health and places focus on institutional racism as a key driver of unequal treatment. In other words, if the way in which health services are organised and delivered means some ethnic groups receive better care than others, including both access to and quality of cancer care, this then reflects institutional racism within the health system. Thus under this lens, interventions become focussed on the health care system and processes within it and how these can better meet the needs of all people.

**Improving Access to, and through, Cancer Services in New Zealand**

As identified by Cormack (Cormack et al., 2005) the pathway for someone diagnosed with cancer is likely to be complex, often involving multiple health professionals within multiple providers, and so the interventions to improve access to services also need to be complex. Certainly, patients diagnosed with stomach cancer have diverse and complex needs (NHS Executive, 2001) which necessitate care from many different professional groups (Palser et al., 2009; NHS Executive, 2001). In addition the causes of ethnic disparities in cancer are multi-level, and therefore according to Cormack et al (Cormack et al., 2005) approaches to addressing disparities in cancer care should also be multi-level and comprehensive. Others support addressing multiple issues or implementing multi-factor interventions in order to optimise cancer services responsiveness to priority groups and effectively address equity (Porter, 2008; New Zealand Guidelines Group, 2009; Power et al., 2009). In line with this call for a multi-factorial approach this section looks at possible interventions within the different levels of the Mandelblatt et al framework introduced above.
Understanding Inequity and Interventions

Three key reports, and three qualitative studies, summarise how and where to intervene to improve access to cancer services, generally rather than specifically for stomach cancer, for Māori in New Zealand. The interventions suggested below are primarily based on key informant views highlighting the general lack of evidence on the effectiveness of interventions to improve equity in health care, although the work of Cram (Cram, 2014a; Cram, 2014b) does include a review of available equity-related intervention literature.

The first of the key reports, that of Cormack et al identified above (Cormack et al., 2005), outlined barriers to access for Māori at each of the three levels of the Mandelblatt framework. However while Cormack et al undertook a stock take of interventions to improve access they conclude that there was a “lack of comprehensive interventions, current or planned, to specifically address Māori access to cancer services” and that “those interventions that were identified were limited and isolated” (Cormack et al., 2005: 48). The report did though identify a range of high level interventions that the authors considered would contribute to improved access. While supported through review of relevant literature the interventions recommended within the report appear to be based primarily on the findings of key informant interviews, albeit (as health professionals working within the health care system) informants well informed about the provision of cancer services to Māori in New Zealand. Some of these interventions have been wholly or in part addressed in the time since this report was released in 2005. For example, initiatives such as the nationally funded 57 Cancer Nurse Coordinators have begun to address the call for patient navigation or case coordination to enable patients to better navigate the complex cancer care system. Although these positions are based in DHBs and the report also calls for additional resource for Māori Health Providers to better enable Māori to attend to the needs of people with cancer. Other interventions are likely to be on-going, including interventions such as strengthening the inequalities focus of cancer control policies, providing community-based or outreach cancer services, comprehensive training of the cancer control workforce to provide culturally safe and responsive services for Māori, involving Māori expertise in multidisciplinary teams and improved service coordination and discharge planning. Table 3 below summarises the
interventions put forward by Cormack et al according to the framework of Mandelblatt et al.

The second and third more recent reports both by Cram are results of a literature review (Cram, 2014a) and health professional key informant interviews (Cram, 2014b). Although this key informant work focussed not only on access to cancer care but also to care for diabetes and cardiovascular disease for Māori, the findings are relevant. In the literature review Cram reviewed 42 individual and seven review papers on interventions to improve access to cancer care for indigenous people and minority groups. Importantly Cram also did not find papers specific to stomach cancer (Cram, 2014a). Following the review of literature Cram then utilised 41 New Zealand health professional key informant interviews to identify further interventions (Cram, 2014b).

The key findings from the two reports by Cram are outlined below within the framework popularised by Mandelblatt. Again, see Table 3 below for a summary of interventions.

**Health systems factors** identified by Cram included the health system having the commitment to, as well as leadership in, improving equity, the use of local and/or relevant data to plan and monitor services along with the establishment of universal health targets, rather than different targets for different ethnic groups.

**Health care process factors** identified by Cram centred around developing health practitioners cultural competency and skill in communicating with Māori patients as well as utilising brokers (such as community health workers or patient navigators) to help bridge any cultural gap between Māori and the predominately mainstream (non-Māori) cancer services. Both of these approaches improved both knowledge and self-reported efficacy of health professionals in dealing with indigenous patients with cancer. Patient navigation was shown in the literature reviewed by Cram to improve access, adherence and timeliness through the cancer pathway over that of non-navigated control groups. Importantly though Cram highlighted the need for health care organisations to also make services easier to navigate alongside the use of patient navigators or nursing care coordinators. Key informants also advocated for changes in health workforce roles and funding formulas especially those that support
an increased nursing workforce. Specific interventions suggested by key informants to improve cultural competency included educating health practitioners, taking time to develop a personal connection with Māori patients and partnering to include culturally competent practitioners within teams. As well, the development of decision-making tools and guidelines were shown to support equitable decision making by practitioners.

*Patient factors* identified by Cram’s key informants included the need to mitigate barriers such as cost of, and transport to, services and to support whānau-based and holistic self-management. While the need for improved health literacy was seen as important, it was framed as the responsibility of health care system and the services within it to provide culturally tailored and responsive information and services thus making them more likely to be acceptable to Māori.

Three further qualitative studies made similar recommendations to those above (Walker et al., 2008; Slater et al., 2013; Dew et al., 2015). Each of these three studies examined Māori experiences of cancer and cancer care, based on focus groups and interviews. Together these studies represent the views of 75 Māori patients, survivors and whānau. Walker and colleagues (Walker et al., 2008) explicitly used the framework of Mandelblatt to organise the findings while the remaining two studies can be considered in this way. Their findings are summarised here and in Table 3. Participants’ suggestions at the *health systems level* included providing more frequent specialist clinics in rural areas, better coordination of service delivery and better resourcing of Māori health providers to deal with cancer. At the *health care process level* participants suggested recruiting more Māori health care staff, increasing cultural competence of all staff, allowing longer consultation times and the use of cancer navigators. *Patient level* suggestions focussed on finding ways to better include whānau and to integrate Māori medicines or approaches to health in cancer care and taking a more active approach to informing Māori of the support available to them.

Importantly the findings and recommendations of each of the reports and studies above are similar. To rephrase, key informants, both health care professionals working within the cancer sector and Māori themselves who have experienced cancer
care, have for the preceding decade concurred on how to improve cancer services for Māori. Interventions highlighted as being effective in improving equity within these reports and studies are summarised below in Table 3. The interventions are considered again within the discussion of this thesis also using the framework of Mandelblatt et al. Importantly though, while relevant, none of these studies are specific to improving access to or through stomach cancer services in New Zealand.
Table 3: Interventions identified within the literature according to the framework of barriers to access; Mandelblatt et al

<table>
<thead>
<tr>
<th>Framework Level</th>
<th>Issue identified</th>
<th>Interventions suggested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health system-level</td>
<td>Total population or mono-cultural focus</td>
<td>Develop cancer control policy for Māori and strengthen equity focus in existing policy</td>
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<tr>
<td></td>
<td></td>
<td>Have commitment to, and leadership in, improving equity</td>
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<tr>
<td></td>
<td></td>
<td>Use local and/or relevant data to plan and monitor services by equity</td>
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<tr>
<td></td>
<td></td>
<td>Establish universal health targets</td>
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<tr>
<td></td>
<td></td>
<td>Engage with Māori leaders, communities and organisations</td>
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<td></td>
<td></td>
<td>Involve Māori expertise in multi-disciplinary teams</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Incorporate Māori healing interventions and a whānau-based approach to care</td>
</tr>
<tr>
<td>Funding, resourcing and location of</td>
<td>Address differential access to services</td>
<td></td>
</tr>
<tr>
<td>cancer services</td>
<td>and to entitlements by region</td>
<td></td>
</tr>
<tr>
<td>Health care process-level</td>
<td>Provide community based or outreach</td>
<td></td>
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<tr>
<td></td>
<td>cancer services</td>
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<tr>
<td></td>
<td>Ensure any guidelines are implemented</td>
<td></td>
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<tr>
<td></td>
<td>and monitored for equity</td>
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<tr>
<td></td>
<td>Better resource Māori Providers and</td>
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<td></td>
<td>locate services in Māori settings</td>
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<td></td>
<td>where appropriate</td>
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<tr>
<td></td>
<td>Strengthen networks with other health</td>
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<td></td>
<td>organisations, that have commitment to</td>
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<td></td>
<td>improving access to health care for</td>
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<tr>
<td></td>
<td>Māori</td>
<td></td>
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<tr>
<td>Communication between services</td>
<td>Patient navigation or care coordination</td>
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<tr>
<td></td>
<td>Change health workforce roles and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>funding formulas to support an increased</td>
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<tr>
<td></td>
<td>nursing workforce</td>
<td></td>
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<tr>
<td></td>
<td>Engage community health workers to</td>
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<tr>
<td></td>
<td>provide a bridge between community and</td>
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<td></td>
<td>cancer services</td>
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<td></td>
<td>Make services easier to navigate</td>
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<td></td>
<td>alongside the use of patient navigators</td>
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<tr>
<td></td>
<td>or nursing care coordinators</td>
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<tr>
<td></td>
<td>Comprehensive care plans and discharge</td>
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<tr>
<td></td>
<td>planning</td>
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<tr>
<td>Patient – provider communication</td>
<td>Build a culturally competent workforce i.e. through training of health practitioners</td>
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<td>---------------------------------</td>
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<tr>
<td></td>
<td>Provide health literacy communication education for health practitioners</td>
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<tr>
<td></td>
<td>Partner to include culturally competent practitioners within teams</td>
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<tr>
<td>Provider bias</td>
<td>Debunk health practitioner stereotypes of Māori</td>
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<tr>
<td></td>
<td>Develop clear decision-making tools and guidelines</td>
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<tr>
<td>Cancer workforce</td>
<td>Employ more Māori within cancer care including in governance roles</td>
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<tr>
<td></td>
<td>Improved cultural safety and responsiveness of ‘mainstream’</td>
<td></td>
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<tr>
<td>Patient-level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-economic status</td>
<td>Address financial barriers of cancer care and proactively inform of available support</td>
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<tr>
<td>Travel</td>
<td>Address transport barriers to cancer care</td>
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</tr>
<tr>
<td>Patient preference/choice</td>
<td>Support whānau-based and holistic self-management</td>
<td></td>
</tr>
<tr>
<td>Health literacy</td>
<td>Provide culturally tailored and responsive information and services</td>
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</tr>
</tbody>
</table>
Intervening at Key Points of the Stomach Cancer Pathway

In addition to the suggestions above that are targeted towards improving cancer services overall for Māori, there are likely to be specific issues relating to improving particular points of the stomach cancer pathway for all. While not focussed specifically on providing more equitable outcomes for Māori, improving the pathway overall has the potential to impact on those groups currently disadvantaged through it. Monitoring and evaluation for equity of access, and outcomes, for different groups would need to be paramount throughout the pathway.

The interventions points outlined above may all be important and it is likely that a combination of interventions is needed to in order to improve the responsiveness of stomach cancer services to Māori. It must be noted though, that even a well-designed, fully functioning and equitable health system is only intervening at the level of health services. The broader underlying determinants of health, or issues related to the “differential access to the goods, services, and opportunities of society by race” (Jones, 2000: 1212), are not being fully addressed by this approach. In the case of stomach cancer, the determinants of health impact greatly on the risk of developing the disease in the first instance. The determinants are also highly likely to influence access to, and through, stomach cancer services irrespective of how well designed and implemented those services are. Still institutionalised racism can also manifest as inaction in the face of need, and with such disparate stomach cancer incidence, mortality and survival seen within New Zealand (as outlined in Chapter 3) there is clearly need to investigate stomach cancer services in New Zealand.

Summary of Inequity and Interventions

This chapter has noted three pathways through which health inequities occur: differential access to the underlying determinants of health, differential access to health care and differential quality of health care received (Jones et al., 2009). This chapter has been concerned with the latter two pathways or Māori/non-Māori disparities in access to, and quality of, cancer care.
There is much evidence of inequitable access to, and quality of, health care between Māori and non-Māori in New Zealand, at primary, secondary and tertiary levels (Scott et al., 2003; Crengle et al., 2005; Ministry of Health, 2014a; Ministry of Health, 2008; Jansen et al., 2008; McCreanor and Naim, 2002). As with the health system in general, findings from a number of studies suggest that Māori and non-Māori New Zealanders diagnosed with cancer experience differential access to, and quality of, health care with Māori less likely to receive quality (Seneviratne et al., 2014c; Hill et al., 2010a; Stevens et al., 2008b; Obertova et al., 2015), and timely care (Hill et al., 2010b; Stevens et al., 2008b; Alexander et al., 2010; Obertova et al., 2015; Seneviratne et al., 2014a). Furthermore this differential care impacts negatively on subsequent survival for Māori (Hill et al., 2010a; Seneviratne et al., 2015).

As a thesis within Public Health it was considered important to not only investigate whether Māori/non-Māori disparities exist but to also consider how, and where, to intervene to minimise any inequities. No previous studies were found that described interventions to improve indigenous peoples or Māori access to stomach cancer services, instead this chapter draws on related literature that investigates how to improve cancer services more generally for Māori. A number of studies, published over the preceding decade (Cormack et al., 2005; Cram, 2014a; Cram, 2014b; Walker et al., 2008; Slater et al., 2013; Dew et al., 2015) all argue for similar interventions to improve cancer services for Māori, thus for the preceding decade key informants have concurred on how to improve the responsiveness of cancer services to Māori. The framework, of Mandelblatt and colleagues (Mandelblatt et al., 1999), is used to consider possible interventions and to remain focussed on structural responses however it is likely that a multilevel and comprehensive approach encompassing both Māori-centred interventions and improvements to the treatment pathway overall are needed.

While the broader underlying determinants of health are not being addressed by intervening in differential access to, and quality of, health care, the Māori/non-Māori inequities in stomach cancer (documented in Chapter 3) and in access to health and
cancer services (documented in this chapter) provide clear need for action to improve stomach cancer services in New Zealand for Māori.
Chapter 5: Methods

This study uses a mixed method approach, with both quantitative and qualitative phases. To begin, this chapter briefly discusses the mixed methods approach used in this study.

This chapter next outlines the quantitative methods used to create an historical cohort of people diagnosed with stomach cancer and to explore their presentation, subsequent treatment and survival.

It does this in three separate sections:

- The first section outlines the creation of an historical cohort through clinical note review including identifying and selecting the study population, data sources and data collection and extraction.

- The second section describes the preparation and analysis of the quantitative data including data preparation, how missing data were managed and the variables used in analyses.

- The third section describes data analyses including how and why age and sex standardisation was used, how the Māori and non-Māori cohorts were compared in their patient, disease treatment and health care access factors, and survival.

Finally, this chapter outlines the methods used in the qualitative phase of the study, including key informant sampling, recruitment, data collection, and analysis. The objectives of this phase were to qualitatively investigate key informant views of those points of the stomach cancer treatment pathway that the quantitative findings suggested were inequitable (if present), along with how and where to intervene to improve the treatment pathway, with a focus on Māori.
**Methods**

**Introduction**

This study uses a mixed method approach, with both quantitative and qualitative phases. When using mixed methods it needs to be clear why mixed methods are appropriate and justification provided for the sequence of the methods, along with how and where the methods will be synthesised (Padgett, 2011; Lingard et al., 2008).

Sequential methods have been used in this study: a quantitative phase followed by a qualitative phase. Sequential methods are useful when the results from one method help to inform the other method (Creswell, 2003). This was the intention of this study. In this study quantitative methods were used to investigate the stomach cancer treatment pathway and whether there were points on the pathways that were inequitable for Māori, and if present whether that inequitable care contributed to ethnic survival inequities. Then qualitative methods were used to explore possible interventions or solutions to improve the stomach cancer treatment pathway. These interventions were focussed on those points of the treatment pathway that the quantitative data suggested were inequitable for Māori. The study research questions 1 – 3 (below) are answered using quantitative methods and 4 – 5 using qualitative methods.

The specific objectives of this study were to investigate:

1. What are patient (age, sex, comorbidity), disease (stage at diagnosis, tumour site, grade), treatment (receipt and timing of surgery, chemo and radiotherapy), health care access (deprivation, rurality) and outcome (survival) characteristics of a cohort of patients with stomach cancer in New Zealand?

2. Are there any Māori/non-Māori differences in treatment timeliness, quality and quantity?

3. If differences exist, how do these differences contribute to Māori/non-Māori stomach cancer survival?
4. What do key informants identify as issues for stomach cancer treatment in New Zealand, with a focus on Māori?

5. Which interventions do key informants identify that may improve access to, and quality of, stomach cancer treatment in New Zealand, with a focus on Māori?

The two methods were integrated during interpretation (Lingard et al., 2008). As the two methods answer distinct but related research questions, they each have a separate results section. Synthesis of these results occurs within the discussion chapter only.

**Analytic Framework**

As discussed previously this study uses Mandelblatt et al.’s conceptual framework of barriers to accessing cancer services (Mandelblatt et al., 1999) as the overall theoretical approach. Using this framework informed how the variables used in quantitative data analyses were organised. It also informed the research design of the qualitative phase of this study impacting on participant sampling, the development of the interview schedule through guiding the types of questions to ask participants and qualitative data analysis. In addition, this framework guided the organisation of quantitative/qualitative results synthesis and resultant recommendations within the discussion chapter of this thesis.
Quantitative Methods

Background to the Quantitative Phase

The purpose of the quantitative phase of this study was determine the presenting characteristics, treatment and survival of Māori and non-Māori patients with stomach cancer in New Zealand, to compare the results between Māori and non-Māori and to examine the contribution of any observed differences to survival disparities.

Quantitative Phase Research Questions

As mentioned in the introduction to this chapter, three research questions guided the quantitative phase of this study, they were:

1. What are the patient (age, sex and comorbidity), disease (stage at diagnosis, tumour site and grade), treatment (receipt and timing of surgery, chemo and radiotherapy), health care access (deprivation and rurality) and outcome (survival) characteristics of a cohort of patients with stomach cancer in NZ?

2. Are there differences in stomach cancer treatment timeliness, quality and quantity between Māori and non-Māori?

3. If differences exist, how do these differences contribute to differences in outcomes from stomach cancer between Māori and non-Māori?
Creating a Historical Cohort through a Clinical Note Review

Study Population

The target population of this study was all patients diagnosed with stomach cancer between 2006 and 2008 in Aotearoa/New Zealand (Table 4). This target population was then restricted to those 25 years or over with a histological diagnosis of stomach adenocarcinoma or gastrointestinal stromal tumour (GIST). Adenocarcinoma and GIST are distinct neoplasms originating from different cell layers but as they both have a similar well-defined treatment pathway it was decided to include GIST within this study. For practical reasons, only cancers registered to patients who resided in the North Island at time of diagnosis were included. The reasons were 1) the majority (around 90%) of Māori reside in the North Island (Statistics New Zealand, 2007) and thus substantial resources would have been needed to obtain data on the remaining 10% of Māori and 2) the two major Christchurch earthquakes, September 2010 and February 2011, impacted on the resources available to Canterbury DHB, limiting their ability to provide data and participate in the study. Cancer treatment and survival were key outcomes of interest so the target population was also restricted to those with a cancer diagnosis confirmed prior to death.
Table 4: Study eligibility criteria

<table>
<thead>
<tr>
<th>Eligibility criteria</th>
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<tbody>
<tr>
<td>Newly diagnosed stomach cancer (ICD code C16.0-16.6, 16.7, 16.8).</td>
</tr>
<tr>
<td>Cancers registered between 1 January 2006 and 31 December 2008.</td>
</tr>
<tr>
<td>No previous diagnosis of stomach cancer.</td>
</tr>
<tr>
<td>Aged 25 years or over at diagnosis.</td>
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<tr>
<td>Normally resident in the North Island of New Zealand.</td>
</tr>
<tr>
<td>Diagnosis made prior to death or post-mortem.</td>
</tr>
<tr>
<td>Morphology consistent with adenocarcinoma or gastrointestinal stromal tumour.</td>
</tr>
</tbody>
</table>

The target population was identified from all cases of primary stomach cancer notified to the New Zealand Cancer Registry with a registration date between 1 January 2006 and 31 December 2008 (Table 5: Step 1). The target population was grouped into Māori and non-Māori groups, based on the ethnicity data from the Cancer Registry. The study eligibility criteria were then applied using the information available from the Cancer Registry records (Step 2).

Table 5: Steps in the study selection process

<table>
<thead>
<tr>
<th>Steps in the study selection process</th>
<th>Māori</th>
<th>non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Cancer Registrants 2006 – 2008 with primary stomach cancer</td>
<td>all</td>
<td>all</td>
</tr>
<tr>
<td>2 Target populations meeting study eligibility criteria based on Cancer Registry records</td>
<td>all</td>
<td>all</td>
</tr>
<tr>
<td>3 Sampled study cohorts all Māori and random sample of non-Māori</td>
<td>all</td>
<td>random sample</td>
</tr>
<tr>
<td>4 Eligible study cohorts meeting study criteria after medical notes review</td>
<td>all eligible</td>
<td>all eligible from random sample</td>
</tr>
</tbody>
</table>

The sampled study cohort included all Māori cases and an equal number of non-Māori cases. The non-Māori cases were a random sample, determined by assigning a unique
random six-digit number to all non-Māori cases, placing these in numerical order and selecting the first 181 cases (i.e. the size of the Māori cohort). The sampled cohort was then comprised of the Māori cases combined with the randomly-sampled non-Māori cases (Step 3).

Following a full clinical note review (see ‘Data Sources’ below) it was found that a number of cases included in the sampled study cohort did not actually meet the criteria of the study and were thus excluded. In these cases information was incomplete or miscoded in the Cancer Registry records. Even though these patients had appeared to meet the study eligibility criteria at Step 3, if they failed to meet the study eligibility criteria based on clinical records they were considered ineligible and excluded from the final study cohort (Step 4).

Despite a detailed review of all available clinical records complete data could not be obtained for some patients. However for each relevant variable only a small fraction of patients had missing data and no patients were excluded from the study due to missing data. Proportions of missing data are identified within appropriate places in the descriptive analyses of the Quantitative Results chapter. The method for how missing data for key variables within survival analyses was managed is detailed later in this chapter.

**Data Sources**

This study used a combination of national routinely-collected data and data derived from a full review of clinical records within patient medical notes. Data on incident stomach cancer cases, ethnicity (the exposure of interest), demographic details, health care access measures and mortality were gained from the national-level databases. Data on patient and clinical factors such as stage, comorbidity at time of diagnosis, disease characteristics and receipt of treatment were gained from a manual review of clinical records in patient medical notes (Figure 5).
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Figure 5: Data sources used in this study

National Level Data Sources

New Zealand Cancer Registry

Incident cases of stomach cancer were identified from the New Zealand Cancer Registry (NZCR). The NZCR is a population-based register of all primary cancers diagnosed in New Zealand, with the exception of non-melanoma skin cancers. While the prime function of the NZCR is to collect and store cancer incidence data it is also used to assess and compare cancer rates and trends and acts as a resource for cancer screening programmes and research (Cancer Control New Zealand, 2010; Stevens et al., 2008a).

The NZCR has been operating since 1948 however in 1993 the Registry Act was passed. The Act made pathological reporting of cancer diagnoses by laboratories mandatory, binding the Crown and its entities to report cancer within 21 days after the end of the calendar month in which the cancer test was carried out. A small proportion of data (<10%) is also gained from discharge summaries from public and private hospitals, death certificates, and autopsy reports when needed (New Zealand Cancer Registry (NZCR), 2008).

The information captured in the NZCR system is outlined below (Table 6). The NZCR collects demographic information (to ensure that each new cancer is recorded only once
in incidence statistics) and detailed pathological information about each tumour where this information is available (New Zealand Cancer Registry (NZCR), 2008).

**Table 6: Information held by the New Zealand Cancer Registry**

<table>
<thead>
<tr>
<th>In relation to the <strong>person:</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>name</td>
<td></td>
</tr>
<tr>
<td>NHI number</td>
<td></td>
</tr>
<tr>
<td>sex</td>
<td></td>
</tr>
<tr>
<td>address</td>
<td></td>
</tr>
<tr>
<td>ethnicity</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>In relation to the <strong>tumour:</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>date of diagnosis</td>
<td></td>
</tr>
<tr>
<td>site of primary cancer (or secondary site if primary unknown)</td>
<td></td>
</tr>
<tr>
<td>type of diagnostic test</td>
<td></td>
</tr>
<tr>
<td>morphology</td>
<td></td>
</tr>
<tr>
<td>grade</td>
<td></td>
</tr>
<tr>
<td>tumour site-specific information (eg, Breslow's thickness for melanoma, ER/PR status for breast cancer)</td>
<td></td>
</tr>
<tr>
<td>extent of disease at diagnosis</td>
<td></td>
</tr>
</tbody>
</table>

*Source: NZCR, Data Dictionary (New Zealand Cancer Registry (NZCR), 2008)*

The clinical coding of tumour site and histology on the NZCR is applied according to the International Classification of Disease, an international standard in clinical coding (Steindel, 2010). During the timeframes of this study the NZCR used the Tenth Revision of the International Classification of Diseases, Australian Modification, second edition (ICD-10-AM 2nd ed.) to record tumour site and histology (New Zealand Cancer Registry (NZCR), 2008). Stage (or, more accurately, extent of disease) is assigned on the NZCR according to the National Cancer Institute’s Surveillance, Epidemiology, and End Results Programme (SEER) summary staging system (National Cancer Institute, 2013b; Stevens et al., 2008a), based on information obtained up to four months following the date of diagnosis (New Zealand Cancer Registry (NZCR), 2008). The SEER summary staging system groups cancer
into five main categories (Table 7). In addition, the regional stage can be subcategorised by the method of spread.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>In situ</td>
<td>Abnormal cells are present only in the layer of cells in which they developed</td>
</tr>
<tr>
<td>B</td>
<td>Localised</td>
<td>Cancer is limited to the organ in which it began, without evidence of spread</td>
</tr>
<tr>
<td>C</td>
<td>Regional</td>
<td>Cancer has spread beyond the primary site to nearby lymph nodes or tissues and organs</td>
</tr>
<tr>
<td>D</td>
<td>Regional</td>
<td>Cancer has spread to regional lymph nodes</td>
</tr>
<tr>
<td>E</td>
<td>Distant</td>
<td>Cancer has spread from the primary site to distant tissues or organs or to distant lymph nodes</td>
</tr>
<tr>
<td>F</td>
<td>Unknown</td>
<td>There is not enough information to determine the stage</td>
</tr>
</tbody>
</table>


**National Health Service Data**

National level health service data were used primarily to identify hospital admissions and generate a list of hospitals for the medical note review that provided care to patients within the study cohort. National data were obtained from two national datasets, the National Minimum Data Set (NMDS) and National Non-Admitted Patient Collection (NNPAC) databases.

The NMDS is a database containing public and private hospital inpatient discharge information. It also includes some day patient information. Data has been submitted by public hospitals since 1993 and by private hospitals, for publicly funded events only, since 1997. Clinical information including data on the date and type of diagnostic or treatment procedure, length of stay, any surgery, chemotherapy or radiotherapy received as part of an inpatient stay, patient comorbidities and (sometimes) complications of treatment are collected (Ministry of Health, 2013a).
METHODS

The NNPAC is a database containing non-admitted patient, outpatient and emergency department, information. It provides procedure or diagnosis information including date, facility and type of service or treatment. It holds information on chemotherapy or radiotherapy received as an outpatient and first specialist appointments (FSA) when these are held as an outpatient (Ministry of Health, 2013b).

For a research capacity these national datasets have limitations. These datasets have the primary purpose of assisting the Ministry of Health and DHBs in the determination of funding for provision of services (Ministry of Health, 2011) and there is known underreporting of cancer treatment, both medical and surgical oncology. Additionally private providers are not mandated to report data on services which are privately funded and these data are largely missing within these datasets (Gurney et al., 2013a). For these reasons the clinical treatment data held within national datasets can be either missing or limited in detail. For example little information was available within the national datasets regarding the purpose of an oncology visit and whether treatment was actually received.

Clinical data from medical note review has been shown to be more accurate than that within national datasets (Stevens et al., 2008a). For this reason, study data on treatment were obtained directly from patient medical notes for the current study.

Mortality Records

Mortality data were obtained from the national Mortality Collection. The Mortality Collection holds information on all deaths in Aotearoa/New Zealand. The Mortality Collection provides data for policy, monitoring, cancer survival studies and research, including international comparisons of mortality statistics by the World Health Organisation (WHO). The underlying cause of death for all deaths registered in New Zealand is classified using the ICD-10-AM 6th Edition and the WHO Rules and Guidelines for Mortality Coding (Ministry of Health, 2009).
Collection of Clinical Data from Patient Medical Notes

A manual review of clinical records within patient medical notes provided the core of clinical data for the study. In New Zealand patient medical notes are held at each individual hospital, including private hospitals, which the patient has attended. The data gathered provided detailed clinical information on the presentation (including stage at diagnosis and comorbid conditions) and management of all eligible patients; much of these data were not available from the administrative databases nationally.

Patients’ medical notes included letters pertaining to clinic appointments, outcomes of diagnostic tests, pathology reports and notes of both inpatient and outpatient events. These detailed note review data thus allowed a comprehensive comparison of patient factors, tumour or disease characteristics and health care received by Māori and non-Māori patients diagnosed with stomach cancer, and to then assess the impact of these factors on survival outcomes.

The order of determining the study data is shown below in Table 8.

<table>
<thead>
<tr>
<th>Order of Determining Study Data</th>
<th>Data Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Total cohort/target population identified by date of diagnosis, ethnicity (the exposure), age and sex</td>
<td>New Zealand Cancer Registry</td>
</tr>
<tr>
<td>2 Sampled study cohort determined by randomisation of non-Māori cohort</td>
<td></td>
</tr>
<tr>
<td>3 Treatment hospitals for sampled study cohort identified by receipt of treatment events around diagnosis</td>
<td>National Health System Data (NMDS &amp; NNPAC)</td>
</tr>
<tr>
<td>4 Collection of patient (comorbidity), disease (stage, site, grade), and treatment factors (receipt and timing), including definitive date of diagnosis</td>
<td>Review of clinical data in individual patient medical notes</td>
</tr>
<tr>
<td>5 Eligible study cohort determined by meeting study criteria after medical notes review</td>
<td></td>
</tr>
<tr>
<td>6 Collection of health care access factors (deprivation and rurality)</td>
<td>New Zealand Cancer Registry</td>
</tr>
<tr>
<td>7 Collection of mortality data including date of and underlying cause of death up to 31 Dec 2010</td>
<td>National Mortality Collection</td>
</tr>
</tbody>
</table>
Methods

Ethics Approval

The quantitative phase of this study was given ethical approval by the Multi-Regional Ethics Committee in 2010 (ref. # MEC 10/042/EXP). All aspects of this phase of the study were carried out in accordance with the approved study protocol.

Once ethics approval was gained, study data were obtained from national and cancer treatment centre databases and clinical data were obtained from a manual review of individual patient notes held in hospitals throughout the North Island of New Zealand.

Identification of Providers and Inpatient Episodes

For each patient within the cohort, public and private hospital admissions were identified from NMDS data and outpatient events from NNPAC data. The receipt of treatment events that occurred around the time of each patient’s cancer diagnosis were then identified and used to generate a list of hospitals providing care to patients within the study cohort. For each hospital, a list of patients was generated. Patients were often cared for at more than one facility during their cancer journey, necessitating review of medical notes at multiple hospitals for many patients.

Approval to Review Patient Medical Notes at Individual Hospitals

For each public and private hospital the Chief Medical Adviser (or equivalent) was contacted to seek permission to review notes from that facility. In most cases permission was fairly quickly granted. However some hospitals had specific protocol pertaining to approval of medical note review; this often involved protracted consultation that delayed the collection of data, in some cases by more than a year. Once permission was obtained the list of patients treated at each individual institution was sent to the Medical Records Department asking that the patient notes be available at a pre-arranged time.
Study Proforma

A standardised proforma was developed for the extraction of clinical data (See Appendix 1). The proforma was developed in consultation with the clinical advisory team set up to support the C3 group of studies (as outlined in the Statement of Participation), including specialist surgeons (Upper GI and rectal), medical oncologists and public health researchers with expertise in Māori health, survey design, epidemiology and biostatistics. The questionnaire contained 70 variables covering the treatment pathway from date of first presentation and initial signs and symptoms to referral and receipt of palliative care. It was piloted using clinical records, in both electronic and paper form, of 50 patients cared for at one major cancer centre public hospital.

Review of Patient Medical Notes in Public and Private Health Facilities

All clinical data were obtained through a manual review of individual patient’s medical notes. These data were primarily obtained from public hospitals as in New Zealand stomach cancer is more likely to be treated in a public hospital due to clinical complexity (National HBP/Upper GI Tumour Standards Working Group, 2013). A number of the larger public hospitals operated either fully or partially computerised clinical records systems i.e. Auckland, Hamilton and Wellington hospitals; however the majority of medical note review was completed through manual review of paper-based patient files. Data gathered included details of patients’ presentation, investigation and diagnosis, comorbid conditions present at the time of diagnosis, tumour characteristics (including stage, tumour site and grade), surgical treatment, medical and radiation oncology treatment and referral to palliative care services.

In total 362 patient’s medical notes were reviewed in 13 public and one private hospital. This process is further discussed in the selection of study cohort in Chapter 6: Quantitative Results. Data from six additional hospitals was also reviewed either via
remote computer access or through the physical transport of the paper-based medical notes to a larger facility within the jurisdiction of the relevant DHB/hospital.

Three study participants’ data were substantially incomplete after the review of public hospital medical notes. These were augmented with data obtained through review of specific medical notes requested from a private hospital and a private specialist physician.

Pathology Reports

Pathology reports were viewed within the medical notes for all study patients. They were reviewed to confirm histological diagnosis (often by biopsy report), for information on tumour site, grade, size (where reported) and for operative details such as cancer margins and extent of lymph node resection. The pathology reports also contributed to determining the stage at diagnosis for many patients in the study.

Data Extraction, Entry and Checking

All data were extracted and entered onto the standardised proforma, including the data obtained through private physicians. Where there were queries regarding key pieces of clinical data, such as exact diagnosis, date of diagnosis or stage, photocopies were made of the relevant patient note (often a histology report, operation report or specialist clinic letter) and these were reviewed by this study’s primary supervisor (Diana Sarfati) and/or the Upper GI cancer surgeon supervising this study (Jonathan Koea).

Data from all study proforma were entered into an electronic database. Validation of data extraction and entry was carried out in two ways. Firstly validation of the extraction of data was carried out on a randomly selected subset of patients treated at one major cancer centre facility. In this case data extraction was completed for all data points on the standardised proforma and double checked to the data already extracted. Secondly validation of data entry was carried out by double entry of specific key data points. This was carried out for all patients in the stomach cancer cohort. The specific data points...
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were date of diagnosis, date of surgery, TNM stage at diagnosis, date of first appointment with medical oncology and/or radiation oncology and finally date of receipt of chemotherapy and/or radiotherapy. Validation checks were undertaken and any discrepancies in data extraction, or recording, were resolved by referencing back to the paper-based proforma and any clinical information on the patient held with the proforma.

Challenges and Benefits of Data Collection and use of a Reflective Diary

Manual review of individual patient medical notes was the most time intensive and costly part of this study; however it also added immense value. The data gathered provided more detailed information than that routinely available from administrative databases, especially with respect to staging and detailed treatment data. The review of patient medical notes also had a number of other benefits. In depth review of medical notes in a variety of hospitals in the North Island of New Zealand provided a good understanding of the strengths and limitations of the data gathered, allowed the visualization of the patient journey as a whole and created opportunity for discussion with clinical staff. It also provided insight into the context of the delivery of cancer care in the many different facilities of Aotearoa New Zealand.

A reflective diary was kept during the data collection process, a summary of which is included as an appendix to this thesis (see Appendix 2). Use of reflexivity is common within qualitative research, while less common within quantitative research it is a useful tool in the collection and analysis of quantitative data (Hesse-Biber and Johnson, 2015) and has been used previously in the clinical note review process (Walker et al., 2013). Use of reflexivity during the process of note review was said to add value to the data collected, helped assess data quality and provided transparency of the impact of the researcher on analysis of data and research decisions (Walker et al., 2013).
Data Preparation and Variables

Data Preparation

Results of the clinical note review were entered and managed in a Microsoft Access (2010) dataset. Data from the NZCR and mortality records were linked together with the results of the medical notes review using individual patient identifiers. This created one integrated dataset with a single line of data for each patient within the study cohort. The dataset was then imported into SAS (version 9.3, SAS Institute Inc., Cary, NC) and the data cleaned.

Variables used in Study Analyses

All variables used in study analyses are outlined in Table 14 (pg 174). Explanation for selected key variables (marked in Table 14 with an asterisk) is provided below.

Exposure: Māori or non-Māori

As this study is primarily interested in comparing stomach cancer treatment and survival between Māori and non-Māori, accurate ethnicity data was essential. Ethnicity for patients in this study was assigned on the basis of NZCR ethnicity data, up to the point of cancer registration. The NZCR uses an ‘ever-Māori’ approach where patients are classified as being Māori if they have identified as Māori on any previous health record (including all in- and out-patient events). This ethnicity classification method is used to minimise a known historical under-count of Māori in health service databases (Robson et al., 2006; Robson et al., 2010). There is some evidence that under-count of Māori in hospitalisation databases and the NZCR continues (Robson and Purdie, 2007b; Swan et al., 2006) although a 2008 – 2009 study shows this to be of smaller magnitude than once thought (Rumball-Smith and Sarfati, 2011). Ethnicity was not revised after the date of
METHODS

cancer registration to reduce the chance of follow-up bias, where those who have had more contact with health services subsequent to their cancer diagnosis are more likely to be identified as Māori. Additionally, patient ethnicity was checked during the manual review of patient medical notes with no misclassifications noted.

In this study patients were classified as Māori if their ethnicity was recorded as Māori by the NZCR. All other patients were classified as non-Māori.

**Date of Diagnosis**

An indicative date of diagnosis was identified from the national level databases (largely the NZCR). This was used to generate the list of hospitals providing care to these patients around time of diagnosis and to determine which hospitals to visit during the clinical note review.

Definitive patient date of diagnosis was determined through the medical note review. It was determined through supporting evidence within patient notes such as histology report, gastroscopy findings, radiological report or specialist letter. Date of diagnosis was most commonly based on the date of histology that included a diagnosis of stomach cancer, or if this was absent it was based on information within the remaining supporting evidence.

Date of diagnosis was used to determine time until key points in the treatment pathway and in survival analyses.

**Comorbidity**

Comorbidity is the presence of health conditions other than the disease of interest, in this case stomach cancer. During the clinical note review information was collected on a list of comorbidities. These comorbidities were identified as being important from review of literature and with reference to the C3 clinical advisory group which helped to identify conditions most likely to affect stomach cancer treatment or survival. In addition
comorbid conditions documented by clinicians in the patients’ medical notes were assumed to be important. All comorbid conditions present at the time of diagnosis were recorded, with the exception of previous malignancies and past conditions that had completely resolved at time of diagnosis (e.g. appendicitis or cholecystitis resolved with surgery). Gastrointestinal (GI) ulcers, GI bleeding and blood loss anaemia were collected but not included in any analyses as these conditions may reflect symptoms relating to undiagnosed stomach cancer.

The 12 most common comorbid conditions in this study were included in the analysis. These conditions were: angina, hypertension, myocardial infarction, arrhythmia, mild chronic pulmonary disease, moderate/severe chronic pulmonary disease, congestive heart failure, cerebrovascular accident, obesity, diabetes, other malignancy and renal disease. Comorbidities were analysed both as individual conditions and as a categorised ‘count’ to assess the overall burden of comorbidity at diagnosis. The comorbidity count was categorised into 1, 2, 3 and 4+ comorbidities for the purposes of descriptive analysis, and kept as a continuous variable (0-12) for the purposes of survival analyses.

**Small Area Deprivation**

Level of deprivation was conceptualised as a marker of access to cancer services in this study. Patient domicile at time of diagnosis from the NZCR was used to assign each patient to the New Zealand Index of Deprivation 2006 (NZDep) (Salmond and Crampton, 2012). The NZDep is a measure developed from nine variables collected within the Statistics NZ 2006 Census of Population and Dwellings: income, benefit receipt, single parent family, home ownership, employment, qualifications, living space, access to communication and access to transport. The NZDep uses these variables to provide a summary deprivation score (1 – 10, with 1 being the least deprived and 10 the most deprived) for small geographical areas. For this study the deciles were collapsed into quintiles (1 - 5).
Rurality

Place of domicile was also conceptualised as a marker of access to cancer services in this study and the patients rural/urban profile was also based on the patient’s domicile from the NZCR at time of diagnosis. Statistics New Zealand assigns a seven level urban/rural classification code to each census unit in New Zealand (Statistics New Zealand, 2004). For this study these seven levels were aggregated into three categories: urban (including main urban and satellite urban areas), independent urban (independent urban areas) and rural (including rural areas with high or moderate urban influence, rural areas with low urban influence and highly rural areas).

Surgical Facility Type

For the purposes of describing the place where definitive surgery was performed health care facilities were classified into one of three categories: main centres, smaller centres and private centres. Main centres were public cancer hospitals and included the following hospitals: North Shore, Auckland, Middlemore, Manukau Super Clinic, Waikato, Palmerston North, and Wellington. Smaller centres were public non-cancer center hospitals and included: Whangarei, Tauranga, Thames, Rotorua, Whakatane, Gisborne, Hawkes Bay, New Plymouth, Taranaki, Whanganui, Masterton and Hutt. Private centres were any privately funded hospital including: Wakefield, Gilgit Road Specialist Centre, MercyAscot, Braemar, and Southern Cross. The name of the primary surgical facility was obtained from manual review of surgical records and clinical letters.

Tumour Stage

The TNM staging classification system was used to analyse variables in this study. TNM stage was determined during the clinical note review using all available information: investigation results, histological findings, operation reports and clinical notes or medical
letters. In keeping with the approach used by the NZCR, data up to four months post-diagnosis were included.

In the TNM system, cancer stage can be based on the results of physical examination, clinical or imaging results as well as histo-pathological findings (Abrams and Wang, 2010). This study used a combination of clinical and pathological staging. If pathological stage information was available within four months of patient diagnosis it was used as the basis for determining stage, otherwise all available clinical information was used. The TNM system for staging contains 3 key pieces of information: T (tumour) indicates the depth of penetration into the stomach, N (nodes) indicates the amount of lymph node invasion, and M (metastasis) indicates the presence, or not, of distant metastases (American Joint Committee on Cancer (AJCC), 2012; Abrams and Wang, 2010). The TNM staging system is further outlined in the tables below (Table 9 and Table 10).
Table 9: AJCC TNM staging definition for stomach cancer

<table>
<thead>
<tr>
<th>T category definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>TX</td>
</tr>
<tr>
<td>T0</td>
</tr>
<tr>
<td>Tis</td>
</tr>
<tr>
<td>T1</td>
</tr>
<tr>
<td>T1a</td>
</tr>
<tr>
<td>T1b</td>
</tr>
<tr>
<td>T2</td>
</tr>
<tr>
<td>T3</td>
</tr>
<tr>
<td>T4</td>
</tr>
<tr>
<td>T4a</td>
</tr>
<tr>
<td>T4b</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>N category definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>NX</td>
</tr>
<tr>
<td>N0</td>
</tr>
<tr>
<td>N1</td>
</tr>
<tr>
<td>N2</td>
</tr>
<tr>
<td>N3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>M category definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>M0</td>
</tr>
<tr>
<td>M1</td>
</tr>
</tbody>
</table>


In the TNM system, after the TNM categories have been determined they are combined and grouped to assign a stage denoted by a roman numeral I – IV, with stage I having the best prognosis and stage IV the worst (Table 10) (American Joint Committee on Cancer (AJCC), 2012). In this study the stage groupings below were then grouped into broader categories: stage I, stage II, stage III, and stage IV rather than using the subcategories (IIA, IIB etc.). These stage groupings were then used in subsequent analyses.
Table 10: TNM stage grouping for adenocarcinoma of the stomach

<table>
<thead>
<tr>
<th>Stage Grouping</th>
<th>Tumour</th>
<th>Nodes</th>
<th>Metastasis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0</td>
<td>Tis (carcinoma in situ)</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>Stage IA</td>
<td>T1</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T2</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T1</td>
<td>N1</td>
<td>M0</td>
</tr>
<tr>
<td>Stage IIA</td>
<td>T3</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T2</td>
<td>N1</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T1</td>
<td>N2</td>
<td>M0</td>
</tr>
<tr>
<td>Stage IIB</td>
<td>T4a</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T3</td>
<td>N1</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T2</td>
<td>N2</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T1</td>
<td>N3</td>
<td>M0</td>
</tr>
<tr>
<td>Stage IIIA</td>
<td>T4a</td>
<td>N1</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T3</td>
<td>N2</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T2</td>
<td>N3</td>
<td>M0</td>
</tr>
<tr>
<td>Stage IIIB</td>
<td>T4b</td>
<td>N0 or N1</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T4a</td>
<td>N2</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T3</td>
<td>N3</td>
<td>M0</td>
</tr>
<tr>
<td>Stage IIIC</td>
<td>T4b</td>
<td>N2 or N3</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>T4a</td>
<td>N3</td>
<td>M0</td>
</tr>
<tr>
<td>Stage IV</td>
<td>Any T</td>
<td>Any N</td>
<td>M1</td>
</tr>
</tbody>
</table>


Tumour Grade

Tumour grade was classified according to the WHO International Classification of Tumours (Hamilton and Aaltonen, 2000) see Table 11 below. Histological grade was obtained from the patients’ pathology report, either biopsy or subsequent resection report. Generally these pathology reports used the terminology as defined by the WHO below (Table 11). However in some cases the terms low grade or high grade were used by the pathologist. In these cases low grade was taken to mean well-differentiated and
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high grade to mean poorly-differentiated (National Cancer Institute, 2013a). Tumour grade was unable to be obtained for 40% of the final cohort overall, 49% of the Māori cohort and 37% of the non-Māori cohort. As this variable was only used in descriptive statistics no attempt was made to impute missing data.

Table 11: Tumour grade according to WHO International Classification of Tumours

<table>
<thead>
<tr>
<th>Histological Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well differentiated</td>
<td>An adenocarcinoma with well-formed glands, often resembling metaplastic</td>
</tr>
<tr>
<td></td>
<td>intestinal epithelium.</td>
</tr>
<tr>
<td>Moderately differentiated</td>
<td>An adenocarcinoma intermediate between well differentiated and poorly</td>
</tr>
<tr>
<td></td>
<td>differentiated.</td>
</tr>
<tr>
<td>Poorly differentiated</td>
<td>An adenocarcinoma composed of highly irregular glands that are recognized</td>
</tr>
<tr>
<td></td>
<td>with difficulty, or single cells that remain isolated or are arranged in</td>
</tr>
<tr>
<td></td>
<td>small or large clusters with mucin secretions or acinar structures.</td>
</tr>
</tbody>
</table>

Source: Hamilton and Aaltonen, World Health Organization Classification of Tumours (Hamilton and Aaltonen, 2000)

Tumour Site

Tumour site, or where in the stomach the tumour has originated, was obtained from a number of sources within the patients’ medical notes. If the patient had undergone surgical resection the pathology report of the resection was the primary source of tumour site data. In some cases the information gained from pathology report was augmented with the written operative report. If surgical resection did not occur, or this information was not available from this source, the biopsy report was reviewed for site data. If the site data were not obtained from either of these pathological sources the remainder of the patients’ clinical record was reviewed for this information. Tumour site was recorded as one of four categories (Table 12). These categories were determined after consultation with Jonathan Koea, the Upper GI surgeon supervising this study.
Table 12: Tumour site categories used in this study

<table>
<thead>
<tr>
<th>Tumour site</th>
<th>Description</th>
<th>Corresponding ICD Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proximal</td>
<td>Includes the cardia, fundus and body of the stomach, along with tumours originating in the cardia that cross the OG junction</td>
<td>C160, C161, C162</td>
</tr>
<tr>
<td>Distal</td>
<td>Includes the antrum and pylorus of the stomach</td>
<td>C163</td>
</tr>
<tr>
<td>Proximal and Distal</td>
<td>Overlapping lesion of the stomach including both distal and proximal sites</td>
<td>C168, C164</td>
</tr>
<tr>
<td>Other Description</td>
<td>Lesser curvature or greater curvature of the stomach without specifying further</td>
<td>C165, C166</td>
</tr>
</tbody>
</table>

**Post-operative Complications**

Post-operative complications were defined as complications which occurred in the 30 days following surgical resection of the primary tumour. The presence of any of a list of specific conditions in this time-period was categorized as a post-operative complication (Table 13).

Table 13: Post-operative complications as defined in this study

<table>
<thead>
<tr>
<th>Complication</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reoperation</td>
<td>Reoperation related to the surgical resection of the primary tumour. Reasons for reoperation included anastomotic leakage, bleeding, infarcted bowel, adhesions requiring division and intra-abdominal abscess</td>
</tr>
<tr>
<td>Sepsis</td>
<td>Generalised sepsis or localised sepsis with systematic symptoms</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>Documented diagnosis of pneumonia</td>
</tr>
<tr>
<td>Heart failure</td>
<td>Documented heart failure requiring organ support (intravenous medication)</td>
</tr>
<tr>
<td>Respiratory failure</td>
<td>Documented respiratory failure requiring organ support (artificial ventilation)</td>
</tr>
<tr>
<td>Renal failure</td>
<td>Documented renal failure requiring organ support (renal dialysis)</td>
</tr>
<tr>
<td>Death</td>
<td>Death within 30 days of surgery</td>
</tr>
</tbody>
</table>
Survival Outcomes

Time, until the study participant dies, is the outcome of interest in survival analyses (Kleinbaum and Klein, 2012). In order to calculate survival, mortality data from 2006 to 2010 were obtained from the Ministry of Health’s National Collections and linked to individual study members using their national health system identifier (NHI number).

The mortality data were then merged with study data. Each death was classified as either attributable to stomach cancer, or due to other causes, based on the NZHIS information. Three non-Māori in the cohort whose death was classified as malignant neoplasm of lower third of oesophagus (C155) were assumed to have died of stomach cancer and their death attributed to stomach cancer. In all three cases the patient was originally registered with adenocarcinoma of the cardia (C160).
<table>
<thead>
<tr>
<th>Variable set</th>
<th>Variables</th>
<th>Values</th>
<th>Comments/Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td>Ethnicity*</td>
<td>Māori or non-Māori</td>
<td>Prioritised ethnicity, as determined from the NZCR. Options include Māori and non-Māori. A patient was considered non-Māori if they belonged to a non-Māori ethnic group (or had ‘missing’ residency status) and were a New Zealand resident</td>
</tr>
<tr>
<td>Time origin</td>
<td>Date of diagnosis*</td>
<td>1 January 2006 – 31 December 2008</td>
<td>Date on which a diagnosis of stomach cancer was made, based on supporting evidence: histology report, gastroscopy findings, radiological report or specialist letter</td>
</tr>
<tr>
<td>Demographics</td>
<td>Gender</td>
<td>Male or female</td>
<td>Gender as recorded on index hospital admission sheet</td>
</tr>
<tr>
<td></td>
<td>Age at diagnosis</td>
<td>25 - 99</td>
<td>Age at cancer diagnosis, based on date of birth and the diagnosis date from notes review</td>
</tr>
<tr>
<td></td>
<td>Age at diagnosis - categories</td>
<td>25 – 49, 50 – 64, 65 – 74, 75+</td>
<td>Age at cancer diagnosis, grouped into categories</td>
</tr>
<tr>
<td>Patient characteristics</td>
<td>Comorbidity*</td>
<td>Yes or no for each condition</td>
<td>The presence or absence of comorbid conditions: angina, hypertension, myocardial infarction, arrhythmia, mild CPD, mod/severe CPD, CHF, CVA, obesity, diabetes, other primary cancer, renal disease. NB: Blood loss anaemia, GI ulcer disease and GI bleeding were excluded as these were likely to be present in the buildup to diagnosis</td>
</tr>
<tr>
<td></td>
<td>Comorbidity - count</td>
<td>0, 1, 2, 3, 4+</td>
<td>The number of comorbid conditions present at diagnosis, from the 12 most common in this study</td>
</tr>
<tr>
<td></td>
<td>Comorbidity -</td>
<td>0 – 12</td>
<td>The number of comorbid conditions present at diagnosis, from the 12 most common in this study as a continuous variable</td>
</tr>
</tbody>
</table>
### METHODS

<table>
<thead>
<tr>
<th>Smoking status</th>
<th>Current, ex-smoker, unknown</th>
<th>Patient smoking status at diagnosis according to clinical records</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care access</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small area deprivation*</td>
<td>1 - 5</td>
<td>Measured at New Zealand Deprivation Index 2006 (NZ Dep). Values aggregated into quintiles (1 – 5) for descriptive and survival analyses</td>
</tr>
<tr>
<td>Rurality*</td>
<td>Urban, Independent urban, Rural</td>
<td>Calculated through patient domicile code at time of diagnosis. Values aggregated into three categories for descriptive and survival analyses</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disease characteristics</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage*</td>
<td>TNM, stages I – IV and unstaged</td>
<td>Tumour stage as determined, based on supporting evidence histology report, gastroscopy findings, surgical report, radiological report or specialist letter</td>
</tr>
<tr>
<td>Tumour site*</td>
<td>Proximal, distal, both proximal and distal, other description</td>
<td>Tumour site as recorded in histology report, gastroscopy findings, radiological report or specialist letter</td>
</tr>
<tr>
<td>Tumour grade*</td>
<td>Well-, moderately- or poorly differentiated</td>
<td>Tumour grade as recorded in histology report or specialist letter</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Investigations</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gastroscopy</td>
<td>Yes or no</td>
<td>Gastroscope/endoscopy of stomach, performed as part of diagnostic work-up for stomach cancer</td>
</tr>
<tr>
<td>CT Scan</td>
<td>Yes or no</td>
<td>Computerised topography performed as part of the diagnostic work-up or staging for stomach cancer</td>
</tr>
<tr>
<td>MRI Scan</td>
<td>Yes or no</td>
<td>Magnetic resonance imaging scan performed as part of the diagnostic work-up or staging for stomach cancer</td>
</tr>
<tr>
<td>Endo Ultrasound</td>
<td>Yes or no</td>
<td>Endoscopic ultrasound of the stomach performed as part of the diagnostic work-up or staging for stomach cancer</td>
</tr>
<tr>
<td>Laparoscopy</td>
<td>Yes or no</td>
<td>Surgical laparoscopy performed as part of the staging for stomach cancer</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Surgical treatment</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Removal of primary tumour</td>
<td>Yes or no</td>
<td>Surgical removal of primary tumour either during gastroscopy or during abdominal or abdominal/thoracic surgery</td>
</tr>
<tr>
<td>Method</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Type of surgery</td>
<td>Type of surgery as documented in operative report. Local excision/EMR = local excision during gastroscopy, Ivor-Lewis oesophagogastrectomy = resection of distal oesophagus and proximal stomach, Gastrojejunostomy = resection of distal stomach with anastomosis between the stomach and the proximal loop of the jejunum, Partial Gastrectomy = resection of the distal stomach, Total Gastrectomy = resection of the whole stomach, Laparotomy without resection = open and close procedure</td>
<td></td>
</tr>
<tr>
<td>Surgical facility type*</td>
<td>Main centre, smaller centre or private</td>
<td></td>
</tr>
<tr>
<td>Surgical facility type*</td>
<td>Main centre = North Shore, Auckland, Middlemore, Manukau Super Clinic, Waikato, Palmerston North, and Wellington. Smaller centre = Whangarei, Tauranga, Thames, Rotorua, Whakatane, Gisborne, Hawkes Bay, New Plymouth, Taranaki, Whanganui, Masterton and Hutt. Private hospitals = Wakefield, Gilgit Road Specialist Centre, MercyAscot, Braemar, and Southern Cross</td>
<td></td>
</tr>
<tr>
<td>Surgeon type</td>
<td>Specialist or generalist</td>
<td></td>
</tr>
<tr>
<td>Surgeon type</td>
<td>The most senior surgeon involved in the operation, as self-identified in clinic letters, on operative report or (if not clear) confirmed with DHB records</td>
<td></td>
</tr>
<tr>
<td>Nodes resected</td>
<td>0-14</td>
<td></td>
</tr>
<tr>
<td>Nodes resected</td>
<td>15+</td>
<td></td>
</tr>
<tr>
<td>Postoperative complications*</td>
<td>Yes or no for each condition</td>
<td></td>
</tr>
<tr>
<td>Postoperative complications*</td>
<td>Presence or absence of specific conditions in the 30 days following surgical removal of primary tumour: Reoperation, sepsis, pneumonia, heart failure, respiratory failure, renal failure, death</td>
<td></td>
</tr>
<tr>
<td>Oncology treatment</td>
<td>Referred to oncologist Yes or no Documented referral to medical or radiation oncologist</td>
<td></td>
</tr>
<tr>
<td>Date referred</td>
<td>Date Documented date referred to medical or radiation oncologist</td>
<td></td>
</tr>
<tr>
<td>Reviewed by oncologist</td>
<td>Yes or no Documented review by medical or radiation oncologist</td>
<td></td>
</tr>
<tr>
<td>Date reviewed</td>
<td>Date Documented date reviewed by medical or radiation oncologist</td>
<td></td>
</tr>
<tr>
<td>Offered chemo/radiation</td>
<td>Yes or no Documented discussion of chemotherapy or radiation therapy with patient, without explicit statement that treatment was not offered</td>
<td></td>
</tr>
</tbody>
</table>
TABLE 1: VARIABLES INCLUDED IN THE ‘ONCOLOGY’ DATABASE TO MEASURE TIMELINESS OF CARE

<table>
<thead>
<tr>
<th>Variable</th>
<th>Data Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received chemo/radiation</td>
<td>Yes or no</td>
<td>Documented receipt of chemotherapy or radiotherapy</td>
</tr>
<tr>
<td>Date received chemo/radiation</td>
<td>Date</td>
<td>Documented date first received treatment</td>
</tr>
<tr>
<td>Timeliness of care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosis – First intervention</td>
<td></td>
<td>Time, in days, from date of diagnosis until first intervention, one of: chemotherapy, radiotherapy, definitive surgery or other intervention (i.e. stent, paracentesis, jejunostomy feeding tube)</td>
</tr>
<tr>
<td>Diagnosis – Definitive surgery</td>
<td></td>
<td>Time, in days, from date of diagnosis until surgical removal of primary tumour</td>
</tr>
<tr>
<td>Diagnosis – Referred to Med Onc</td>
<td></td>
<td>Time, in days, from date of diagnosis until referred to medical oncology</td>
</tr>
<tr>
<td>Referred Med Onc – Review by Med Onc</td>
<td></td>
<td>Time, in days, from referred to medical oncology until reviewed by medical oncology</td>
</tr>
<tr>
<td>Review Med Onc – Received chemo</td>
<td></td>
<td>Time, in days, from reviewed by medical oncology until documented receipt of chemotherapy</td>
</tr>
<tr>
<td>Diagnosis – Received chemo</td>
<td></td>
<td>Time, in days, from date of diagnosis until documented receipt of chemotherapy</td>
</tr>
<tr>
<td>Palliative care</td>
<td>Yes or no</td>
<td>Documented referral for palliative care; any of palliative chemo, palliative radiotherapy or palliative care services</td>
</tr>
<tr>
<td>Date referred Palliative care</td>
<td>Date</td>
<td>Documented date referred to palliative care</td>
</tr>
</tbody>
</table>

*: Variables for which an explanation has been given in text prior to this table
**Missing Data for Key Variables**

Many patients within the study had missing data for some variables, proportions of which are identified within appropriate places in the descriptive analyses (Chapter 6). Data were also missing for some of the key ‘covariates’ determined during the course of this study: namely tumour stage, tumour site, deprivation and rurality. These variables were used within survival analyses and the management of missing data for these variables is further discussed below. No patients were excluded from the study due to missing data.

Date of diagnosis was determined for all patients within this study. This variable is important as it is the beginning point for all survival analyses and thus essential to these analyses.

**Unstaged Cancer**

Tumour stage was determined for all but five (2%) non-Māori patients after reviewing all relevant supporting evidence (histology report, gastroscopy findings, surgical report, radiological report or specialist letter), and discussing with study supervisors when tumour stage was unclear. These five patients therefore represented an important category whereby a decision had been made not to proceed with investigations rather than just having the absence of information. On this basis it was decided to include an ‘unstaged’ group as a category for both the descriptive and survival analyses.

**Deprivation and Rurality**

Deprivation and rurality variables were missing data for 4% (n=12) of patients. As these variables were considered as indicators of level of access to cancer services it was decided to impute the missing data. Additionally as level of deprivation is closely linked to tumour site, through the H. pylori causal pathway, the imputed deprivation variable was used in the tumour site imputation model below.
METHODS

Tumour Site

Tumour site was ascribed based on data from the notes review, or if that was missing, from the NZCR. The NZCR usually receives its first notification of a stomach cancer diagnosis from a biopsy report. If there is no indication of where in the stomach the biopsy was taken the initial ICD-10-AM code is assigned as C169 - Malignant neoplasm of stomach, unspecified. If there is information in the report of where in the stomach the biopsy was taken from a more specific site code is entered. When and if the NZCR receives subsequent information, generally an operative histology report, the site code will be reviewed and updated to the more specific sub-site as indicated. The site code can be updated at any time subsequent information is received, not just within four months from date of diagnosis as for the extent of disease field (personal communication, Shirley Miles, Team Leader, NZ Cancer Registry, Classification and Terminology).

Even using all available data sources, tumour site was missing from 22% of cases (15% Māori, 24% non-Māori, age- and sex-standardised). Given the importance that tumour site plays in patient prognosis (McLoughlin, 2004; Abrams and Wang, 2010), it was decided to impute the missing data.

Imputation of Missing Data for Tumour Site, Deprivation and Rurality

Multiple imputation for missing tumour site, deprivation and rurality was carried out using Stata (Version 12) before analysis was continued in SAS.

Before tumour site imputation was carried out the four level tumour site variable was collapsed into two levels. Tumours that were categorised as both proximal and distal (n= 5) were combined with proximal, as these two categories would both be surgically treated with a total gastrectomy; other description (n= 11) was combined with distal.

A binary logistic regression model was then used to impute the missing tumour site data. The predictive model included variables for ethnicity, age at diagnosis, gender, stage, count of the top 12 comorbid conditions and deprivation.
METHODS

The imputed model was imported back into SAS and run 35 times using the SAS Phreg procedure. This produced 35 cohort datasets with imputed estimates of tumour site, deprivation and rurality for patients with missing data. The logistic regression analyses were re-run using the imputed tumour site, deprivation and rurality variables. Models produced 35 estimates (based on the 35 cohorts generated by multiple imputations); coefficients and variance estimates from these 35 cohorts were then pooled to give a single result for each variable using the SAS Mianalyze procedure.

Data Analyses

Data analyses were carried out in three parts (Table 15). Firstly, the presentation of the Māori and non-Māori cohorts was compared descriptively. This step involved comparing patient factors, tumour or disease factors and markers of health care access. Secondly, the management of the Māori and non-Māori cohorts including the receipt and timing of treatment were compared descriptively. In these two steps the variables were adjusted for age and sex only, since these were considered pure confounders. Thirdly, survival analyses were carried out. Kaplan-Meier cancer survival curves were compared for Māori and non-Māori cohorts and Cox proportional hazards models were fitted to produce cancer specific hazard ratios. These were adjusted in a sequential fashion for age and sex, stage and tumour site, patient comorbidity and deprivation and rurality. All analyses were carried out using SAS (Version 9.3). More detail about these methods is provided in the following section.

While significance of differences was assumed at P values of less than 0.05, a considered decision was made when presenting the results to not focus and report solely on the basis of whether results were statistically significant (or not). This approach is in line with concerns by leading practitioners that labelling results as “statistically significant” or “statistically non-significant” dependent on a calculated p-value being below/above 0.05 is too reductionist and simplistic to provide useful information, and often leads in misleading reporting (or non-reporting) of results.
(Kyriacou, 2016; Nuzzo, 2014; Sterne and Davey Smith, 2001; Wasserstein and Lazar, 2016).

**Table 15: Cohort analysis and statistical methods**

<table>
<thead>
<tr>
<th>Analysis</th>
<th>Statistical Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Comparison of cohorts</td>
<td>• Crude and standardised prevalence rates</td>
</tr>
<tr>
<td>2. Comparison of treatment and management</td>
<td>• Crude and standardised prevalence rates</td>
</tr>
<tr>
<td></td>
<td>• Crude median waiting times for cancer treatment</td>
</tr>
<tr>
<td></td>
<td>• Surgeon and surgical facility type by stratification and logistic regression</td>
</tr>
<tr>
<td>3. Comparison of survival</td>
<td>• Kaplan-Meier survival curves</td>
</tr>
<tr>
<td></td>
<td>• Cancer-specific hazard ratios (Cox proportional models) sequentially adjusted for:</td>
</tr>
<tr>
<td></td>
<td>I. Demographics</td>
</tr>
<tr>
<td></td>
<td>II. Disease factors</td>
</tr>
<tr>
<td></td>
<td>III. Patient comorbidity</td>
</tr>
<tr>
<td></td>
<td>IV. Health care access factors</td>
</tr>
</tbody>
</table>

**Linking Data Analyses to the Mandelblatt Framework**

The variables used in these data analyses were organised according to the Mandelblatt et al framework (Mandelblatt et al., 1999) pertaining to Māori/non-Māori treatment disparities as discussed in Chapter 4 (see Table 16). Comparing the treatment and management received by Māori and non-Māori and adjusting for variables in survival analyses in a sequential manner allowed this thesis to remain focussed on health system-level factors (small area deprivation and rurality) and health care process-level factors (surgical and medical oncology intervention rates and waiting times, and surgical facility type and surgeon type) while also acknowledging the importance of patient-level factors (patient characteristics – age, sex and comorbidity and disease characteristics – stage, grade and tumour site).
Table 16: Framework and variables used in data analysis

<table>
<thead>
<tr>
<th>Framework Level</th>
<th>Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-level</td>
<td>• Patient factors</td>
</tr>
<tr>
<td></td>
<td>- Age</td>
</tr>
<tr>
<td></td>
<td>- Sex</td>
</tr>
<tr>
<td></td>
<td>- Comorbidity</td>
</tr>
<tr>
<td></td>
<td>• Disease factors</td>
</tr>
<tr>
<td></td>
<td>- Stage</td>
</tr>
<tr>
<td></td>
<td>- Grade</td>
</tr>
<tr>
<td></td>
<td>- Tumour site</td>
</tr>
<tr>
<td>Health care process-level</td>
<td>• Intervention rates</td>
</tr>
<tr>
<td></td>
<td>• Timeliness to treatment</td>
</tr>
<tr>
<td></td>
<td>• Surgical facility type</td>
</tr>
<tr>
<td></td>
<td>• Surgeon type</td>
</tr>
<tr>
<td>Health system-level</td>
<td>• Deprivation</td>
</tr>
<tr>
<td></td>
<td>• Rurality</td>
</tr>
</tbody>
</table>

**Patient-level factors** lie outside of the dominion of the secondary and tertiary cancer care system. While patient (comorbidity) and disease factors (grade and tumour site) existing at presentation to secondary services are important influencers of cancer treatment and subsequent survival, they reflect differences in the underlying determinants of health and institutionalised racism in society as a whole. In this study they have been conceptualised as patient-level factors, as have age and sex.

Stage at diagnosis could be thought of as a process-level factor, with differences by ethnicity reflecting differential access to primary health care, prompt referral and timely diagnostic investigation; however in this study stage has been conceptualised as a patient-level factor as it also represents a crucial individual patient measure influencing patient survival.

**Health care process-level factors** include communication between services and patients and their whānau which in turn may impact on the pathways of care experienced by patients. Thus surgical and medical oncology intervention rates and waiting times are conceptualised as process-level factors, with any differences by ethnicity conceptualised as institutionalised racism. Surgical treatment facility type...
and surgeon type are presented as health care process level factors within the
descriptive results, however they could also be conceptualised as health system-level
factors.

*Health system-level factors* include the focus, funding and location of cancer services
which in turn affect the accessibility of services according to socioeconomic status and
geographical location. Thus small area deprivation and rurality, while broad
measures, are conceptualised as markers of health care access reflecting
institutionalised racism that may privilege or discriminate according to ethnicity.

**Age (and Sex) Standardisation**

Standardising for age (and sex) is important when two groups being compared have
different underlying age (and/or sex) distributions and these variables are related to
the outcome of interest, as in the case of this study. Māori have a younger age
structure as well as differential sex distribution compared to non-Māori (Statistics
New Zealand, 2007). All age- and sex-standardised rates were calculated by direct
standardisation, using the total New Zealand cancer population (2006-2008) as
standard (Table 17). The use of a New Zealand cancer population standard creates
rates that are a closer approximation of the crude overall cancer rates than would
rates standardised to other standard populations such as Segi’s world population or
the World Health Organization (WHO) population. Standardising to these populations
would result in rates that are generally higher (because these standard populations
are younger than cancer populations). Thus the use of a New Zealand cancer
population standard better reflects the age structure and experience of cancer
patients in New Zealand (Robson and Purdie, 2007b).
METHODS

Table 17: New Zealand cancer population (all new cancer registrations diagnosed 2006-2008), used as the standard population for age standardisation

<table>
<thead>
<tr>
<th>Age Category</th>
<th>Women (n)</th>
<th>Men (n)</th>
<th>Total (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>25-49</td>
<td>9936</td>
<td>3236</td>
<td>13172</td>
</tr>
<tr>
<td>50-64</td>
<td>10255</td>
<td>9810</td>
<td>20065</td>
</tr>
<tr>
<td>65-74</td>
<td>6955</td>
<td>10373</td>
<td>17328</td>
</tr>
<tr>
<td>&gt;75</td>
<td>9189</td>
<td>10916</td>
<td>20105</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>36335</strong></td>
<td><strong>34335</strong></td>
<td><strong>70670</strong></td>
</tr>
</tbody>
</table>

Comparison of Māori and Non-Māori Cohorts and Treatment

Prevalence rates (proportions) were calculated for key patient characteristics, tumour or disease factors, markers of health care access, receipt of diagnostic investigations/treatment and timing of treatment (Table 14: Variables used in study analyses). The crude prevalence rates were adjusted for the pure confounders, age and sex only. To do this, study participants were stratified by age and sex, then overall Māori and non-Māori standardised prevalence rates were calculated by summing the strata-specific prevalence rates weighted by the proportion of the New Zealand cancer population in each strata (defined above).

Survey methods were used to calculate population estimates for the total New Zealand stomach cancer cohort over the time frame of the study. Because all Māori patients were included and a sample of non-Māori the final Māori and non-Māori samples were weighted to the total eligible Māori and non-Māori stomach cancer populations (Table 18).

To test the significance of any Māori/non-Māori differences P values were calculated on crude data. They were calculated from Cochrane-Mantel-Haenszel chi-squared tests stratified by age or age-sex group, or by t-test in the case of mean age at diagnosis. Crude, age- and sex-standardised and total weighted prevalence rates along with their P values are presented for discussion.
### Methods

**Table 18: Population estimate calculations for weight**

<table>
<thead>
<tr>
<th>Calculations</th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study sample after exclusions applied</td>
<td>181</td>
<td>584</td>
</tr>
<tr>
<td>Total sample</td>
<td>181</td>
<td>181</td>
</tr>
<tr>
<td>Final cohort (after excluding patients found ineligible during medical note review)</td>
<td>172</td>
<td>163</td>
</tr>
<tr>
<td>Actual eligible population</td>
<td>$\frac{172}{181} \times 181 = \textbf{172}$</td>
<td>$\frac{163}{181} \times 584 = \textbf{526}$</td>
</tr>
<tr>
<td>Weight (actual eligible pop/final cohort)</td>
<td>$\frac{172}{172} = \textbf{1.00}$</td>
<td>$\frac{526}{164} = \textbf{3.2}$</td>
</tr>
</tbody>
</table>

### Access to Specialist Surgical Care: Further Assessment of Surgeon Type and Facility Type

Initial analysis suggested that stage I – III Māori patients were less likely to receive specialist surgical care and care within main centres. To ascertain whether these were related to the differences in surgery type (due to the different tumour site distribution between Māori and non-Māori), stratified analyses were done by surgery type. For these analyses main centres and private centres were collapsed together.

A logistic regression model was also fitted for receipt of specialist surgeon within a main centre as the outcome, ethnicity as the primary exposure of interest and age (continuous), tumour site (proximal and distal) and stage (collapsed to a binary variable stages I/II and III) (Table 19). Age was fitted to the model first as a pure confounder. Then, in order to ascertain if the different tumour site distribution between Māori and non-Māori explained the type of surgeon performing surgery, tumour site was fitted next to the model. Site impacts on the extent of surgery needed and thus on the level of specialised skill needed by the surgeon. Finally stage was adjusted for as stage also influences the complexity of the surgery performed and thus potentially impacts on the level of specialisation needed by the surgeon.
Table 19: Variables used to calculate receipt of specialist surgical care in Māori and non-Māori cohorts (n= 81) diagnosed at stage I – III and who had surgery in a main centre

<table>
<thead>
<tr>
<th>Variable</th>
<th>Values</th>
<th>Reference group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td>Māori, non-Māori</td>
<td>non-Māori</td>
</tr>
<tr>
<td>Age</td>
<td>Continuous</td>
<td></td>
</tr>
<tr>
<td>Tumour site</td>
<td>Proximal, distal</td>
<td>Proximal</td>
</tr>
<tr>
<td>Stage</td>
<td>Stages I/II, III</td>
<td>Stage I/II</td>
</tr>
</tbody>
</table>

Adjusted for

Ethnicity and Age
Ethnicity, Age and Tumour site
Ethnicity, Age, Tumour site and Stage

Access to Multidisciplinary Meetings

Data on access to multidisciplinary meetings (MDM) were gathered but this information was often missing within patient notes and thus there was a substantial amount of missing data. These data were not analysed further.

Comparison of Timeliness to Cancer Treatment

Median times between key steps in the treatment pathway were calculated for the stage I - III study population. In cases where the date (day) of a key treatment step was missing, but the month and year were recorded, the day was defined as the 15th of the month and these cases were then used in analyses. First intervention was defined as earliest of either radiotherapy, chemotherapy, definitive surgery, or other surgical intervention such as abdominal paracentesis, gastric or oesophageal stent or jejunostomy feeding tube insertion. The SAS *Univariate* procedure was used to examine the distribution of data within all waiting time variables. The procedure was also used to determine the 50% quantile (i.e. median time point), for the total cohort and for the Māori and non-Māori cohorts. To test the significance of any differences between the Māori and non-Māori cohorts P values were calculated using the log-rank test.
Comparison of Cancer Survival

Survival analyses were carried out using cancer specific survival methods. Kaplan-Meier survival curves were compared between Māori and non-Māori. Cox proportional hazard modelling was carried out to calculate hazard ratios and assess the relative risk of dying after diagnosis for Māori compared with non-Māori (Kleinbaum and Klein, 2012; Robson and Purdie, 2007b). All patients were followed-up from date of diagnosis until death or December 31 2010, whichever came sooner; patients who were still alive at December 31, 2010 were censored at that date. This resulted in a minimum follow-up time of two-years (and maximum of five-years) for each patient. Person-years to end of follow-up were calculated for each patient in the study. Kaplan-Meier survival curves were generated using the SAS Lifetest procedure, while Cox proportional hazard ratios and 95% confidence intervals used the SAS Phreg procedure. Log-rank tests were used to compare the survival distributions of the Kaplan-Meier curves; 95% confidence intervals were determined to assess the precision of the hazard ratio result and the likely range of the estimate.

Time to death for the Māori and non-Māori cohorts was assessed and compared using Kaplan-Meier survival curves, for both all-cause and stomach cancer specific survival. Stomach cancer specific modelling only was undertaken as few patients died of other causes and a primary aim of the study was to investigate how any differences in patient, disease, treatment and health care access factors impacted on survival from stomach cancer.

Covariates used in Survival Modelling

In order to explore key relationships between ethnicity and survival crude (unadjusted) Cox models were fitted, following which a series of potentially confounding covariates were introduced into the model in a sequential fashion to illustrate the effect of each on the hazard ratios (Figure 6 and Table 20).
Firstly the model was fitted using crude data; it was then adjusted sequentially for patient demographic and disease characteristics: age at diagnosis (continuous variable), gender, stage at diagnosis (categories: I, II, III, IV and unstaged) and tumour site (using imputed tumour site data, which included the collapsed tumour site variable). The model was then adjusted for level of comorbidity, using a count of the twelve most common comorbid conditions in this study (continuous variable, 0-12). Finally the model was fitted with the variables used as proxy for markers of health care access, imputed deprivation (quintiles) and rurality (collapsed into three categories).

Mortality hazard ratios (HR) and their 95% confidence intervals were compared for the total Māori cohort relative to the total non-Māori cohort.
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Table 20: Variables used to calculate adjusted hazards ratios

<table>
<thead>
<tr>
<th>Variable</th>
<th>Values</th>
<th>Reference group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unadjusted</td>
<td>Māori, non-Māori</td>
<td>non-Māori</td>
</tr>
<tr>
<td>Age</td>
<td>Continuous</td>
<td>Continuous</td>
</tr>
<tr>
<td>Sex</td>
<td>Male, Female</td>
<td>Female</td>
</tr>
<tr>
<td>Stage</td>
<td>Stages I, II, III, IV, Unstaged</td>
<td>Stage I</td>
</tr>
<tr>
<td>Tumour site</td>
<td>Proximal, Distal</td>
<td>Proximal</td>
</tr>
<tr>
<td>Comorbidity – Top 12</td>
<td>Continuous</td>
<td>Continuous</td>
</tr>
<tr>
<td>NZDep Quintile</td>
<td>1, 2, 3, 4, 5</td>
<td>NZDep 1</td>
</tr>
<tr>
<td>Rurality</td>
<td>Urban, Independent Urban, Rural</td>
<td>Urban</td>
</tr>
</tbody>
</table>

**Demographic Factors: Age and Sex**

Age and sex can be considered ‘pure’ confounders in the association between ethnicity and survival (Figure 6). As previously outlined Māori compared to non-Māori populations have different age structures and sex distributions (Statistics New Zealand, 2007); both of these variables are known to impact on cancer survival.

Chronological age is a predictor of survival in patients with stomach cancer with survival probability declining with increasing patient age at diagnosis (Saito et al., 2006; Yang et al., 2011) in part due to differential treatment received by patients in older age groups (Saif et al., 2010). Sex is also an important independent predictor of survival with women shown to have better survival likelihood (Yang et al., 2011). Thus these patient level factors were adjusted for first to ascertain how much of the survival differences were explained by these variables before adjusting for disease factors, patient comorbidity and health care access factors.

**Disease Factors: Stage and Tumour Site**

Stage and tumour site were both conceptualised as potential mediators between ethnicity and survival (Figure 6). As outlined in the previous chapter, ethnicity can impact on stage at diagnosis through pathways such as differential access to primary health care or timely diagnostic investigation. Ethnicity is also related to tumour site with Māori patients more likely to be diagnosed with distally located tumours. Stage at diagnosis is the most important predictor of stomach cancer survival, impacting on
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treatment and with a strong association to mortality (McLoughlin, 2004; Crew and Neugut, 2006; Abrams and Wang, 2010). Likewise tumour site plays an important role in survival from stomach cancer impacting both on treatment options and prognosis (Mann and Thomas, 2001; Abrams and Wang, 2010). These two variables were added next in order to ascertain if there were differences in survival once demographic and disease factors (or the factors not amenable to intervention in the secondary cancer care system) had been accounted for. This then allowed the assessment how much of the remaining inequity was explained by patient comorbidity and factors related to access to health services.

Patient Comorbidity

Comorbidity was conceptualised as a potential mediator in the relationship between ethnicity and cancer survival (Figure 6). It is well documented that Māori with cancer have higher levels of comorbidity than non-Māori (Hill et al., 2010a; Brewer et al., 2011). Comorbidity can impact on survival directly as well as indirectly through its negative impact on treatment receipt. For example comorbidity is known to impact both on the quality of care received and on the likelihood of survival of patients from colorectal cancer (Hill et al., 2010a; Lemmens et al., 2005; Sarfati et al., 2009; Sarfati et al., 2014a). It is also a mechanism through which inequitable survival outcomes can appear or widen once patients have been diagnosed with cancer. Fitting comorbidity to the model subsequent to the factors that are not amenable to secondary sector intervention explores the effect that unequal comorbidity plays on Māori/non-Māori survival disparity once diagnosed with stomach cancer.

Health Care Access Factors: Deprivation and Rurality

Deprivation and health care utilisation are both independently related to survival in stomach cancer patients (Yim et al., 2012) thus small area deprivation (NZDep) and rurality were both considered potential mediators in this study (Figure 6). As previously explained deprivation and rurality while conceptualised as markers of access to services are very crude measure of access and not a measure of health care quality once within the system. Fitting these factors last in the model was a
deliberate attempt to explore the effect of health care access once key patient and
disease factors have been accounted for or whether any residual survival disparity at
this point is explained by differential access to, and through, services.

**Receipt of Treatment Factors and Stage Specific Survival**

Limited study numbers did not allow the meaningful assessment of patient survival for
potentially curable stage I-III only. However a model was constructed to explore the
survival of the 172 patients with stage I – III disease. This model replicates the step-
wise model described above for the total cohort, using the same variables in the same
order.

Limited study numbers also meant that variables pertaining directly to treatment such
as, receipt of surgery, surgeon type or surgical facility type were not included in
survival modelling.

**Other Possible Confounders or Mediators**

Factors such as smoking status or disease morphology may well impact on patient
survival but were unable to be included in the model as data for these variables was
not complete. It is probable there were additional confounding factors that were not
able to be adjusted for as data on these factors was not collected, or not complete.

**Summary of the Quantitative Phase**

The purpose of the quantitative phase of this study was to compare the presenting
characteristics, treatment and management of Māori and non-Māori patients with
stomach cancer and to examine the contribution of any differences to survival. The
target population was all Māori and non-Māori, aged 25 years and over and residing in
the North Island of New Zealand with a first diagnosis of stomach cancer registered
between 1 January 2006 and 31 December 2008.

Once appropriate ethics approval was gained, individuals meeting the study criteria
were identified from records held by the New Zealand Cancer Registry. Based on
Registry records all Māori patients diagnosed during the study period and an equal-sized random sample of all non-Māori patient were identified. Study data were gained from national and cancer treatment centre databases while clinical data were primarily gained by a manual review of patient medical notes in individual hospitals attended by patients. Patient medical notes, including pathology reports, were reviewed in detail and relevant information extracted onto a standardised questionnaire. The study cohort was linked to the national mortality database to identify all deaths occurring to the end of 2010. Deaths were classified into those attributed to stomach cancer and those due to other causes.

All study data were entered and managed in a single electronic dataset and were analysed using SAS software. Data were imputed for the key variables tumour site, deprivation and rurality. Data were analysed in three parts. Descriptive comparison of the presentation of the Māori and non-Māori cohorts was carried out; this included comparison of patient and disease factors and markers of health care access. The management of the Māori and non-Māori cohorts including the receipt and timing of treatment were then compared. In these two steps the variables were adjusted for pure confounders, age and sex, only. Survival analyses were carried out last. Cancer survival curves were compared for Māori and non-Māori cohorts and cancer specific hazard ratios were sequentially adjusted for age, sex, stage, tumour site, comorbidity, deprivation and rurality.
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Qualitative Methods

Background to the Qualitative Phase

In order to build on the findings of phase one (the quantitative study) a qualitative phase was undertaken to investigate those points of the stomach cancer treatment pathway that the quantitative findings suggested were inequitable for Māori. This was done through fifteen key informant (also referred to as participant) interviews intended to assess:

   a. What the sector sees as the issues impacting on equity for Māori within New Zealand’s stomach cancer treatment pathway.

   b. How the sector interprets the findings of the quantitative phase.

   c. The interventions the sector advises that could be implemented to improve the stomach cancer treatment pathway for New Zealanders with a focus on Māori.

Phase Two Research Questions

Two research questions guided the qualitative phase of this study, they are:

1. What do key informants identify as issues for stomach cancer treatment in New Zealand, with a focus on Māori?

2. Which interventions do key informants identify that may improve access to, and quality of, stomach cancer treatment in New Zealand, with a focus on Māori.
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The Study Population

Participant Sampling

Participants were selected for the interviews using purposive sampling. Purposive sampling is commonly used in qualitative research to select information-rich participants who can generate insights and in-depth understanding of the questions under study (Patton, 2005; Padgett, 2011; Patton, 2014). As this phase of the study was primarily interested in the response of people working in the health system to inequities within the stomach cancer treatment pathway the interview participants were all health care, or health policy, professionals.

The eligibility criteria for participants were that they must have knowledge of the stomach cancer treatment pathway, be actively working within the health care system and have knowledge of the issues for Māori within cancer treatment services.

The participants were purposefully drawn from:

- Clinicians – Specialist and Generalist Surgeons, Medical Oncology
- Māori Cancer Coordinators
- Specialist Upper Gastrointestinal Nurses
- Specialist Cancer Nurse Coordinators
- Regional Cancer Networks – Managers and Equity Managers
- District Health Board Planning and Funding
- Ministry of Health Cancer Team.

A maximum variation sampling approach was taken which involves purposefully selecting a range of participants in order to get variation on the factors of interest (Patton, 2005; Padgett, 2011; Patton, 2014). In this case sampling aimed for a mix of Māori and non-Māori informants, clinician and policy professionals along with a mix of centre type in which the participants were employed (main centre and smaller centre). Sampling in this way allowed a range of views across these three key factors.
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of interest: indigeneity, health care professional role type and treatment centre type. This range of views then allowed for the identification of variations across these three factors as well as the identification of important common themes that cut across each of the three factors (Patton, 2005; Patton, 2014). The final of these three factors was included, as differences in surgical management of patients were observed by treatment centre type in the quantitative phase of this study; this phase was, in part, undertaken to further investigate any points of the treatment pathway that the quantitative findings suggested were inequitable.

Recruitment

Recruitment of participants was undertaken using the snowball method which is useful to access specific populations. Initial participants nominated other potential participants within their networks who met the eligibility criteria and could contribute specific knowledge to the study (Padgett, 2011; Liamputtong, 2012). The interview schedule was discussed with one health care policy professional and trialled with one clinician whose advice was sought on others who met the sampling criteria and would be useful to interview. Knowledge of my own and supervisors networks were also drawn on to establish an initial participant list. All recommended participants were discussed with the study supervisors before recruitment. At the completion of each interview each participant was asked to recommend future participants thus snowballing from the initial list. As the number of interviews progressed participants were asked to recommend participants that would meet the maximum variation mix of participants. Recruitment was discontinued once key names began to be repeated and no new names were suggested by participants.

Once it was determined to include a potential participant an initial email was sent to them briefly discussing the study and requesting their involvement in a telephone interview. If the potential participant agreed to an interview they were then emailed the study information sheet (see Appendix 3) and consent form (see Appendix 4). In this second email the participants were alerted that consent would be gained verbally
and digitally recorded at the beginning of the interview and an interview time arranged, for a time convenient to the participant.

**Data Collection**

The one-on-one key informant interview was chosen as the primary research tool for the qualitative phase of this study as key informant interviews are an effective way to gain in-depth insights into a topic of interest from well informed experts. The key informant interview has been widely used in health care research over a number of decades, including research interested in the views of health care professionals and research interested in developing interventions within the cancer context internationally (Marshall, 1996; Boon et al., 2009; van der Weijden et al., 2013; Chubak et al., 2012; Hahn et al., 2013) and in New Zealand (Cormack et al., 2005; Cram, 2014b). Additionally qualitative research can be useful to policymakers as it often describes the settings in which policies, or interventions, will be implemented (Anderson, 2010).

The purpose of these interviews was to determine what key people working within services relevant to the New Zealand stomach cancer treatment pathway see as the issues impacting on equity for Māori within pathway, to present the findings of the quantitative phase and seek expert advice on them and to explore possible interventions to improve the pathway, with a focus on Māori.

**Development of the Interview Schedule**

The interview schedule was developed in three steps. Firstly it was drafted using findings of the quantitative phase of this study and personal knowledge of the cancer sector. This draft was reviewed by the supervisors of this study and revised to better reflect this study’s research questions. Secondly in keeping with the advice by Padgett (Padgett, 2011) on conducting interviews, the draft interview schedule was discussed with a key informant with current knowledge of the cancer sector. The
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interview schedule was again revised after this stage to better reflect current developments i.e. questions were specifically asked about the ‘Upper GI Service Delivery Standards’. Thirdly the interview schedule was then trialled with a clinician working within the field of stomach cancer (and whose data was subsequently used in analysis as no issues were identified with the method or interview schedule). Trialling interview questions on someone drawn from the population of interest is recommended to ensure the questions are not ambiguous and that they elicit the type of discussion needed (Padgett, 2011; Braun and Clarke, 2013). This step also allowed assessment of the time needed for the interviews so future participants could be informed of the likely impact on their time.

The interview schedule (see Appendix 5) was structured in the following order, with questions asked about:

1. The participants’ role in relation to the stomach cancer treatment pathway.
2. The stomach cancer treatment pathway: what is done well currently, what is not done well currently and whether there are particular issues for Māori or those with comorbidity.
3. Treatment decision making: multidisciplinary meetings and whether anything significant had changed in the preceding five years to improve the treatment pathway.
4. The National Upper GI Service Provision Standards: implementation of and their potential to impact on equity.
5. *At this stage the key findings of the quantitative phase of this study were discussed.*
6. Referral pathways into specialist care: both surgical and oncological.
7. How to improve the pathway for all, but especially for Māori.
8. What specific interventions would be useful and feasible in New Zealand.

The semi-structured interview was chosen for this study as this type of interview allows for both control, with a set line of questioning, but also freedom to develop an
interview as it progresses (Braun and Clarke, 2013; Padgett, 2011). While the information being sought was complex, participants were purposefully sampled for their expertise in the area. Interviewing these participants required a careful conversation and considered questioning to allow participants to discuss, at times sensitive, issues in depth. The interview schedule was developed to reflect this semi-structured nature. The questions were open-ended allowing the participant to reveal issues of importance to them. The questions developed sequentially around topics or categories of information and included prompts to allow further questioning in areas of interest so that participants could provide more detail where needed. The semi-structured interview schedule also allowed for questions to be skipped if they had been answered earlier in the interview (Padgett, 2011; Braun and Clarke, 2013).

The order of questions is important in in-depth interviewing. Starting with less sensitive ice-breaker questions is recommended (Padgett, 2011; Braun and Clarke, 2013). So while gaining knowledge about what the participants saw as issues within the stomach cancer treatment pathway was of primary interest, less challenging questions about the participants role in relation to stomach cancer and ‘what works well’ for patients in the pathway currently were asked first. A question was also deliberately asked regarding whether there had been any improvements to the stomach cancer treatment pathway during the preceding five years before the findings of the quantitative phase were presented. Five years was chosen as this was the length of time since the last date of diagnosis of patients in the quantitative phase of this study. This question provided an opportunity for participants to discuss recent developments that might have impacted on the pathway in the timeframe subsequent to patients in the quantitative phase receiving their cancer care.

Consent and Confidentiality

Informed consent is described as “the provision of information to participants, about the purpose of the research, its procedures, risks, benefits and alternatives, so that the participant can make a voluntary decision whether to enrol and continue to participate” (Emanuel et al., 2000: 2703). As previously stated the participant consent
form was emailed to potential participants. Participants were asked to read the consent form carefully and consent was obtained verbally, and digitally recorded, at the start of the interview. In the consent process participants were asked to agree to take part in the study and explicitly to the interview being recorded and were also asked to confirm that they knew they were free to withdraw from the study at any time during data collection without any disadvantage.

Due to the relatively small sector from which participants were drawn (the New Zealand cancer sector) maintaining participant confidentiality was deemed important (Liamputtong, 2012). A commitment was made to not identify participants personally in this thesis or any subsequent publications. Participants were advised that their role and ethnicity would be recorded and used to describe the participants but that they would not be named and that every effort would be made to ensure that they were not identified in any reported data.

As a number of the participants are in well-established roles and potentially recognisable within the cancer sector special care was taken to ensure that they would feel comfortable speaking freely and without discrimination now or in the future. Padgett (Padgett, 2011) advises that consideration be given to limiting direct quotes from well-known ‘experts’ in order to maintain their confidentiality. As a compromise participants were offered the ability to approve direct quotes. Seven participants indicated that they wished at approve direct quotes taken from their interview. Of these, direct quotes of four participants were used after approval was gained.

**Conducting the Interviews**

Generally interviewing by telephone is seen as an alternative measure if face-to-face interviewing is not possible (Padgett, 2011). While some of the participants were available to be interviewed in person, in order to have a consistent method of data collection all participants were interviewed by telephone no matter where they were in New Zealand. Each interview lasted between 25 and 110 minutes.
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The interviews followed the previously prepared interview schedule and involved the following steps:

1. Establishing rapport by explaining who I was, my professional background, how I became interested in the topic and thanking the participant for their time.

2. Briefly outlining the study and its ‘fit’ into the wider C3 study if participants requested (in some cases participants thought they knew enough about the study from email contact and the information sheet).

3. Obtaining consent verbally, reminding participants about their confidentiality and giving time for the participant to ask any questions or express concerns.

4. Carrying out the interview guided by the interview schedule, starting with ice-breaker questions and moving sequentially through the topic areas of interest.

5. Ending the interview by asking if there was anything else the participant wished to discuss, asking for recommendations of further participants and collecting demographic data.

All interviews were held at a time of the participants choosing and with the participant at a place of their choosing. I conducted the interview in a private office using a speaker phone in order to record and take notes of the interview as it progressed. Each participant was formally interviewed once only.

Recording and Transcription

Capturing an accurate record of the interview is vital in qualitative research (Braun and Clarke, 2013) thus all interviews were recorded using a digital voice recorder (Olympus WS-1100). Recording an interview allows the researcher to follow, and process, what the participant is saying instead of trying to take accurate and detailed notes. Recording also allows for better interaction with the participant such as being able to probe when needed. As well, transcripts of the interview in the participants own words enabled in-depth analysis of the data.
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As a back-up to the audio-recording, notes were taken as the participant spoke. Participants were informed at the start of the interview that some notes would be taken together with the audio-recording; importantly this was not intrusive as the participant could not see written notes being taken (Liamputtong, 2012). These notes captured key points discussed and aligned to the interview schedule questions. The information in these notes was synthesised and summarised throughout the interviewing stage of this study and discussed regularly with the study supervisors. Working in this way helped to clarify thinking about two key factors: the issues for Māori along the stomach cancer treatment pathway and possible ways of intervening to improve the quality of care. In keeping with good interview practice as identified by Braun and Clarke (Braun and Clarke, 2013), field notes were taken after each interview. These recorded perceptions of the interview and whether there were any important ideas or issues about the interview process to note.

The interviews were all professionally transcribed. Padgett (Padgett, 2011) advises that if using an ‘outside’ transcriber they be included as part of the research team wherever possible. The transcriber employed for this study was concurrently working on transcribing data of the qualitative side of the overall C3 studies. Thus the transcriber had some understanding of the context these interviews were held in and was familiar with the content. The interviews were transcribed into a Word document with a mainly verbatim level of transcription which omitted verbal padding (e.g. ‘sort of thing’, ‘know what I mean) and hesitations (e.g. ‘er’, ‘um’). The audio-recordings and transcripts were transferred to, and from, the transcriber through the University of Otago, Wellington secure drop-box in order to maintain confidentiality of the data.

Using a professional transcriber meant that I missed what some say is a crucial step in beginning to understand and analyse the data (Padgett, 2011; Liamputtong, 2012). Transcribing your own audio-recordings allows one to get ‘up close and personal’ with the data, to remind oneself of the nuances and emotions of the participant response and to better understand your interviewing style and its impact on the data gathered. Transcription is described as “a form of data transformation that can either enrich or deprive a study ...” (Padgett, 2011: 158). However a number of compromises can be
made when one does not transcribe their own data (Padgett, 2011). As articulated above, the transcriber was a professional transcriber and familiar with the content area of these interviews. We had email discussions about this study and why the participants were chosen. We also negotiated the level of transcription required. When the first transcript was completed I listened to the entire interview while reading the transcript to ensure the transcriber had accurately captured the data. Through this process I was able to correct a key omission where ‘tumour stream’ was transcribed throughout as ‘chemistry’, otherwise the transcript was accurate. I proof-read each transcript as it was delivered to me in order to become familiar with the data and throughout the data analysis phase I listened to each of the remaining 14 interviews, checking them against the transcript and my field notes of the interview to assess whether any further important ideas or issues emerged.

Six participants requested to approve their interview transcript and were sent a copy within a month of the transcript being typed. Of these, four participants identified minor revisions only. These revisions were made before the transcripts were imported into NVivo for analysis.

Data Analysis

While data analysis is said to begin early in the process of data collection it is through immersion in the data or iterative processes of reading, re-reading, describing and interpreting that the researcher is able to make sense of what has been collected (Saldana, 2009; Liamputtong, 2012).

A number of different types of data analysis are described as appropriate to qualitative research. Content analysis looks to the data to count how many times a predetermined category occurs, in narrative analysis participants stories or ‘lived experiences’ are analysed and re-told and in discourse analysis the words and text themselves are analysed to determine the participant’s social reality (Liamputtong, 2012). However thematic analysis was the most appropriate form of analysis to undertake and was used in this study. It was chosen because of its usefulness when
investigating people’s views and opinions (Joffe and Yardley, 2004) and because of its emphasis on identifying and interpreting emerging patterns within data (Liamputtong, 2012; Padgett, 2011).

**NVivo**

Computer assisted qualitative data analysis software (NVivo 10) was used to manage and organise the qualitative data. NVivo was used to easily allow data coding, retrieval and linking and to allow comparison of the data across the three key factors identified above: indigeneity, health care professional role type and centre size of employment. Importantly, while computer assisted software can assist in data management; its use does not replace intellectual management of data. Ultimately qualitative analysis needs human analytic reflection. Analysis remains a process of interpretation, driven by what the researcher sees in the data, the opinions they form on what they see and how they make sense of those opinions (Liamputtong, 2012; Patton, 2014).

The Word transcripts were imported into NVivo and attributes applied to each participant. These attributes included gender, age group, ethnicity (Māori or non-Māori), role in the health care system (policy or clinician, as well as a more detailed role title) and centre size of employment (small, main or national). The data were then ready to begin coding and analysis.

**Coding**

Expressed simply coding is the process of naming or labelling units of data. This labelling then is a method that enables the organisation or grouping of similarly coded data into categories which share a common characteristic. In this way, patterns can be seen and themes begin to emerge (Braun and Clarke, 2013; Padgett, 2011).

The process of coding of the qualitative data for this study involved the following steps:
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- Reading through the transcripts in NVivo and coding initially to the interview questions, including the question on relevant interventions.
- Re-reading the transcripts and re-coding each interview question using a stomach cancer pathway framework.
- Re-reading the transcripts and also re-coding each interview question according to emergent themes.
- Simultaneously writing memos directly into NVivo which were attached to the participants data file in NVivo.

As seen in the steps listed above the framework used to code evolved throughout the coding process. Initially coding was undertaken using the interview schedule questions but this evolved into a coding framework that focussed on the stomach cancer pathway and emergent themes. Coding is meant to be an on-going and cyclic process (Padgett, 2011; Liamputtong, 2012; Braun and Clarke, 2013). As Saldana (Saldana, 2009) points out “rarely is the first cycle of coding data perfectly attempted”. In fact the initial coding structure or framework may not be useful and often evolves as analysis progresses. In some cases a modified or entirely different coding framework may be needed (Saldana, 2009). Each coding cycle in qualitative research allows the researcher to become more immersed in the data and further filters, highlights, and focuses the features of the data most relevant to the study. Through these cycles categories, themes, and concepts are generated and theories built (or in the case of this study, ideas of interventions generated) (Saldana, 2009).

As the data analysis progressed NVivo was used to retrieve large amounts of coded data passages for comparison. As any text passages can be coded with multiple keywords (or in multiple nodes) NVivo could be used to find where data were coded in multiple places, for example coded both as issues for Māori (which was an interview question) and specific points of the treatment pathway. Specific queries were also run on key points of the treatment pathway that allowed the comparison of responses for the three key factors of interest. For example a query was run to further investigate the differences and similarities in the responses of those working in smaller and larger centres when discussing the issues for Māori and the possible interventions that could
happen to improve access to surgery. These queries were printed out into hard-copy to allow easy reading and comparison.

**Ensuring Rigour**

Ensuring rigour in, and validity of, qualitative research has been subject to much debate (Padgett, 2011). Quantitative research aims for validity, through adherence to rules and standards of a chosen methodology, and reliability, where findings are potentially reproducible by other researchers (Liamputtong, 2012). This is not necessarily the case in qualitative research. This phase of the current study was not intended to be reproducible nor generalisable to a wider set of people. Rather it was conducted to give practical meaning and depth to the findings of the quantitative phase of this study, to stimulate the thinking of decision-makers within the health care system and ultimately to improve policy and practice, thus improving the quality of care given to people diagnosed with stomach cancer in New Zealand.

Despite the debate around qualitative rigour there are certain processes that can be built into a qualitative study to help enhance the trustworthiness of its findings (Liamputtong, 2012; Padgett, 2011). Commonly these processes are concerned with purposively selecting participants based on their unique knowledge, collecting appropriate and adequate data, in-depth documentation of both the research process and decisions made during the research process and gaining feedback on, or validation of, the findings. In this study commitment was made to build in the following processes:

- Carefully selecting a range of participants with in-depth and current knowledge of the stomach cancer treatment pathway and issues for Māori.

- Triangulation of the data through holding key informant interviews and then building on the findings through discussion with C3 advisory groups and through presentation at Department of Public Health meetings and meetings held specifically to feedback the findings of the C3 set of studies to interested parties (such as clinicians and people working in health policy).
METHODS

- Building on the findings, especially the key themes and types of interventions put forward by participants, through discussion about emergent ideas with subsequent participants during the interview process, at the end of each subsequent interview.

- Discussing findings with supervisors of this study, which also provided the opportunity to articulate internal thinking processes, clarify emergent ideas and to make new insights about the data.

- Auditing or leaving a decision making trail as well as taking field notes of the interviews and notes on analysis within NVivo.

- Taking a systematic approach to the collection and analysis of the data.

Ethics

Before data collection for this phase began ethical approval was gained. As the interview participants were all health care or health policy professionals this study was considered ‘low-risk’ and thus this study was suitable for level B University of Otago departmental ethical approval.

Summary of the Qualitative Phase

A qualitative phase was undertaken to build on the findings of the quantitative phase of this study, to investigate those points of the stomach cancer treatment pathway that the quantitative findings suggested were inequitable for Māori and to assess possible interventions.

Fifteen key informants were interviewed one-on-one. Participants were purposively sampled; all were actively working within the health care system and had knowledge of the stomach cancer treatment pathway or of the issues for Māori within cancer treatment services. Semi-structured interviews were held by telephone using an
METHODS

Interview schedule trialed with a clinician working within the field of stomach cancer. All interviews were digitally recorded and professionally transcribed.

Data were managed and organised within computer assisted qualitative data analysis software (NVivo 10). Data were coded and re-coded and number of times, they were then thematically analysed. Ethical approval was gained before data collection began.
Chapter 6: Quantitative Results

This chapter presents the results of quantitative data analysis. It sets these results out in four sections: selection of study cohorts, comparison of study cohorts, comparison of patient management and treatment and comparison of patient survival.

- The first section briefly outlines how the study cohort was derived from all patients diagnosed with stomach cancer and notified to the New Zealand Cancer Registry from 1 January 2006 to 31 December 2008.

- The second section describes the final study cohort and compares the presenting characteristics of Māori and non-Māori patients, looking at patient level factors, disease level factors and markers of health care access.

- The third section describes the management and treatment of the final cohort and compares the management and treatment of Māori and non-Māori patients.

- The fourth section describes the cancer specific survival of the final cohort and compares the survival of Māori and non-Māori patients. It then assesses the contribution of patient level factors, disease level factors and markers of health care access on survival for Māori and non-Māori patients.
QUANTITATIVE RESULTS: MĀORI/NON-MĀORI COMPARISON
Selection of Study Cohort

This section describes the progression from the original cohort of patients identified from the New Zealand Cancer Registry (NZCR) though to the final study cohort. It identifies which patients were included and excluded at each step in this process. Of this final cohort, nine patients (4 Māori and 5 non-Māori) were diagnosed with a gastrointestinal stromal tumour; the remaining patients were diagnosed with adenocarcinoma.

Table 21 shows the cohort numbers at each step of the study selection process. The NZCR had a total of 1115 registrations for stomach cancer (ICD codes C16.0-16.6, 16.8, 16.9) nationally during the study period, of which 210 were Māori and 893 non-Māori (Table 21: Step 1). The study eligibility criteria were applied using the information available from NZCR records. Patients with missing ethnicity data were included in the non-Māori cohort prior to random selection on the basis that their ethnicity was more likely to be non-Māori (Swan et al., 2006) and 278 patients (16 Māori and 262 non-Māori) were excluded as they resided in the South Island of New Zealand (Table 21: Steps 2 - 7).

After all study exclusion criteria were applied all eligible Māori (n=181) were included in the sample along with a randomly-selected equal number of eligible non-Māori patients (n=181). This resulted in an initial total sample of 362 patients (Table 21: Step 8). Following a full clinical note review, 7.5% of the sampled study cohort (n=27) were observed to not meet the criteria of the study and were excluded at this stage. This resulted in a final cohort of 335 patients (172 Māori and 163 non-Māori) (Table 21: Step 9). Of this final cohort, nine patients (4 Māori and 5 non-Māori) were diagnosed with a gastrointestinal stromal tumour; the remaining patients were diagnosed with adenocarcinoma.
Table 21: Progression of exclusions: patient numbers at each step of the selection process

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>Missing Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Total Stomach Cancer Registrants 1 Jan 2006 – 31 Dec 2008</td>
<td>1115</td>
<td>210</td>
<td>893</td>
<td>12</td>
</tr>
<tr>
<td>2</td>
<td>Excluding previous same cancer (2001-2005)</td>
<td>1113</td>
<td>210</td>
<td>891</td>
<td>12</td>
</tr>
<tr>
<td>3</td>
<td>Excluding Dx made &gt; 90 days prior to NZCR Dx</td>
<td>1106</td>
<td>208</td>
<td>886</td>
<td>12</td>
</tr>
<tr>
<td>4</td>
<td>Excluding those aged under 25 years at Dx</td>
<td>1099</td>
<td>205</td>
<td>882</td>
<td>12</td>
</tr>
<tr>
<td>5</td>
<td>Excluding non-NZ residents</td>
<td>1060</td>
<td>204</td>
<td>846</td>
<td>10</td>
</tr>
<tr>
<td>6</td>
<td>Excluding Dx made on date of death or post-mortem</td>
<td>1043</td>
<td>197</td>
<td>836</td>
<td>10</td>
</tr>
<tr>
<td>7</td>
<td>Excluding South Island patients</td>
<td>765</td>
<td>181</td>
<td>584</td>
<td>0*</td>
</tr>
<tr>
<td>8</td>
<td>Sample (+ Non-Māori group randomly selected)</td>
<td>362</td>
<td>181</td>
<td>181</td>
<td>0*</td>
</tr>
<tr>
<td>9</td>
<td>Excluding patients found ineligible after notes review</td>
<td>335</td>
<td>172</td>
<td>163</td>
<td>0*</td>
</tr>
</tbody>
</table>

Abbreviations: Dx = Diagnosis.  
* Patients with missing ethnicity data were merged with the non-Māori cohort prior to random selection of the control group.

Table 22 gives a breakdown of those twenty seven cases (7.5% of sampled cohort) excluded after the clinical note review as they did not meet the criteria of the study. There were nine Māori and 21 non-Māori patients excluded during this stage. Common reasons for exclusion were patients with miscoded histological diagnosis, miscoded primary site (most commonly squamous cell cancer of the oesophagus) and being a non-resident of New Zealand or diagnosed out of this study’s registration date criteria. All six patients with squamous cell carcinoma of the oesophagus were non-Māori.
Table 22: Cases excluded (ineligible) after notes review (Step 9 of Table 21)

<table>
<thead>
<tr>
<th>Total excluded as ineligible</th>
<th>Māori</th>
<th>% of sampled</th>
<th>n</th>
<th>% of sampled</th>
<th>n</th>
<th>% of sampled</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miscoded Primary site</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oesophageal</td>
<td>8</td>
<td>2.2%</td>
<td>1</td>
<td>0.6%</td>
<td>7</td>
<td>3.8%</td>
</tr>
<tr>
<td>Rectal</td>
<td>1</td>
<td>0.3%</td>
<td>1</td>
<td>0.6%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Anal</td>
<td>1</td>
<td>0.3%</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>0.6%</td>
</tr>
<tr>
<td>Not confirmed as adenocarcinoma or GIST</td>
<td>13</td>
<td>3.6%</td>
<td>5</td>
<td>2.8%</td>
<td>8</td>
<td>4.4%</td>
</tr>
<tr>
<td>Histology other than adenocarcinoma or GIST</td>
<td>9</td>
<td>2.5%</td>
<td>5</td>
<td>2.8%</td>
<td>4</td>
<td>2.2%</td>
</tr>
<tr>
<td>No histological diagnosis</td>
<td>4</td>
<td>1.1%</td>
<td>3</td>
<td>1.7%</td>
<td>1</td>
<td>0.6%</td>
</tr>
<tr>
<td>Non-Resident of New Zealand</td>
<td>3</td>
<td>0.8%</td>
<td>-</td>
<td>-</td>
<td>3</td>
<td>1.7%</td>
</tr>
<tr>
<td>Diagnosis outside of study date</td>
<td>2</td>
<td>0.6%</td>
<td>1</td>
<td>0.6%</td>
<td>1</td>
<td>0.6%</td>
</tr>
<tr>
<td>Diagnosis made post-mortem</td>
<td>1</td>
<td>0.3%</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>0.6%</td>
</tr>
</tbody>
</table>

Table 23 compares the final study cohort with cancer registrants who had a first time diagnosis of stomach cancer notified between January 2006 and December 2008 and who were not excluded in step 1 – 6 of this study’s exclusions. The study cohort comprises 32% of all registrants during this period. Patients in the final study cohort were more likely to be Māori which is in keeping with study design. The final study cohort were also slightly younger at diagnosis and more likely to live in the most highly deprived quintile (9-10) and rurally most probably reflecting the higher proportion of Māori within the study cohort. The NZCR extent of disease is also compared below with similar extent of disease seen between the study cohort and all stomach cancer registrants, although slightly less of the study cohort were unstaged (F).
# QUANTITATIVE RESULTS: MĀORI/NON-MĀORI COMPARISON

<table>
<thead>
<tr>
<th></th>
<th>Study cohort</th>
<th></th>
<th>All registrants</th>
<th></th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>335</td>
<td>1043</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>172</td>
<td>197</td>
<td>51%</td>
<td>19%</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>197</td>
<td>668</td>
<td>62%</td>
<td>64%</td>
<td></td>
</tr>
<tr>
<td>Mean age</td>
<td>64.9</td>
<td>68.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extent of Disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>43</td>
<td>103</td>
<td>13%</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>10</td>
<td>38</td>
<td>3%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>65</td>
<td>174</td>
<td>19%</td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>E</td>
<td>115</td>
<td>333</td>
<td>33%</td>
<td>32%</td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>102</td>
<td>395</td>
<td>32%</td>
<td>38%</td>
<td>0.23</td>
</tr>
<tr>
<td>NZ Dep (Quintile)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2</td>
<td>25</td>
<td>121</td>
<td>9%</td>
<td>13%</td>
<td></td>
</tr>
<tr>
<td>3-4</td>
<td>41</td>
<td>149</td>
<td>16%</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>5-6</td>
<td>52</td>
<td>192</td>
<td>18%</td>
<td>20%</td>
<td></td>
</tr>
<tr>
<td>7-8</td>
<td>71</td>
<td>243</td>
<td>24%</td>
<td>25%</td>
<td></td>
</tr>
<tr>
<td>9-10</td>
<td>134</td>
<td>286</td>
<td>33%</td>
<td>25%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Rurality</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>233</td>
<td>732</td>
<td>76%</td>
<td>75%</td>
<td></td>
</tr>
<tr>
<td>Independent urban</td>
<td>47</td>
<td>163</td>
<td>13%</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>43</td>
<td>96</td>
<td>11%</td>
<td>9%</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

a) Extent of disease (SEER summary system) is the staging system used by the NZCR
Comparison of Study Cohorts

This section describes the Māori and non-Māori cohorts and compares their presenting characteristics looking at the patient and disease factors likely to impact on management, treatment and subsequent survival from stomach cancer.

Patient Factors

Age and Sex

Table 24 shows the age and sex of the total cohort, and the Māori and non-Māori cohorts. Figure 7 and Figure 8 show the age and sex proportions of the Māori and non-Māori cohorts.

New Zealand’s Māori population has a younger age structure than does the non-Māori population (Statistics New Zealand, 2014; Robson and Harris, 2007a). This is reflected in the study cohorts, with a younger age structure and younger average age at diagnosis in Māori compared with non-Māori. The average age of Māori patients at diagnosis was 10 years younger than non-Māori (overall mean age at diagnosis: Māori 60 years, non-Māori 70 years, p<0.01). Within female patients, this ethnic difference was greater still (female mean age at diagnosis: Māori 57 years, non-Māori 70 years) (data not shown).

While stomach cancer within this study cohort was more common among males overall, a higher proportion of the Māori cohort were female (47% female) compared to the non-Māori cohort (35% female; p=0.11). The higher proportion of women within the Māori cohort remained once the data were age standardised to account for the different age structures within the Māori and non-Māori cohorts.
Table 24: Total, Māori and non-Māori cohorts by age at diagnosis and sex

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% a)</td>
<td>n % b) % c)</td>
</tr>
<tr>
<td>25-49</td>
<td>64</td>
<td>16%</td>
<td>44 26% -</td>
</tr>
<tr>
<td>50-64</td>
<td>87</td>
<td>22%</td>
<td>58 34% -</td>
</tr>
<tr>
<td>65-74</td>
<td>91</td>
<td>28%</td>
<td>44 26% -</td>
</tr>
<tr>
<td>&gt;75</td>
<td>93</td>
<td>35%</td>
<td>26 15% -</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>335</strong></td>
<td><strong>172</strong></td>
<td><strong>163</strong></td>
</tr>
</tbody>
</table>

Mean age at diagnosis

<table>
<thead>
<tr>
<th>Sex</th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n % b) % c)</td>
</tr>
<tr>
<td>Male</td>
<td>197</td>
<td>62%</td>
<td>91 53% 56%</td>
</tr>
<tr>
<td>Female</td>
<td>138</td>
<td>38%</td>
<td>81 47% 44%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>335</strong></td>
<td><strong>172</strong></td>
<td><strong>163</strong></td>
</tr>
</tbody>
</table>

Abbreviation: n, number

a) Population estimates  
b) Crude  
c) Age standardised

Figure 7: Māori and non-Māori cohorts by age at diagnosis
Comorbidity

Table 25 shows the prevalence of comorbidity within the total cohort and the Māori and non-Māori cohorts. Overall 70% of the total cohort (both Māori and non-Māori) had at least one chronic disease or other comorbid condition at the time of their stomach cancer diagnosis. The proportion of Māori and non-Māori patients with no comorbidity at the time of diagnosis was similar; 30% of the Māori cohort had no comorbidity versus 34% of the non-Māori cohort (age- and sex-standardised; p =0.11). However it appears that compared with non-Māori, the Māori patients may have been more likely to present with multiple chronic diseases or other comorbid conditions alongside their stomach cancer. The likelihood of three or more comorbidities was 31% in Māori and 17% in non-Māori although the difference was not statistically significant (age- and sex-standardised; p =0.11).

Of the 12 most common individual comorbid conditions noted in this study, hypertension was the most common overall, with age- and sex-standardised proportions of 43% in Māori and 39% in the non-Māori patients. Māori were significantly more likely to have congestive heart failure (age- and sex-standardised proportion: 14% in Māori vs 5% in non-Māori, p=<0.01) and renal disease (age- and
QUANTITATIVE RESULTS: MĀORI/NON-MĀORI COMPARISON

sex-standardised proportion: 11% in Māori vs 3% in non-Māori, p = <0.05). Diabetes also appeared to be more common among Māori, but this was not statistically significant (age- and sex-standardised proportion: 26% in Māori vs 15% in non-Māori, p=0.09). The age- and sex-standardised prevalence of myocardial infarction, mild and moderate/severe chronic pulmonary disease, cerebrovascular disease and other primary cancer were all similar between Māori and non-Māori patients.

Table 25: Total, Māori and non-Māori cohorts by comorbidity

<table>
<thead>
<tr>
<th>Comorbid conditions (count)</th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>108 30%</td>
<td>64 37% 30%</td>
<td>44 27% 34%</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>79 25%</td>
<td>37 22% 21%</td>
<td>42 26% 24%</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>67 22%</td>
<td>27 16% 18%</td>
<td>40 25% 24%</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>42 13%</td>
<td>21 12% 14%</td>
<td>21 13% 10%</td>
<td></td>
</tr>
<tr>
<td>4+</td>
<td>39 11%</td>
<td>23 13% 17%</td>
<td>16 10% 7%</td>
<td>0.11</td>
</tr>
<tr>
<td>Total</td>
<td>335 100%</td>
<td>172 51%</td>
<td>163 49%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Comorbid conditions (individual)</th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angina</td>
<td>52 16%</td>
<td>25 15% 18%</td>
<td>27 17% 12%</td>
<td>0.31</td>
</tr>
<tr>
<td>Hypertension</td>
<td>133 41%</td>
<td>64 37% 43%</td>
<td>69 42% 39%</td>
<td>0.33</td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td>29 10%</td>
<td>12 7% 9%</td>
<td>17 10% 8%</td>
<td>0.97</td>
</tr>
<tr>
<td>Arrhythmia</td>
<td>54 17%</td>
<td>25 15% 20%</td>
<td>29 18% 17%</td>
<td>0.76</td>
</tr>
<tr>
<td>Mild CPD</td>
<td>22 7%</td>
<td>11 6% 8%</td>
<td>11 7% 7%</td>
<td>0.83</td>
</tr>
<tr>
<td>Moderate/Severe CPD</td>
<td>27 9%</td>
<td>10 6% 7%</td>
<td>17 10% 8%</td>
<td>0.69</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>29 8%</td>
<td>18 10% 14%</td>
<td>11 7% 5%</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>CVA</td>
<td>38 13%</td>
<td>13 8% 9%</td>
<td>25 15% 11%</td>
<td>0.49</td>
</tr>
<tr>
<td>Obesity</td>
<td>21 5%</td>
<td>14 8% 8%</td>
<td>7 4% 4%</td>
<td>0.26</td>
</tr>
<tr>
<td>Diabetes</td>
<td>70 19%</td>
<td>42 24% 26%</td>
<td>28 17% 15%</td>
<td>0.09</td>
</tr>
<tr>
<td>Other primary cancer</td>
<td>29 9%</td>
<td>13 8% 9%</td>
<td>16 10% 9%</td>
<td>0.83</td>
</tr>
<tr>
<td>Renal disease</td>
<td>22 5%</td>
<td>17 10% 11%</td>
<td>5 3% 3%</td>
<td>&lt;0.05</td>
</tr>
</tbody>
</table>

Abbreviation: n, number; CPD, chronic pulmonary disease; CVA, cerebrovascular accident
a) Population estimates
b) Crude
Smoking Status

Smoking status was not well recorded within medical records and so these data had a large percentage either recorded as unknown or missing within the dataset. Within the Māori cohort n=87 patients had smoking status data missing or recorded as unknown, while in the non-Māori cohort n=102 patients had smoking status data missing or recorded as unknown. The following represents crude data only.

Of the 85 Māori who had data captured 49% (n=42) were recorded as current smokers, 32% (n=27) were ex-smokers and 19% (n=16) were non-smokers. While of the 61 non-Māori who had data captured 21% (n=13) were recorded as current smokers, 38% (n=23) were ex-smokers and 41% (n=25) were non-smokers.

Disease Factors

Stage

Nearly half (46%) of the total cohort were diagnosed at stage IV of disease (Table 26 and Figure 9). Table 26 and Figure 9 also show that there were no substantial differences in the overall distribution of tumour stage between Māori and non-Māori patients (p = 0.31). Fifteen percent of each of the Māori and non-Māori cohorts were diagnosed at stage I disease. The proportion of patients diagnosed with stage IV disease was also very similar between ethnic groups; 47% of the Māori cohort and 49% of the non-Māori cohort were diagnosed at stage IV (age- and sex-standardised). Five non-Māori remained unstaged after clinical note review, this compares with 109 patients unstaged within the original New Zealand Cancer Registry data. These five unstaged patients had an older age profile (age range from 85 years – 93 years) than that of the total cohort and had at least one comorbid condition (data not shown).
Table 26: Total, Māori and non-Māori cohorts by stage at diagnosis

<table>
<thead>
<tr>
<th>Stage (TNM)</th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% a)</td>
<td>n</td>
</tr>
<tr>
<td>Stage I</td>
<td>55</td>
<td>17%</td>
<td>25</td>
</tr>
<tr>
<td>Stage II</td>
<td>58</td>
<td>16%</td>
<td>35</td>
</tr>
<tr>
<td>Stage III</td>
<td>59</td>
<td>19%</td>
<td>27</td>
</tr>
<tr>
<td>Stage IV</td>
<td>158</td>
<td>46%</td>
<td>85</td>
</tr>
<tr>
<td>Unstaged</td>
<td>5</td>
<td>2%</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>335</td>
<td></td>
<td>172</td>
</tr>
</tbody>
</table>

a) Population estimates  
b) Crude  
c) Age and sex standardised

Figure 9: Māori and non-Māori cohorts by stage at diagnosis; age- and sex-standardised
Grade

Overall, 42% of the total cohort presented with a poorly differentiated grade of stomach cancer (i.e. a more aggressive cell type on histological examination).

Table 27 shows that Māori appeared less likely to have a poorly differentiated cancer than non-Māori (age- and sex-standardised). Māori also appeared more likely to have data missing from this variable, although when the missing grade data were removed, there was little difference between Māori and non-Māori in this measure (age- and sex-standardised proportion: 71% Māori poorly differentiated vs 72% non-Māori).

### Table 27: Total, Māori and non-Māori cohorts by grade of disease

<table>
<thead>
<tr>
<th>Tumour grade</th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;a&lt;/sup&gt;</td>
<td>n</td>
</tr>
<tr>
<td>Well differentiated</td>
<td>12</td>
<td>5%</td>
<td>3</td>
</tr>
<tr>
<td>Moderately differentiated</td>
<td>43</td>
<td>13%</td>
<td>20</td>
</tr>
<tr>
<td>Poorly differentiated</td>
<td>134</td>
<td>42%</td>
<td>64</td>
</tr>
<tr>
<td>Missing</td>
<td>146</td>
<td>40%</td>
<td>85</td>
</tr>
<tr>
<td>Total</td>
<td>335</td>
<td></td>
<td>172</td>
</tr>
</tbody>
</table>

<sup>a</sup> Population estimates  
<sup>b</sup> Crude  
<sup>c</sup> Age and sex standardised

Tumour Site

There were significant differences in the distribution of tumour site between Māori and non-Māori patients (Table 28). This difference remained when missing site data were removed (Figure 10). Compared with non-Māori patients, Māori had a much higher proportion of distal stomach cancers and a lower proportion of proximal stomach cancers. The age- and sex-standardised rates for distal tumour site were 43% in Māori vs 26% in non-Māori, p=0.004 (age- and sex-standardised proportion: 58% in
QUANTITATIVE RESULTS: MĀORI/NON-MĀORI COMPARISON

Māori vs 40% in non-Māori when the missing data were removed). Conversely non-Māori had a higher proportion of proximally located tumours. The age- and sex-standardised rates for proximal tumour site were 25% in Māori and 34% in non-Māori, \( p = <0.05 \) (age- and sex-standardised proportion: 39% in Māori and 61% in non-Māori when the missing data were removed).

Table 28: Total, Māori and non-Māori cohorts by tumour site

<table>
<thead>
<tr>
<th>Tumour site</th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Proximal</td>
<td>107</td>
<td>35%</td>
<td>44</td>
<td>26%</td>
</tr>
<tr>
<td>Distal</td>
<td>103</td>
<td>26%</td>
<td>69</td>
<td>40%</td>
</tr>
<tr>
<td>Proximal and Distal</td>
<td>5</td>
<td>1%</td>
<td>3</td>
<td>2%</td>
</tr>
<tr>
<td>Other Description</td>
<td>11</td>
<td>2%</td>
<td>9</td>
<td>5%</td>
</tr>
<tr>
<td>Missing</td>
<td>109</td>
<td>35%</td>
<td>47</td>
<td>27%</td>
</tr>
<tr>
<td>Total</td>
<td>335</td>
<td>172</td>
<td>163</td>
<td></td>
</tr>
</tbody>
</table>

a) Population estimates  
b) Crude  
c) Age and sex standardised

Figure 10: Māori and non-Māori cohorts by tumour site, missing data removed; age- and sex-standardised
Stratifying the two main tumour sites (distal and proximal) by sex (Figure 11) shows that Māori women were the group least likely to present with a proximally located tumour while non-Māori men were the group most likely to present with a proximally located tumour (age- and sex-standardised proportion: 16% in Māori women vs 43% in non-Māori men). On the converse Māori women were most likely to present with a distally located tumour (age- and sex-standardised proportion: 54% in Māori women vs 19% in non-Māori men). Māori men were slightly more likely to present with a proximally located tumour than a distally located one (age- and sex-standardised proportion: 36% proximal vs 31% distal). Non-Māori women were equally as likely to present with either distally or proximally located tumours (29% for each, age- and sex-standardised).

Figure 11: Māori and non-Māori cohorts by sex and tumour site (proximal and distal only); age- and sex-standardised

Health Care Access Factors

Deprivation and Rurality

As this study is primarily interested in patient management, treatment and survival once diagnosed with stomach cancer (rather than disease incidence) small area
deprivation (NZDep) and geographical location (rurality) were considered markers of access to cancer services. Data on NZDep were missing for 12 patients, 7 Māori and 5 non-Māori.

There was a strong socioeconomic gradient for patients in this study; only a quarter of the total cohort resided in the least deprived quintiles (1-2), compared with 40% of the population by definition. In contrast, over half of the total cohort resided in the most deprived quintiles (4-5) (Table 29). Both Māori and non-Māori were more likely to live in areas of higher deprivation although this was more marked in the Māori patients, of whom 59% resided in the most deprived quintile (compared with 29% of non-Māori patients, age- and sex-standardised, p<0.01).

The majority of patients lived in urban areas (Table 29). Slightly less Māori (68%) than non-Māori (81%) lived in main or satellite urban areas, on the converse it appeared that more Māori lived in rural areas (age- and sex-standardised proportion: 16% Māori vs 7% non-Māori, p=0.02).

Table 29: Total, Māori and non-Māori cohorts by NZDep and rurality

<table>
<thead>
<tr>
<th>NZDep (Quintile)</th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% a)</td>
<td>n % b)</td>
<td>% c)</td>
</tr>
<tr>
<td>1</td>
<td>25</td>
<td>9%</td>
<td>10 6%</td>
<td>7%</td>
</tr>
<tr>
<td>2</td>
<td>41</td>
<td>16%</td>
<td>10 6%</td>
<td>5%</td>
</tr>
<tr>
<td>3</td>
<td>52</td>
<td>18%</td>
<td>21 13%</td>
<td>11%</td>
</tr>
<tr>
<td>4</td>
<td>71</td>
<td>24%</td>
<td>30 18%</td>
<td>19%</td>
</tr>
<tr>
<td>5</td>
<td>134</td>
<td>33%</td>
<td>94 57%</td>
<td>59%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Rurality</th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban</td>
<td>233</td>
<td>76%</td>
<td>125 79%</td>
<td>81%</td>
</tr>
<tr>
<td>Independent Urban</td>
<td>47</td>
<td>13%</td>
<td>29 18%</td>
<td>16%</td>
</tr>
<tr>
<td>Rural</td>
<td>43</td>
<td>11%</td>
<td>28 17%</td>
<td>16%</td>
</tr>
<tr>
<td>Total</td>
<td>323</td>
<td>165</td>
<td>158</td>
<td>0.02</td>
</tr>
</tbody>
</table>

a) Population estimates  
b) Crude  
c) Age and sex standardised
Patient Treatment and Management

This section describes the management and treatment of the total study cohort and compares the management and treatment received by Māori and non-Māori patients. When describing surgical and oncological treatment the results focus on those patients with potentially curable disease at diagnosis (i.e. those diagnosed with stage I-III disease). Referral to palliative care services is shown for patients diagnosed with stage IV disease.

Diagnosis and Staging Investigations

Overall the majority of patients were diagnosed and staged by gastroscopy (n=319) and/or computerised tomography (CT) scan (n=300) while 81 patients also received a laparoscopy. Only 14 patients received an MRI scan and four patients an endoscopic ultrasound as part of their staging process.

There was little difference in the proportions of diagnostic and staging investigations received by Māori and non-Māori patients (Figure 12).
Surgical Treatment

Table 30 shows the characteristics of surgery for the total stage I-III cohort and the Māori and non-Māori stage I-III cohorts. Of the 172 patients with stage I-III disease overall, two-thirds (66%) had definitive surgery including 4% of patients who received a laparotomy without resection or an ‘open and close’ procedure. Māori and non-Māori patients had similar rates of definitive surgery with age- and sex-standardised proportions of 71% for Māori and 68% for non-Māori (p = 0.79). Post-operative complications (within 30 days of definitive surgery) were also similar across the two groups (any post-operative complication at all, age- and sex-standardised proportion; Māori=59%, non-Māori=55%, p = 0.43). Only three patients died within 30 days post-operatively.

Differences in Surgical Management

There were a number of key differences in the surgical management of the two groups (Table 30).
QUANTITATIVE RESULTS: MĀORI/NON-MĀORI COMPARISON

Surgery Type

Although not statistically significant Māori appeared more likely to have a partial gastrectomy with age- and sex-standardised proportions of 59% for Māori and 49% for non-Māori ($p=0.14$). On the converse non-Māori appeared more likely to have a total gastrectomy or Ivor-Lewis Oesophagectomy (both surgeries combined, age- and sex-standardised proportion: 37% in Māori vs 48% in non-Māori, $p=0.14$). This is consistent with the different tumour site distribution in the two groups.

Surgical Facility Type and Surgeon Type

There were statistically significant differences between Māori and non-Māori patients in two important areas: the type of facility where patients received their surgical treatment and the type of surgeon performing the surgery.

Compared with non-Māori, Māori were less likely to receive their surgical treatment in a main centre (age- and sex-standardised proportion: 43% in Māori vs 83% in non-Māori patients, $p<0.01$) and more likely to be treated in a smaller centre (age- and sex-standardised proportion: 54% in Māori vs 12% in non-Māori patients, $p<0.001$). Overall, few patients received surgical treatment in a private facility (n=5).

Māori were also less likely to have surgery performed by a specialist upper gastrointestinal surgeon (age- and sex-standardised proportion: 38% in Māori vs 79% in non-Māori patients, $p<0.01$), and more likely to have their surgery performed by a general surgeon (age- and sex-standardised proportion: 62% in Māori vs 21% in non-Māori patients, $p<0.01$).
# QUANTITATIVE RESULTS: MĀORI/NON-MĀORI COMPARIISON

Table 30: Total, Māori and non-Māori cohorts (stage I - III) by characteristics of definitive surgery

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitive surgery</td>
<td>119</td>
<td>65</td>
<td>54</td>
<td>0.79</td>
</tr>
<tr>
<td></td>
<td>172</td>
<td>87</td>
<td>85</td>
<td></td>
</tr>
<tr>
<td>Type of surgery</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local excision/EMR</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Ivor-Lewis Oesophagectomy</td>
<td>9</td>
<td>1</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Gastrojejunostomy</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Partial Gastrectomy</td>
<td>56</td>
<td>35</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Total Gastrectomy</td>
<td>46</td>
<td>25</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Laparotomy without resection</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>0.14</td>
</tr>
<tr>
<td></td>
<td>119</td>
<td>65</td>
<td>54</td>
<td></td>
</tr>
<tr>
<td>Postoperative complications</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any Postoperative complication</td>
<td>70</td>
<td>35</td>
<td>35</td>
<td>0.43</td>
</tr>
<tr>
<td>Reoperation</td>
<td>13</td>
<td>7</td>
<td>6</td>
<td>0.78</td>
</tr>
<tr>
<td>Organ failure</td>
<td>13</td>
<td>6</td>
<td>7</td>
<td>0.65</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>17</td>
<td>8</td>
<td>9</td>
<td>0.97</td>
</tr>
<tr>
<td>Sepsis</td>
<td>17</td>
<td>9</td>
<td>8</td>
<td>0.93</td>
</tr>
<tr>
<td>Death following surgery</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>0.8</td>
</tr>
<tr>
<td></td>
<td>119</td>
<td>65</td>
<td>54</td>
<td></td>
</tr>
<tr>
<td>Surgical facility type</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Main centre</td>
<td>76</td>
<td>33</td>
<td>43</td>
<td></td>
</tr>
<tr>
<td>Smaller centre</td>
<td>38</td>
<td>30</td>
<td>8</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Private</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>0.54</td>
</tr>
<tr>
<td></td>
<td>119</td>
<td>65</td>
<td>54</td>
<td></td>
</tr>
<tr>
<td>Type of surgeon</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Specialist surgeon</td>
<td>69</td>
<td>29</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>General surgeon</td>
<td>50</td>
<td>36</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td></td>
<td>119</td>
<td>65</td>
<td>54</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: EMR, Endoscopic Mucosal Resection

a) Population estimates
b) Crude
c) Age and sex standardised
d) Limited to those who received definitive surgery
e) Limited to those who received definitive surgery

1) Reasons for reoperation included anastomotic leakage, bleeding, infarcted bowel or stomach, division of adhesions and intra-abdominal abscess
2) Includes cardiac, respiratory and renal failure
Assessment of Surgeon Type and Facility Type using Stratification

As described in Chapter 5: Methods, to ascertain whether the differences observed above were related to the differences in surgery type received by Māori and non-Māori the type of surgeon performing surgery and the type of facility where patients received their surgical treatment were further investigated through stratification by surgery type. Surgery type was limited to the two main surgical procedures; partial and total gastrectomy. As shown in Figure 13 regardless of whether a partial gastrectomy or a more complex total gastrectomy was performed, Māori appeared to be less likely than non-Māori to have their surgery performed by a specialist surgeon and more likely to have their surgery performed by a general surgeon (age- and sex-standardised proportions).

Figure 13: Māori and non-Māori cohorts (stage I –III) who had total or partial gastrectomy, by surgeon type; age- and sex-standardised

Māori also appeared to remain less likely than non-Māori to be treated in a main centre and more likely to be treated in a smaller centre (Figure 14).
The data were then reanalysed, to investigate the type of surgeon who performed surgery (any of the surgery types) within the centre types (main and smaller centres). Figure 15 shows that when age- and sex-standardised it appears that Māori remain less likely than non-Māori to have their surgery performed by a specialist upper gastrointestinal surgeon within either a main (p=0.12) or smaller centre (p=0.15), although the results do not reach statistical significance. Conversely Māori are more likely to be treated by a general surgeon in both main (p=0.12) and smaller centres (p=0.15).
Assessment of Surgeon Type and Facility Type using Logistic Regression

As all of the previous results indicated differential access to specialist surgical care for Māori, the surgeon and surgical facility type were further explored through logistic regression modelling. Due to the small numbers of patients treated by specialist surgeons within smaller centres these results focus on patients who received their care within main (including private) centres only. Thus the model investigated receipt of specialist surgical care within a main centre by ethnicity. As described in Chapter 5: Methods, Māori/non-Māori hazard ratios were adjusted in a sequential manner using continuous or binary variables: age (continuous), stage (stage I and II versus stage III) and tumour site (proximal and distal only).

After adjusting for age, Māori were half as likely to be treated by a specialist surgeon although the 95% confidence intervals are wide and include the null (HR 0.50; 95% CI, 0.17 – 1.46) (Table 31). Additional adjustment for stage produced little change to the hazard ratio (HR 0.54, 95% CI, 0.18 – 1.61). However, following additional adjustment for tumour site the hazard ratio fell to 0.27, although the confidence intervals remain wide and include the null (95% CI, 0.07 – 1.04).
In conclusion after adjusting for age, stage and tumour site, the differences observed between Māori and non-Māori remained, with Māori appearing 73% less likely than non-Māori to receive surgery by a specialist surgeon.

Table 31: Hazard ratios for receipt of Specialist Surgeon for Māori and non-Māori cohorts (stage I – III) who received surgery within a main centre

<table>
<thead>
<tr>
<th>Adjusted for:</th>
<th>HR</th>
<th>(95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unadjusted</td>
<td>0.47</td>
<td>(0.17 - 1.28)</td>
</tr>
<tr>
<td>Age</td>
<td>0.50</td>
<td>(0.17 – 1.46)</td>
</tr>
<tr>
<td>Age and Stage</td>
<td>0.54</td>
<td>(0.18 – 1.61)</td>
</tr>
<tr>
<td>Age, Stage &amp; Tumour site</td>
<td>0.27</td>
<td>(0.07 – 1.04)</td>
</tr>
</tbody>
</table>

**Extent of Nodal Resection**

Of the n=119 stage I-III patients treated with definitive surgery, nodal resection would be expected in n=112 patients (removing EMR n=2 and laparotomy without resection n=5 from analysis). However data were only found for n=96 of these patients (89% of eligible Māori had these data vs. 82% of non-Māori). These data are discussed below.

Table 32 shows that overall just over half (55%) of these patients had the recommended 15 or more nodes resected during surgery. Similar proportions of Māori and non-Māori patients had 15 or more nodes resected (age- and sex-standardised proportion: 61% of Māori vs 58% non-Māori, p<0.5).

Table 32: Total, Māori and non-Māori cohorts (stage I – III) by number of nodes resected in patients who received surgery

<table>
<thead>
<tr>
<th>Number of nodes resected</th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%a</td>
<td>n</td>
</tr>
<tr>
<td>0-14</td>
<td>40</td>
<td>45%</td>
<td>20</td>
</tr>
<tr>
<td>15+</td>
<td>56</td>
<td>55%</td>
<td>34</td>
</tr>
<tr>
<td>Total</td>
<td>96</td>
<td>54</td>
<td>42</td>
</tr>
</tbody>
</table>

a) Population estimates
b) Crude
c) Age and sex standardised
d) Limited to those with data and who received surgery, one of: Ivor-Lewis Oesophagectomy, Gastrojejunostomy, Partial Gastrectomy, Total Gastrectomy
Medical Oncology Treatment

Of the patients in this study with stage I-III disease, 49% overall were referred to medical oncology. Figure 16 shows that after adjusting for age, similar proportions of Māori and non-Māori patients were reviewed by medical oncology (Māori 46%, non-Māori 53%, p=0.25), offered chemotherapy (Māori 28%, non-Māori 32%, p=0.48) and received chemotherapy (Māori 26%, non-Māori 30%, p=0.5).

Figure 16: Māori and non-Māori cohorts (stage I - III) by receipt of medical oncology treatment; age- and sex-standardised

![Bar chart showing receipt of medical oncology treatment for Māori and non-Māori patients](image)

Few patients received chemotherapy in conjunction with surgery (Table 33). Overall 15% of patients with stage I-III disease received pre-operative chemotherapy and 25% received post-operative chemotherapy. There were differences in the proportions of Māori and non-Māori patients who received chemotherapy. Although these were not statistically significant the results again suggest differential treatment (age- and sex-standardised proportion: 13% of Māori received pre-operative chemotherapy vs 20%
of non-Māori, p=0.99 and 22% of Māori received post-operative chemotherapy vs 34% of non-Māori, p=34).

Table 33: Total, Māori and non-Māori cohorts (stage I - III) who received pre or post-operative chemotherapy

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%a)</td>
<td>%b)</td>
</tr>
<tr>
<td>Chemotherapyd)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-operative</td>
<td>20</td>
<td>15%</td>
<td>13</td>
</tr>
<tr>
<td>Post-operative</td>
<td>31</td>
<td>25%</td>
<td>18</td>
</tr>
<tr>
<td>Total</td>
<td>119</td>
<td>65</td>
<td>54</td>
</tr>
</tbody>
</table>

| a) Population estimates  
| b) Crude  
| c) Age and sex standardised  
| d) Limited to those who received definitive surgery and curative chemotherapy

Patient Management

Timeliness to Cancer Treatment

Table 34 shows the timeliness of care in the total stage I – III cohort and compares timeliness between Māori and non-Māori patients, based on median times between key steps in the treatment pathway. Data were collected on initial patient referral into the system but these data were often missing and thus unreliable. As outlined in Chapter 5: Methods, first intervention was defined as earliest of either radiotherapy, chemotherapy, definitive surgery, or other surgical intervention such as abdominal paracentesis, gastric or oesophageal stent or jejunostomy feeding tube insertion.

Overall, the median waiting time from first specialist appointment (FSA) until first intervention was 37 days, with Māori waiting on average 14 more days than non-Māori for first intervention. On average patients waited 31 days from date of diagnosis until first intervention and 35 days from diagnosis until definitive surgery was performed. At each of these steps Māori patients appeared to experience
slightly longer delays through the treatment pathway than non-Māori. Māori appeared to wait on average 13 days longer, once diagnosed, for definitive surgery although the differences were not statistically significant (median 47 days for Māori compared to 35 days for non-Māori patients, p=0.65).

Māori patients also appeared to wait longer once diagnosed before referral to medical oncology (median 34 days for Māori compared to 25 days for non-Māori patients, p=0.31). However, once in the oncology treatment pathway, waiting times were very similar for Māori and non-Māori patients (median 70 days for Māori compared to 72 days for non-Māori patients, p=0.33).

In conclusion, Māori tended to wait longer for both first intervention and definitive surgery. There was less difference between Māori and non-Māori within oncology services. However differences were not statistically significant and these findings must be interpreted with caution.

Table 34: Total, Māori and non-Māori cohorts (stage I – III) timeliness of care for patients with treatment dates available

<table>
<thead>
<tr>
<th>Table 34: Total, Māori and non-Māori cohorts (stage I – III) timeliness of care for patients with treatment dates available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waiting time (days)</td>
</tr>
<tr>
<td>Time FSA - First intervention [c] (n=131)</td>
</tr>
<tr>
<td>Time diagnosis - First intervention [c] (n=139)</td>
</tr>
<tr>
<td>Time diagnosis - Definitive surgery (n=119)</td>
</tr>
<tr>
<td>Chemotherapy [f]</td>
</tr>
<tr>
<td>Diagnosis - Referred to Med Onc (n=72)</td>
</tr>
<tr>
<td>Referred Med Onc - Review by Med Onc (n=57)</td>
</tr>
<tr>
<td>Review Med Onc - Received chemo (n=53)</td>
</tr>
<tr>
<td>Diagnosis - Received chemo (n=56)</td>
</tr>
<tr>
<td>Total median [a]</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>37</td>
</tr>
<tr>
<td>31</td>
</tr>
<tr>
<td>35</td>
</tr>
<tr>
<td>25</td>
</tr>
<tr>
<td>15</td>
</tr>
<tr>
<td>24</td>
</tr>
<tr>
<td>70</td>
</tr>
</tbody>
</table>

Abbreviation: FSA, first specialist appointment; Med Onc, medical oncology

a) Population estimates
b) Crude
c) First intervention is chemotherapy, definitive surgery or other intervention (i.e. stent, paracentesis, jejeunostomy feeding tube)
Given the differences observed between Māori and non-Māori in the type of facility where patients received their surgical treatment these data were further investigated by stratifying waiting times by the two key surgical facility types: main and smaller centres. Results are presented below in text.

Median waiting times in a main centre from diagnosis until receipt of definite surgery for Māori were 56 days and non-Māori were 36 days (p=0.3) while for diagnosis until referral into medical oncology services for Māori were 43 days and non-Māori were 26 days (p=0.2).

In comparison in a smaller centre the median waiting times from diagnosis to receipt of definite surgery for Māori were 33 days and non-Māori were 46 days (p=0.8). The median waiting times from diagnosis to referral into medical oncology services for Māori were 33 days while for non-Māori they were 42 days (p=0.4).

**Stage I – III Patients without Treatment**

There was a substantial group of patients with stage I-III disease who appeared to have no treatment at all (n=33 [19%] of stage I-III patients; n=14 Māori, n=19 non-Māori). This group were older (mean age 79 years) than the stage I-III patients that did have treatment (mean age 63 years) and were more likely to have comorbid conditions at diagnosis (mean comorbidity count of 3.1 versus a mean comorbidity count of 1.6 for those stage I-III patients that did have treatment). Two-thirds of this group (n=22) were referred to a palliative service (data not shown).

**Palliative Care**

Referral into any palliative care service (palliative chemotherapy, palliative radiotherapy or other palliative care) was analysed for stage IV patients only. Radiotherapy was only given to a small number of patients in the palliative setting within this study (n=11).
While Māori patients are less likely to be referred to (or receive) chemotherapy it appears that they are more likely to be referred to (or receive) radiotherapy in the palliative setting than are non-Māori patients (Table 35 and Figure 17). Note that the chemotherapy results are statistically significant however the radiotherapy results are based on very small numbers of patients and are not significant.

It also appears that Māori are more likely to be referred to a hospice service than non-Māori (age- and sex-standardised proportion: Māori 75% and non-Māori 59%, p=0.14). However, Māori (85%) and non-Māori (83%) patients were similarly likely to be referred to any palliative service when the data were age- and sex-standardised (p=0.85) (Table 35).

Table 35: Total, Māori and non-Māori cohorts (stage IV only) by palliative care

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% a)</td>
<td>n b)</td>
</tr>
<tr>
<td><strong>Referred Palliative</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>60</td>
<td>40%</td>
<td>30</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>16</td>
<td>8%</td>
<td>11</td>
</tr>
<tr>
<td>Hospice</td>
<td>101</td>
<td>60%</td>
<td>60</td>
</tr>
<tr>
<td>Any palliative service</td>
<td>128</td>
<td>80%</td>
<td>71</td>
</tr>
<tr>
<td><strong>Received Palliative</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>44</td>
<td>29%</td>
<td>22</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>11</td>
<td>6%</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>158</td>
<td>85</td>
<td>73</td>
</tr>
</tbody>
</table>

a) Population estimates  
b) Crude  
c) Age and sex standardised
QUANTITATIVE RESULTS: MĀORI/NON-MĀORI COMPARISON

Figure 17: Māori and non-Māori cohorts (stage IV) by referral and receipt of palliative chemotherapy and palliative radiotherapy; age- and sex-standardised

![Bar chart showing percentages of referred and received chemotherapy and radiotherapy for Māori and non-Māori cohorts.](chart.png)
Patient Survival

This section describes the survival of the final cohort and compares the survival of Māori and non-Māori patients. Crude survival, both all-cause and cancer specific, is illustrated by Kaplan-Meier plots of survival probability for the Māori and non-Māori cohorts. The Māori/non-Māori hazard ratio of cancer-specific death is then examined and adjusted in a step-wise manner for various potentially confounding factors using multivariable Cox regression modelling.

Overall Survival

Overall, nearly eighty percent (78%) of the total cohort died during follow-up. Time to death varied from to one day to 1822 days (4.9 years), depending on the patient’s date of diagnosis during the three-year study and date of death. The majority of deaths were due to stomach cancer (n=244), with only 16 (4.8%) patients dying of other causes. Seventy five patients remained alive at the end of follow-up. There was little difference in the proportions of deaths between the Māori and non-Māori cohorts (Table 36).

Table 36: Māori and non-Māori deaths due to stomach cancer and other causes

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%a)</td>
<td>n</td>
</tr>
<tr>
<td>Cohort</td>
<td>335</td>
<td></td>
<td>172</td>
</tr>
<tr>
<td>Deaths</td>
<td>260</td>
<td>78%</td>
<td>133</td>
</tr>
<tr>
<td>Stomach Cancer</td>
<td>244</td>
<td>73%</td>
<td>125</td>
</tr>
<tr>
<td>Other</td>
<td>16</td>
<td>4.8%</td>
<td>8</td>
</tr>
</tbody>
</table>

a) Crude
**Crude Māori/non-Māori Survival**

As stomach cancer has such a poor prognosis with few patients dying of other causes the Kaplan Meier curves for all-cause (Figure 18) and stomach cancer specific (Figure 19) survival times were very similar. Additionally, as demonstrated in Figure 18 and Figure 19 there was little difference between Māori and non-Māori patients in either crude all-cause (p=0.9) or stomach cancer specific survival (p=0.9). This similar survival pattern was reflected in a crude Māori/non-Māori hazard ratio for stomach cancer specific mortality of 1.02 (95% CI 0.79 – 1.31) (Table 38).

Median all-cause survival times were 269 days for Māori compared with 271 days for non-Māori, while median stomach cancer specific survival times were 294 days for Māori compared with 274 days for non-Māori.

![Figure 18: All Cause Survival by ethnicity total cohort](image)
Adjusted Māori/non-Māori Survival

This section outlines the covariates used in the modelling and discusses how they are associated with ethnicity (the exposure) using descriptive results from the current study and survival (the outcome) using the fully adjusted model (Table 37).

The fully adjusted stomach cancer specific model shows the independent effect - as a predictor of stomach cancer survival - of each of the variables that were included in the sequentially adjusted multivariable Cox regression model (Table 38). This table is presented using imputed tumour site, deprivation and rurality variables.

Unfortunately study numbers were too limited to produce meaningful hazard ratio estimates stratified by stage (or for stage I-III patients), therefore hazard ratios are shown for the total cohort with adjustment for stage via Cox modelling.

Patient Demographic Factors: Age and Sex

Māori in this study were on average 10 years younger at diagnosis than non-Māori. The expectation of better survival in the Māori cohort due to their younger age structure is borne out in the fully adjusted model (Table 37) where the independent
hazard ratio for age is 1.02. As age is included as a continuous variable, this means that for each additional year of age of the patient there was a 2% greater likelihood of dying.

A differential sex distribution was observed between Māori and non-Māori in this study, with proportionately more women within the Māori cohort than in the non-Māori cohort. As shown in Table 37 women are more likely to die with a hazard ratio of 0.79.

Without adjustment for these variables (age and sex) the impact of them on survival estimates would be conflated, with Māori appearing to have better survival than they actually do.

**Disease Factors: Stage and Tumour Site**

In this study no substantial differences in stage between Māori and non-Māori were observed. However Māori were more likely to have stage II disease and had less stage III and slightly less stage IV disease than non-Māori. Additionally, no Māori patients remained unstaged in this study but 2% of non-Māori patients were unstaged. Taken together this means that Māori actually have a slightly better stage profile than non-Māori. Unsurprisingly, stage is a strong independent predictor of survival within this study (as borne out in the fully adjusted model; Table 37). Compared to patients with stage I disease the risk of mortality for patients with stage II disease was over twice as high and the risk of mortality for patients with stage III disease five times as high, while the mortality risk for stage IV patients was over 16 times that of stage I patients. The mortality risk for patients with unstaged cancer fell between that observed for stage III and stage IV patients.

Tumour site is shown to be an important independent prognostic factor within this study, with patients diagnosed with proximal tumours having a better survival probability (Table 37). Although with imputed site data the 95% confidence intervals are wide and imprecise (0.89 to 1.75), the best estimate is a 25% poorer survival for patients diagnosed with distal disease (Table 37). Māori in this study were significantly more likely to be diagnosed with distally located tumours.
Without adjustment for these variables (stage and site) Māori would appear to have better survival than they actually do.

**Patient Comorbidity**

A high prevalence of comorbidity was observed in this study with 70% of the total cohort having at least one comorbid condition. Māori patients in this study were more likely to have a number of comorbidities and/or present with multiple comorbidity; the likelihood of three or more comorbidities was 31% in Māori and 17% in non-Māori (age- and sex-standardised) albeit not statistically significant. Comorbidity was included in the model as a continuous variable (1 – 12). As seen in Table 37 each additional comorbidity that a patient had increased the probability of mortality by 2%, although again the 95% confidence intervals are imprecise and include the null (0.92 to 1.13).

**Health Care Access Factors: Deprivation and Rurality**

There was a strong socioeconomic gradient for patients overall in this study but this was more pronounced for Māori with twice as many Māori patients than non-Māori living in the most deprived quintile. In addition, over twice as many Māori patients compared with non-Māori lived rurally in areas far from New Zealand’s six main cancer centres. Both deprivation and rurality appear to play some independent role in patient survival, although as seen in Table 37 it appears that the patients living in the most deprived quintiles or rurally have better survival than those living in less deprived quintiles and/or urban areas. It must be noted that these variables are not a measure of health care quality as such, but are included as a crude measure of access to, and through, cancer services.
QUANTITATIVE RESULTS: MĀORI/NON-MĀORI COMPARISON

Table 37: Fully adjusted hazard ratios for stomach cancer specific mortality risk in the total cohort

<table>
<thead>
<tr>
<th>Adjusted for:</th>
<th>HR</th>
<th>95% CI</th>
<th>Reference Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td>1.30</td>
<td>0.96 to 1.76</td>
<td>Non-Māori</td>
</tr>
<tr>
<td>Age</td>
<td>1.02</td>
<td>1.00 to 1.03</td>
<td>Continuous</td>
</tr>
<tr>
<td>Sex</td>
<td>0.79</td>
<td>0.60 to 1.05</td>
<td>Female</td>
</tr>
<tr>
<td>Stage II</td>
<td>2.64</td>
<td>1.42 to 4.90</td>
<td>Stage I</td>
</tr>
<tr>
<td>Stage III</td>
<td>5.05</td>
<td>2.75 to 9.28</td>
<td>Stage I</td>
</tr>
<tr>
<td>Stage IV</td>
<td>16.37</td>
<td>9.25 to 28.28</td>
<td>Stage I</td>
</tr>
<tr>
<td>Unstaged</td>
<td>6.68</td>
<td>2.09 to 21.24</td>
<td>Stage I</td>
</tr>
<tr>
<td>Imputed Site</td>
<td>1.25</td>
<td>0.89 to 1.75</td>
<td>Proximal</td>
</tr>
<tr>
<td>Comorbidity a)</td>
<td>1.02</td>
<td>0.92 to 1.13</td>
<td>Continuous</td>
</tr>
<tr>
<td>NZDep 3 - 4</td>
<td>1.05</td>
<td>0.58 to 1.91</td>
<td>NZDep 1 - 2</td>
</tr>
<tr>
<td>NZDep 5 - 6</td>
<td>1.14</td>
<td>0.65 to 1.98</td>
<td>NZDep 1 - 2</td>
</tr>
<tr>
<td>NZDep 7 - 8</td>
<td>0.54</td>
<td>0.32 to 0.93</td>
<td>NZDep 1 - 2</td>
</tr>
<tr>
<td>NZDep 9 - 10</td>
<td>0.84</td>
<td>0.50 to 1.40</td>
<td>NZDep 1 - 2</td>
</tr>
<tr>
<td>Independent Urban</td>
<td>0.94</td>
<td>0.65 to 1.36</td>
<td>Urban</td>
</tr>
<tr>
<td>Rural</td>
<td>0.69</td>
<td>0.46 to 1.05</td>
<td>Urban</td>
</tr>
</tbody>
</table>

a) 12 most common comorbid conditions in this study (as per Table 25)

The Association between Ethnicity and Survival

The similar survival pattern between Māori and non-Māori seen in the Kaplan Meier curves was reflected in the unadjusted hazard ratio for stomach cancer specific mortality of 1.02 (95% CI, 0.79 – 1.31) (Table 38).

Adjusting for the pure confounders (demographic factors: age and sex) had some impact on the model estimates. Although not a substantial or significant result, the hazard ratio rose to 1.08 (95% CI, 0.82 - 1.41).

Adjusting for the disease factors (stage at diagnosis and tumour site) had the biggest impact on the model, with a rise in the hazard ratio to 1.28 (95% CI, 0.96 - 1.69). In other words Māori appeared more likely to die than non-Māori after adjusting for age, sex, stage and tumour site, with an estimated 28% higher mortality; although confidence intervals around this estimate included the null.
Following additional adjustment for patient comorbidity the hazard ratio changed to 1.25 (95% CI, 0.94 - 1.66) and so while the change in hazard ratio was not substantial and the confidence intervals continue to include the null and remain wide, it appears that comorbidity plays a small role in the survival disparity seen between Māori and non-Māori in this study.

Additionally adjusting for differences in markers of health care access (deprivation and rurality) had a small impact on the hazard ratio but was not able to explain the excess mortality in Māori (HR 1.30; 95% CI, 0.96 – 1.76).

After adjusting for patient demographics, disease factors, patient comorbidity and health care access factors (age, sex, stage, tumour site, comorbidity, deprivation and rurality) Māori patients had an estimated 30% higher mortality than non-Māori (HR 1.30), with 95% confidence intervals showing a plausible range of 4% lower mortality to 76% higher mortality (Table 38). So despite adjusting for a number of key factors including markers of access to cancer services, the apparent Māori/non-Māori survival disparity persisted, with the final best estimate being a 30% poorer survival for Māori compared with non-Māori.

Table 38: Hazard ratios for stomach cancer specific mortality risk in Māori and non-Māori cohorts with sequential adjustment (using imputed variables: tumour site, NZDep and rurality)

<table>
<thead>
<tr>
<th>Adjusted for:</th>
<th>HR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unadjusted</td>
<td>1.02</td>
<td>0.79 to 1.31</td>
</tr>
<tr>
<td>Demographic Factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age and Sex</td>
<td>1.08</td>
<td>0.82 to 1.41</td>
</tr>
<tr>
<td>Disease Factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage and Tumour site</td>
<td>1.28</td>
<td>0.96 to 1.69</td>
</tr>
<tr>
<td>Comorbidity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Comorbidity</td>
<td>1.25</td>
<td>0.94 to 1.66</td>
</tr>
</tbody>
</table>
a) 12 most common comorbid conditions in this study (as per Table 25)

Health Care Access Factors
| NZDep and Rurality        | 1.30 | 0.96 to 1.76 |

245
Very similar results were obtained using non-imputed tumour site data, with minimal difference between the two models (data not shown).

**Stage I – III Survival**

The results obtained when restricting the Māori/non-Māori HR estimates to stage I – III patients only followed a similar pattern to those of the total cohort (see Appendix 6). Because of the smaller numbers the HR were very imprecise with wide confidence intervals which included the null. The final best estimate was a 21% poorer survival for Māori compared with non-Māori for those patients diagnosed with stage I – III disease.

**Summary of Quantitative Results**

This study found both similarities and differences in the presentation, management and survival of stomach cancer for Māori when compared with non-Māori patients.

**Presentation**

There were no significant differences in cancer grade or stage at diagnosis. Māori were on average younger at diagnosis and were more likely to live in the most deprived quintiles and rurally.

Māori had significantly higher prevalence of comorbid congestive heart failure and renal disease and appeared more likely to have multi-morbidity than did non-Māori. This was a highly comorbid cohort overall with 70% of both Māori and non-Māori having at least one chronic disease at the time of their stomach cancer diagnosis.

Māori also presented with a much higher proportion of distally located stomach cancers when compared with non-Māori patients and non-Māori with a higher proportion of proximally located tumours.
Treatment and Management

Of those patients diagnosed with stage I–III disease, Māori were equally likely to receive definitive surgery as non-Māori. Māori were more likely to undergo a partial gastrectomy while non-Māori were more likely to undergo the more complex total gastrectomy or Ivor-Lewis oesophagectomy. Māori were less likely to have surgery performed by a specialist upper gastrointestinal surgeon and less likely to be treated in a main centre. Few patients overall received chemotherapy.

On the whole timeliness through the treatment pathway was similar between the two groups although Māori patients did appear to wait on average 13 days longer between diagnosis and surgery than non-Māori.

Nineteen percent of patients with stage I–III disease appeared to have no treatment at all. This group was older and more likely to have comorbid conditions at diagnosis than the stage I–III patients that did have treatment. Māori and non-Māori patients with stage IV disease were similarly likely to be referred to any palliative service when the data were age- and sex-standardised.

Survival

Māori in this cohort appeared less likely to survive once diagnosed with stomach cancer once patient and disease factors, comorbidity and health care access factors were adjusted for, although the study was underpowered to statistically confirm a 30% excess mortality among Māori patients.
Chapter 7: Qualitative Results

To build on the findings of the quantitative phase of this study, a qualitative phase was undertaken to investigate those points of the stomach cancer treatment pathway that the quantitative findings suggested were inequitable for Māori. One-on-one key informant interviews were used. All informants were health care, or health policy, professionals recruited using the snowball method. Fifteen informants were interviewed to assess what the sector sees as the issues impacting on equity for Māori within New Zealand’s stomach cancer treatment pathway, how they interpreted the findings of the quantitative phase of this study, and which interventions they believed would improve the stomach cancer treatment pathway.

Two research questions guided the qualitative phase of this study;

1. What do key informants identify as issues for stomach cancer treatment in New Zealand, with a focus on Māori?

2. Which interventions do key informants identify that may improve access to, and quality of, stomach cancer treatment in New Zealand, with a focus on Māori?

This chapter outlines the findings of the qualitative phase. Firstly, it identifies the final key informant sample and their attributes. Secondly, it highlights issues identified by key informants along the stomach cancer treatment pathway, including whether there are any particular issues for Māori or those patients with comorbid conditions. Thirdly, it highlights the issues key informants identified at specific points of the stomach cancer pathway. Finally, the interventions suggested by the key informants are identified at each point of the stomach cancer pathway and summarised according to Mandelblatt et al.’s levels of barriers to access to cancer services (Mandelblatt et al., 1999).
Final Key Informant Sample

Fifteen key informants (informants) were interviewed in the qualitative phase of this study. All informants were actively working within the New Zealand health care system and were purposefully chosen as they had specific knowledge of the stomach cancer treatment pathway and/or of the issues for Māori within cancer treatment services. This study used a snowball technique to identify potential informants with rich information. Sampling was stopped once key names began to be repeated and no new names were suggested. The sampling goal of this study, which was to gain a range of perspectives, was met.

Typically the interviews lasted at least 30 minutes although the length of time ranged from 25 minutes through to 110 minutes. Each of these two extreme times were from interviews with medical clinicians. The interview of shortest duration was held while the clinician was on-duty whereas the interview of longest duration was held while the clinician was off-duty.

Attributes of Key Informants

Five informants self-identified as Māori and ten did not and thus were classed as non-Māori. One of the non-Māori informants held a role as an equity cancer nurse specialist which meant they held specific working knowledge of the issues for Māori within cancer treatment services.

Six informants worked within a policy role; of these three identified as Māori. Nine informants worked within a clinical role; of these two identified as Māori.

Five informants held roles at a national or regional level, either within the Ministry of Health or one of New Zealand’s four Regional Cancer Networks. Six held roles in a main centre (as defined in the quantitative phase of this study). Of these six main centre informants five worked within clinical roles, including three specialist upper GI surgeons and two clinical nurse specialists who held either an equity or Māori

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focussed position. The final four informants held roles in smaller centres, of these three were clinical nurse specialists (one with an upper GI cancer focus and one with a GI surgery focus) and one a general surgeon with an interest in Upper GI surgery. Below the informants are identified as either policy or clinical informants, and at times nursing or medical clinicians.

What do Key Informants Identify as Issues?

What is done well overall?

When asked what the New Zealand health system does well for people with stomach cancer the majority of informants felt that overall the health-care system works well in New Zealand. A number of informants talked about how at a national level there is a lot of work happening in cancer control. Particularly highlighted were DHB targets for cancer treatment waiting times, the relatively new cancer nurse specialist roles, the recently developed Standards of Service Provision for Upper Gastrointestinal Cancer Patients (Service Provision Standards) (National HBP/Upper GI Tumour Standards Working Group, 2013) and improving collection and reporting of ethnicity data. This last point led one policy-based informant to say "we are starting to see increasing transparency about the level and timeliness of care we are delivering and seeing how we can improve".

At a regional level the ability to access more specialist services than is available in a particular DHB is seen as positive: "now we have this link to [X main centre DHB] it is much better". There seemed to be the general view that, once diagnosed, most patients will proceed through the treatment pathway relatively quickly and be well linked with the appropriate clinical and support services.
What has improved in the preceding five years?

The general consensus of key informants was that the stomach cancer treatment pathway had improved immensely between 2008, when the last patient in the quantitative phase of this study was diagnosed, and 2014 when these key informants were interviewed. Only two informants, one policy and one clinical, were unable to identify any improvements with both citing that they had not been in the role long enough to comment. In comparison one policy-based informant, at the end of the discussion about recent improvements, commented that “it’s a hugely exciting time, actually. There is a lot of work coming together”. Along with the development of Regional Cancer Network’s (RCN) in 2007 specific improvements mentioned included:

- Cancer wait-time targets for radiotherapy from 2008, and chemotherapy from 2012.
- The Faster Cancer Treatment Programme from 2012, with monitoring for timeliness from the beginning of 2013.
  - The 57 cancer nurse specialists funded in 2012 with a focus on at-risk people or those with complex pathways, comorbidities or access issues.
  - The Service Provision Standards work carried out through 2012-13, including standards for upper GI cancers.
    - At the time of writing RCNs and DHBs were carrying out a process of quality improvement by reviewing their services against the standards, to assess current service delivery and identify gaps and overlaps.
  - Better functionality and coverage of Multi-Disciplinary Meetings (MDM).
- The 2015 announcement of new funding for psychosocial care, with up to 20 extra social workers and psychologists employed across New Zealand, to work with existing cancer support staff and as part of wider multidisciplinary cancer care teams.
Two policy informants specifically mentioned that the process of developing the Service Provision Standards in itself was beneficial; that having a broad range of clinical groups involved in conversations about standardisation of care and improving clinical practice has challenged their own practice: “so by default, they’ve actually moved practice forward, before standards were actually even put into place ... I think it was the first time with cancer that we’ve really had the wider pathway, rather than just medical and radiation oncology”.

In terms of improvements specifically for Māori along the stomach cancer treatment pathway informants discussed initiatives such as Māori-specific cancer nurse specialists in some DHBs, the development of a national Māori cancer leadership group to provide a Māori voice at a policy level and that there is growing awareness by health professionals that certain groups in society have issues with health care access. This last point was coupled with a growing awareness that the health system has a responsibility to respond.

**What needs improving?**

Despite the comments above many informants believed there was still room for improvement. Overall the main area of improvement, which was highlighted by over half the key informants, was that the delivery of cancer services is not consistent around the country. Specific examples of inconsistency included that:

- The 20 DHB’s in New Zealand all deliver varying levels of cancer services.
- DHBs and Regional Cancer Networks all prioritise different cancers.
- The 57 new cancer nurse specialist roles work within one of four different models of care often with different spheres of practice.
- Communication between, or within, DHBs can be people-dependent rather than a more formalised process-dependent practice.

The need for improvement was exemplified by a clinical informant when they reflected that,
"Given the geography and resource in New Zealand, I think we do all right. But I think it is driven by people’s interest and passion. That if people really care about it and they make sure that a good service is provided, then its fine … but we can always improve”.

Are there any particular issues for Māori?

When asked what New Zealand health services don’t do well, particularly for Māori patients a policy informant replied with "we don't achieve the same outcomes, as to why we don't achieve the same outcomes I don't think there is one simple answer, I think it's probably multifactorial". Another policy informant discussing the same question raised concerns: “I have a huge concern that from Vote Health 55 million dollars are going into cancer services in this last political period and we’re going to see outcomes that continue to privilege the privileged; I don't think we are going to see much of a gap-narrowing".

All informants identified at least one specific issue particular to Māori within the stomach cancer treatment pathway. A number of common issues were apparent; these included the mono-cultural focus of New Zealand’s health care services, along with issues related to rurality and health literacy.

In regards to the mono-cultural focus of New Zealand’s health services; three Māori informants specifically mentioned this as being an issue for Māori. This was raised in a broad way "so there are biases in the way we design, deliver and measure across health pathways". As well a number of other informants, who were all in clinical positions, raised related points specifically to do with service delivery. These points included the need for improved cultural friendliness and approachability of services, the need to make services patient focussed rather than provider focussed and that services need to accommodate a more holistic approach which encompasses whānau. While the medical clinicians were aware of these needs and took steps to meet these needs this was not always possible in the clinical environment. As a specialist surgeon from a main centre stated:
"It certainly makes it easier if whānau are involved from the very first appointment. So I think a more holistic, family-oriented meeting is important, but that requires more time at your clinic to discuss various treatment options. I do try to make a longer appointment if I can, or run the clinic late but that is not always possible."

Issues to do with rurality and receiving care within smaller centres were raised in relation to Māori. The need for Māori to travel for multiple appointments with multiple providers and often within a DHB other than that in which they reside was seen as an issue by some, particularly when navigating these services is the responsibility of the patient: "at the moment I think a lot of health providers just go ‘well we don’t do that’, and it is left up to the patient, and that’s the last thing people need."

Health literacy was raised by both clinical and policy informants. Each time it was raised however the informant spoke of the need for the health care system to support people to understand their stomach cancer journey rather than of the patient needing to understand the system. There seemed to be willingness, and effort made, by clinicians to ensure that individual Māori and whānau were supported to see and understand their cancer journey. Although some clinicians also expressed being unsure of how to best do this: "it’s hard from my Pakeha point of view". Some clinicians recognised that the needs of Māori were greater than non-Māori, as cancer needs for Māori were often exacerbated by issues to do with the underlying determinants of health and Māori were not always linked in with the support that would likely benefit them. In comparison other clinicians believed that once diagnosed access for patients along the stomach cancer treatment pathway was the same irrespective of ethnicity. As highlighted by one clinical nursing informant:

"I think from my perspective, some of the knowledge of health professionals about what ethnicity means ‘we treat everybody the same, we don’t treat by ethnicity’ there’s still not quite the depth of understanding about what health inequities are, in terms of it is
helping people meet a standard, to get to the same standard that others enjoy, as opposed to something extra, or privileged”.

Policy-based informants all spoke of initiatives that are already happening to address equity for Māori. For example all Regional Cancer Networks have equity manager positions, a commitment to employing Māori staff and regularly use established tools such as the HEAT tool\(^2\) to assess programmes and policy. As another example, an informant in a DHB based policy position spoke of their hospitals use of ‘whānau ora’ assessments when discharging patients: “we say that Māori health does not stop at the door, so before a patient leaves ... that their care continues, our hospital takes responsibility for ensuring that they are passed onto the most appropriate provider”.

On a broader level, a number of policy informants specifically mentioned the Service Provision Standards and their ability to impact on equity for Māori in the future. The general view seemed to be that the development, and more specifically the quality improvement review process, of the standards will help to identify gaps in the system and any differential treatment, providing transparency and impetus for change.

Are there any particular issues for those with comorbidity?

Each of the 15 informants provided an answer to this question, with the consensus view being that comorbidity is common among patients with stomach cancer and is an important issue, increasing complexity and impacting on both timeliness through the cancer pathway and clinical decision-making.

Five clinical and three policy informants specifically reflected that the presence of comorbidity adds complexity to the patient journey. This complexity was especially highlighted as the patient needing to see multiple services within multiple providers, which are often not well coordinated, impacting on the patient. As stated by a nurse

\(^{2}\) The Health Equity Assessment Tool (Equity Lens) for Tackling Inequalities in Health has a series of 12 questions to assist organisations to consider how particular inequalities in health have come about, and where the effective intervention points are to tackle them. It is used by those working in the health and disability sector to apply a strong equity focus to their work. Te Roopu Rangahau a Erū Pomare, Ministry of Health and Public Health Consultancy. (2003) A Health Equity Assessment Tool. In: Public Health Consultancy (ed). Wellington: Wellington School of Medicine and Health Sciences.
within a smaller centre: "it gets to be confusing for patients, when they've got so many people and so many appointments". One nurse informant previously only had the ability to support patients with lower GI cancers (colorectal) within the description of her role. This nurse advocated for the ability to also work with upper GI patients to be built in to the job’s role description as she saw that patients with upper GI cancers were not only more complex but also more likely to be treated outside of their DHB of domicile and thus “more vulnerable to getting lost in the system”. It was her belief that any DHB treating patients with upper GI cancers should ensure there are effective support and/or case coordination services wrapped around that patient and whānau.

Four clinical and one policy informant also discussed this complexity as impacting on timeliness through the stomach cancer pathway, with all agreeing that comorbidity delays the patient journey. The need to address comorbid medical issues before cancer treatment can begin appears to add significant time to the patient journey; this was especially highlighted by clinicians working within smaller DHBs with the need to refer patients to external providers outside of their DHB of domicile.

Six clinicians also discussed the impact that comorbidity has on clinical decision-making with most agreeing that comorbidity limits treatment options. Each of the medical clinicians spoke of holding in-depth conversations with patients about their comorbidity and treatment options, at times leaving the decision on whether to go ahead with treatment, or not, with the patient. Treatment decision making in the presence of comorbidity was also talked about in a risk reduction manner, with the need to quantify and reduce the risk of complications to the patient as being key. One clinician did stress that comorbidity actually means the patient will be discussed in more depth, with the MDM seen as playing a very important role in managing comorbidity and mitigating risk. Another clinician stressed that while comorbidity increases operative risk to the patient it is up to the clinician to manage that risk on behalf of the patient: “it is my problem, not their problem”. Yet another clinician highlighted that treatment options are still discussed, and commitment made to care for the patient, even when a patient’s level of comorbidity meant that active treatment was not possible:
“And as I’ll say to the patients, ‘we’ll care for you, but we may not be able to operate on you. We may not be able to cure you, but we’ll still care for you and look after you’. I guess it depends on what your treatment outcome is. I’d like to think that benign neglect isn’t part of the pathway”.

It seems that comorbidity is often thought of in clinical practice with one main centre DHB ensuring comorbidity is included in the cancer nurse specialist role descriptions and that IT systems enable not only effective referral pathways but also reporting by comorbidity: “it keeps track of the numbers of patients and tries to quantify the complexity of them ... the idea for management that being able to quantify the work is as important as them providing good care”. In this case there is acknowledgement not only of the impact of comorbidity on the patient (providing good care) but also of the additional workload the presence of comorbidity places on staff and on services or health care resources more generally (quantifying the work involved in dealing with comorbid patients).

Are There Issues Along the Stomach Cancer Pathway?

Prevention and Screening

While this thesis is focussed on the diagnosis treatment and survival of people with stomach cancer and no specific questions were asked about prevention or screening, some informants offered information relating to this.

Four informants specifically mentioned prevention, three in policy roles and one cancer nurse specialist with a background in primary health care. These informants all believe that a focus on stomach cancer prevention is vital to improving outcomes for Māori. Two informants specifically highlighted the link between H. pylori and the
increased incidence of stomach cancer among Māori. One nursing informant urged that “It’s some education in primary care about to think of these things, don't just treat the obvious”. Another policy-based informant emphasised that all of the recently developed Standards of Service Provision have a section on prevention and screening in them as a mechanism for advancing this area.

“I think one of the ways forward across the cancer portfolio is really going to be about health education, health promotion, out in the community ... people say that a third of cases are preventable, and another third should be able to be caught early. That's one hell of a challenge to put out there. But it actually means that we need to be focusing on that front end of the pathway”.

However while there was some support for the prevention of stomach cancer this was not so for organised screening; even for people at high-risk of developing the disease. The two clinicians that raised the issue of screening for stomach cancer did so to warn that an organised screening programme would not be a viable option in New Zealand: “I don’t think that gastric cancer has a high enough incidence to be able to justify what is currently an overburdened system”. Both clinicians specifically discussed this in the context of the Bowel Cancer Screening pilot currently running in Waitemata DHB, and emphasised that screening for bowel cancer should take precedence.

**Early Detection, Diagnosis and Staging**

Eleven informants, both policy and clinical, specifically discussed early detection, diagnosis and staging. The general consensus was that while New Zealand has good services and a number of initiatives taking place to improve early detection and staging of stomach cancer that the delivery of services, or access to those services, is not consistent around the country or for certain groups in society. As an upper GI surgeon in a main centre stated:
“I think it works very well with middle-class well-educated people, who sort of understand the system and are prepared to get back to their doctor. If you’re poorer and going to the family doctor is a big deal, then you’re actually a lot less likely to do that, and there’s a chance you can get lost”.

Two current initiatives specifically mentioned were changes to Primary Health Care IT infrastructure to allow better streamlining and support of referral pathways and the National Endoscopy Quality Improvement Programme which is reviewing the quality and timeliness of endoscopy in New Zealand. However, it was noted that the programme is currently focussed on colonoscopy in preparation for the rollout of the Bowel Cancer Screening pilot being conducted in Waitemata DHB, which once rolled out will potentially divert resource from already overburdened gastroscopy services.

Despite these current initiatives all eleven informants that answered this question agreed that there is a need to improve the stage at diagnosis profile of patients with stomach cancer in New Zealand with three areas identified as possible areas of focus.

Firstly, an organised and national approach to early detection (raised by five informants) which would include a three pronged approach of: targeted community awareness raising of signs and symptoms of stomach cancer, raising awareness within primary health care of signs and symptoms and referral pathways, and, streamlining of referral pathways. Secondly, improving access to endoscopy services was specifically mentioned by six informants, with one clinician highlighting that "probably our biggest failing is access to early endoscopy … the reality is that the resource is just not there … but if you’re going to make a difference you’ve got to make it early" and another clinician, saying that "we have good endoscopy services around the country, but they can be quite difficult for patients to get them" and yet another nursing clinician lamenting the Monday to Friday functioning of New Zealand health services. Each informant did however link this reduced access to available capacity, workforce and funding.

"I think a huge barrier is still within the health profession, a lot of health professionals do not have the mind-set that we are a
24-hour, seven-day a week service. Monday to Friday for the radiology department which is a huge component of diagnostics for the group that I work with ‘we can’t fit them in, we can’t fit them in’. Well let’s open seven days a week, and we’ll fit them in alright”.

Thirdly standardising care nationally was seen as important. Strengthening early detection within the current upper GI Service Provision Standards was discussed as an approach to achieving national consistency by three policy based informants. Improving access to diagnostic and staging investigations within smaller DHBs was highlighted by three clinical informants as they see variable access to specialist imaging around the country, despite being the standard of care for patients with stomach cancer. Finally, demystifying the diagnostic and staging journey for all patients was seen as important by two informants. In this latter case, a cancer nurse within a smaller DHB had independently translated a larger DHBs pamphlet on PET scanning into lay terms and says considerable time is spent with patients discussing the need for the scan, why they must travel for the scan and possible outcomes as well as ensuring patients have travel and accommodation assistance.

**Surgical Management**

Different responses were observed between informants working in different treatment centre sizes when discussing the timeliness and accessibility of surgical oncology services.

Cancer nurse specialists working within smaller centres all spoke about time delays in the treatment pathway, this was especially apparent when patients were being seen outside of their DHB of domicile, as was often needed. At times patients need diagnostic and staging investigations in DHBs other than those in which they reside. More commonly, patients need treatment outside of their own DHB. Nurses, who closely follow the patient and coordinate their care, spoke of frustration in accessing services in other DHBs: "once you have done that referral, you don't automatically get
in quickly ... you're then entering someone else's urgent waiting system". Patients with acute problems are seen quickly and one nurse spoke of a patient who was seen within 24 hours in a large DHB once he began to bleed badly; the point made however was that he had been waiting over three weeks for an outpatient appointment within the larger DHB. Nurses also spoke about the lack of capacity in their small DHBs to meet demand for urgent, or timely, investigations such as CT scans: "as soon as we find their tumours the person's name is forwarded to [external DHB] two weekly MDM, but I've got to get the scans first and that takes on average 2 to 3 weeks, even when I go down there and beg, borrow and steal ... they just don't have the capacity to get all these decent scans done". All spoke of the need to access specialist surgical expertise and/or MDM advice often from other DHBs and the time delays in this process. In one small DHB, specialist upper GI surgeons do hold monthly clinics (in the small DHB) to assess new patients or provide follow-up care, but often the wait times to access this clinic are too long, necessitating an appointment in the main DHB or a four to five-hour car journey (one way) for the patient to be assessed by a specialist surgeon. As summed up by one of the nurse informants from a smaller centre: "I keep saying - it's the inequity of a small DHB".

In comparison the clinicians interviewed that worked in main centre DHBs highlighted a very different picture of the access patients appeared to have to the surgical treatment pathway in those DHBs. For example, in one main centre DHB there are a number of specialist upper GI surgeons who are able to cover each other's workload when needed and the same surgeon assesses and triages patient referrals providing consistent assessment and referral processes. In the same main centre DHB there are gastroenterologists on staff performing most of the diagnostic endoscopies, who have weekly meetings with the surgical team and who in addition make e-referrals into surgical care immediately a tumour is confirmed, streamlining the referral process. One main centre surgeon spoke of patients being on two pathways simultaneously; awaiting assessment by a specialist surgeon while at the same time getting all staging investigations completed quickly: "they are going along a couple of pathways at the same time, which can save time". The clinicians who worked within main centre DHBs also spoke of combining clinics, so that in the work up to surgery, patients see each
specialty needed in one day, greatly speeding up the time to surgery. They also often have access to a cancer nurse specialist who specialises in GI or upper GI cancers providing a more targeted care coordination and support.

In response to the findings of the quantitative phase that Māori were less likely to have a specialist upper GI surgeon perform their surgery a number of informants rationalised why this might be so, with geography often cited. The general view was that Māori are more likely to live in rural and remote areas that are not serviced by a specialist surgical service and thus Māori would be less likely to receive specialist surgical care. No informant was though able to articulate why Māori would be less likely to receive specialist surgical care within main centres, although one did state that this finding “smacks of racism”. Two of the medical clinicians also raised that they see a different approach to treatment decision making between Māori and non-Māori patients, with Māori going away and discussing treatment options with whānau before making a decision while non-Māori patients have said to have a more “individualistic approach”. This was offered as a reason for any possible longer timeframes in moving along the cancer treatment pathway for Māori compared to non-Māori.

A number of other issues were raised more generally in response to the differences in surgical management observed between Māori and non-Māori in phase one of this study including centralisation of services, maintaining a current pathway of care and individual surgical expertise. Centralisation of services (or concentrating services into fewer, larger, more specialised centres) was raised by both policy and clinical informants. Pros and cons were often weighed up as the informant spoke, with the general consensus that debate on centralising services still needs to happen in New Zealand. Increasing centralisation and specialisation could be useful in providing higher volumes of surgery and more specialised postsurgical care, although this would need to be balanced with the increased level of support that patients and whānau would need to access those services. As well the needs of smaller DHB’s, and clinicians working within these DHB’s, was highlighted as needing to be taken into consideration. One informant, a general surgeon who works within a smaller DHB,
outlined giving patients the choice of where to have surgery within one of four options. One, some patients are advised that they can be well managed within the smaller DHB. Two, more complex patients are advised that they would be better managed within a main centre DHB. Three, still other patients (albeit those with financial resource) are offered the choice to undertake surgical and medical oncology in Japan as in the surgeon’s opinion, Japan has the most current practice related to stomach cancer in the world. Finally, for a final group of patients the decision is left with the patient whereby patients are advised that they have a choice of treatment centre, and thus surgeon. The same surgeon cautioned, though, that the decision on surgical treatment centre is not solely about the surgeon and level of surgical expertise, but that other factors are important in the decision making process such as, the level of ICU care available, access to interventional radiology and support staff.

Individual surgical expertise and surgical quality were raised, although only by the surgeons spoken to (both general and specialist). In addition one policy informant highlighted the need for patients to be treated according to evidence-based and agreed protocols. The clinicians also cited a lack of DHB or government mandated protocols in allowing different standards of clinical practice throughout the country, although they urged that any future development of such protocols be clinically led. Caution was expressed by two of the upper GI surgeons to not assume that an upper GI surgeon is ‘better’ than a general surgeon. Rather the medical clinicians argued that clinical competence should be based on a number of factors such as level of training, level of experience, the level of surgical precision undertaken and engagement with peers and professional bodies: "a person who’s been through a two-year fellowship program under the auspices of ANZGOSA, who are submitting their cases to the binational registry, who attend the meetings and interface with people who are talking about their approaches ... who are participating, are highly likely to be doing better surgery". When asked what else might need to change in the stomach cancer treatment pathway in the future one clinician spoke of "credentialing of surgeons for complex cancer surgery ... a critical look at the regionalisation issue, where these cancers should be cared for ... providing more upskilling opportunities for local surgeons through joining regional MDM and operating alongside a specialist
surgeon on more complex cases”. The general consensus observed was that the working model most likely to gain sector support was one of specialist surgical support of generalist surgical practice. This model would enable the provision of surgical care wherever the patient and whānau were best suited to receive that care and help to ensure that all centres have a well-trained well-supported surgical workforce.

Medical Oncology Treatment

Eight clinicians and four policy informants specifically discussed medical oncology. Of these, seven identified the MDM as the key referral mechanism for patients accessing medical oncology, with the view that the majority of patients with stomach cancer are discussed at an organised MDM and referrals set in place. As with accessing surgical treatment, key informants highlighted that the access to medical oncology appears to work well for patients living close to main cancer centres but can be problematic for patients living within smaller DHB areas or rural: “not all places have an easy relationship to facilitate those patients going for chemotherapy, bearing in mind that chemotherapy can be quite prolonged and often quite demanding”. Clinicians in smaller centres spoke of delays between the MDM and receipt of medical oncology referral, slowing the journey for the patient: “it is a bit person dependent at the moment, but it shouldn’t be. It should be process dependent”. In contrast a main centre clinician spoke of a recent initiative whereby the MDM template, which is filled in electronically directly after the meeting, itself is sufficient for referral to medical oncology, speeding up the referral process.

One clinician felt that increasing specialisation in the medical oncology workforce over the last decades has been beneficial, at least to the surgical workforce, with surgeons needing to ‘interface’ with fewer oncologists but ones with more specialist knowledge of upper GI cancers. Each of the medical clinicians spoken with discussed the value of medical oncology within the overall treatment plan for stomach cancer, saying they prefer the patient to ‘at least’ discuss the options with a medical oncologist, although two clinicians did highlight that there is a need for clear clinical decision making criteria so that referral to medical oncology is consistent nation-wide.
Multi-Disciplinary Meetings

All 15 informants agreed that MDM meetings are an important part of the treatment pathway for people with a complex cancer such as stomach cancer. Although, as pointed out by one policy informant, “MDMs are essentially a very cost-rich environment, with all of those heads around the table for that period of time”. Informants disclosed that there is currently extensive work nationally aimed at maximising the functionality of the MDM, such as moving current Ministry of Health MDM guidelines into more prescriptive standards. There is also additional funding for DHBs to increase functioning of, and access to, the MDM which is being used to fund projects such as video conferencing and improved data collection. Informants in this study thought that this level of activity was consistent with MDMs being a very important resource in the stomach cancer treatment pathway.

Despite this extra funding, and its anticipated improvements in the future, currently MDM functioning and access varies around the country. Again smaller DHBs are limited in their capacity to support MDMs within their own DHB, often needing to access MDMs from outside their region which can delay decision making and thus the patient’s journey. As highlighted by a nurse clinician at a smaller DHB, “at the moment if you’re not physically at the meeting you don’t always find out straightaway, or as quickly as I’d like, the plan for the patient … one day we were both away and we just didn’t find out for a week what had actually been discussed”. It appeared that mechanisms for prompt feedback were lacking. In comparison a medical clinician at a smaller DHB spoke of having an on-going collegial relationship with a specialist surgeon within a larger DHB who would “take patients forward” to the main centre upper GI MDM on his behalf and who would call soon after the MDM with the decisions, followed by the appropriate paperwork. In this case decisions could be acted upon immediately by the smaller DHB. It appears that communication into and out of MDM can be ‘relationship dependent’ rather than ‘process dependent’.

Seven clinical informants stated that all patients with stomach cancer would be seen and discussed within an MDM, while four policy and two clinical informants stated
that some patients would not be discussed within an MDM. The main reasons for not discussing patients were acute and/or advanced diagnosis, whereby a patient was placed directly on the palliative care pathway. According to informants, comorbidity is generally considered within the MDM in the context of risk reduction; however ethnicity is not generally considered or discussed within the MDM setting. There was though some agreement to actually consider ethnicity, if not directly within the MDM discussion, then in MDM monitoring and reporting by ethnicity. Improved ethnicity reporting by MDM was seen as one method to improve equity. As a policy-based informant stated “you know, the only way to address these problems is by getting transparency. If you don't know the problem exists, you can't really address it”. The fairly recent phenomenon of cancer nurse specialists attending MDMs was specifically mentioned by three medical clinicians within main centres as being a positive step towards better understanding the social context of patients.

“I've actually found them good, because what we’ve missed at our MDMs is the where's the family at, where's the person at kind of information ... it'd be nice if the GP could come along, but you see they can't. And so those coordinators are now starting to tell us those things. Like, 'Well yeah, you wanted to see them this week, but they'd actually prefer to be seen next week, because then their husband will be back from Perth, where he's working in the mines. So then he can come too'. Those sorts of really practical things”.

**Palliative Care**

Questions were not specifically asked about palliative care however two clinicians raised the importance of focusing on palliative care for a group of patients with a disease of poor prognosis such as stomach cancer:

“And I think the other huge area that will make a massive difference is to do with our palliative care. Because so many of
our patients ... are going to end up in a palliative situation, if you want to make the biggest difference to the greatest number of patients and their quality of life ... we have to focus on them, almost a little more than the patients we can potentially cure”.

Palliative care access was specifically mentioned by one clinician while discussing the pros and cons of centralisation of surgical care, with the argument being that palliative care (in all its forms: palliative radiotherapy, palliative chemotherapy, stents and hospice support) should be widely available and accessible “because 50% of your patients are never even going to see the shiny inside of a brand spanking new hospital built just to care for those patients, because they’re never going to come to surgery”.

How to Improve the Treatment Pathway, especially for Māori

All informants provided answers on how the treatment pathway could be improved, especially for Māori. Six key themes were identified and are discussed below. These themes were standardisation of care, formalised relationships with shared care across DHBs, cancer workforce training and development, improving health literacy, accurate ethnicity data collection and reporting, and a stronger mandate around equity accountability and improving health outcomes for Māori.

Standardisation of Care

The general consensus was that standardisation of care across the country is important in improving outcomes for all patients, including Māori: “we’ve got to be very clear, and very robust, in what is the best clinical pathway for people, regardless of where they come from and what conditions they have .... And everybody deserves the right to have those options open, clearly explained, and they have the right to choose”.
The newly developed upper GI Service Provision Standards are seen a key mechanism that will help to standardise the delivery of care for all patients with stomach cancer, and in the process will improve that care for Māori. Informants were clear that these standards are aiming to establish the minimum level of infrastructure needed by DHBs to meet a minimum standard of care and to set the required outcomes of that care. They are not guidelines for care, clinical protocols nor the gold standard pathway for people with stomach cancer. The development of the Service Provision Standards are however seen as an important first step in the standardisation of care, the second step being the review process currently being undertaken whereby cancer services within DHBs are being reviewed according to how they currently meet or don't meet those standards. Standardisation is seen as important for equity for Māori: “but particularly with equity issues for Māori and particularly for stomach cancers ... if we can improve the overall standards that will bring everyone up”. In addition, the consistent use of established tools throughout the country was seen as important. Currently informants believed that tools such as the HEAT tool, whānau ora assessments and the distress tool and problem checklist (which enables structured assessments at cancer diagnosis, cancer discharge and other key points of the patient journey) were being used by some centres but not others. It was informants’ view that consistent use of these tools would help to standardise care across the country.

Formalised Relationships with Shared Care

It is also hoped that through the processes of developing and reviewing the Service Provision Standards more formalised relationships and shared care across DHBs will occur. This was both in the context of smaller DHBs being able to formally contract other larger DHBs to meet gaps in service delivery, for example PET scanning, and in the context of workforce training and development: "Particularly smaller hospitals, rural hospitals they [the Service Provision Standards] will encourage them and larger hospitals to form mutually beneficial relationships for their patients. Not just smaller hospitals sending people off for surgery, but actually truly shared care". Again this was seen as important for improving the standard care for all New Zealanders, but
especially for Māori as it was noted that Māori were more likely to be treated within a smaller hospital.

**Workforce Development**

Developing the cancer workforce’s knowledge of inequity and the underlying determinants of health was put forward as important by a number of informants. As noted by a policy participant: “The other thing we are really interested in for a more long-term perspective is the workforce development, or the training, with our clinicians” and by a nurse clinical participant: “I think from my perspective improving the knowledge of health professionals about what ethnicity means” Workforce development included developing clinical champions who could lead discussion and challenge clinician behaviour.

**Health Literacy**

Improvements to health literacy were also put forward as important by a number of informants. Improved health literacy was always discussed as a health system issue, so that patients and whānau are better enabled to understand and participate in decision making throughout their cancer journey:

... then once someone is in the system, the issues of health literacy, both from a personal perspective but also from the perspective of the health service and its provision to support people to understand their journey or appropriately make decisions that support that journey, is a concern to me.”

Specific health literacy interventions discussed by participants included:

- Use of the Ministry of Health’s newly developed organisational health literacy framework and guide (Ministry of Health, 2015c; Ministry of Health, 2015b).
- Clinician training with increased understanding of their responsibility in effective communication with patients and whānau.
QUALITATIVE RESULTS: HEALTH PROFESSIONALS’ PERSPECTIVES

- The development of decision-making tools for patients and whānau.
- Reviewing relevant resources from a health literacy viewpoint – e.g. Cancer Society resources.

Ethnicity Data and Reporting

Accurate data collection and reporting by ethnicity was also seen as important for Māori with a number of informants highlighting the importance of transparency of issues that can be seen with accurate data: "the big one is getting good data, so you can actually audit pathways ... There’s so many different data sources that having good consistent data is a challenge, and is only then that we can actually look to see where the inequities are and start working through those". In relation to this quote one informant suggested there was a need for a national-level ethnicity data role to lead the programme of work that would be needed in order to enable good monitoring for equity on all cancer related indicators.

Accountability for Equity

Finally a stronger mandate around equity accountability and improving health outcomes for Māori were seen as important by a number of informants: "I want to see a stronger commitment from government through to DHB, and how they devolve funds to providers, written all through the pathway, and commitment to measuring, reporting and being accountable for improving equity".

How to Improve Specific Points of the Treatment Pathway

In addition to the interventions within the themes above a number of interventions at each step of the stomach cancer treatment pathway were put forward by informants. These interventions are briefly highlighted below.
Early Detection

Early detection interventions were identified focussing on three areas: a national early detection programme, improved access to endoscopy and standardising care nationally.

- A national early detection programme as is currently being developed for lung cancer in NZ comprised targeted community awareness raising of signs and symptoms, raising awareness within primary health care of signs and symptoms and referral pathways, and, streamlining of referral pathways into endoscopy services

- Specific interventions to improve access to endoscopy services, included electronic referrals, an algorithm and checklist that prioritised Māori and assigning a red flag once a patient is prioritised

- Standardising care nationally was seen as important through interventions such as:
  - Strengthening early detection within the current upper GI Service Provision Standards (i.e. Standards 1 – 4) during their upcoming review and rewrite process and passing any improvements through the upper GI tumour standards working group.
  - Improving access to diagnostic and staging investigations within smaller DHBs.
  - Demystifying the diagnostic and staging journey for all patients.

Surgical Management

Three interventions highlighted as important at this point of the treatment pathway were all focussed on patients living remotely or inter-DHB referrals. The interventions were:
QUALITATIVE RESULTS: HEALTH PROFESSIONALS’ PERSPECTIVES

- Combining clinics so complex patients and those living remotely can be seen at one time or on one day and increased use of telehealth clinics to decrease travel for patients living remotely.
- Undertaking a comparative review across two different DHBs (smaller and main centre) to investigate referral pathways, triage processes, patient flows, timeliness and care coordination to determine any differences between DHBs.
- Requiring that all DHBs involved in the surgical resection of stomach cancer appoint a cancer nurse specialist to coordinate care within and across DHBs.

Medical Oncology and Multi-Disciplinary Meetings

Two key areas of improvement were put forward by informants to improve MDMs which informants believe to be the primary mechanism for referral to medical oncology.

Again standardisation of MDM was seen as important to ensure equity of access for all patients. Specifically informants suggested developing firm criteria on who is discussed at MDM, making consideration of ethnicity and comorbidity more explicit in MDM and the upskilling of MDM members in the impacts of ethnicity and comorbidity on cancer treatment and survival. Informants also identified ethnicity data collection and monitoring of MDM as important. As a minimum all MDM should record ethnicity of all patients discussed, they could also undertake a regular equity audit or review to investigate whether any differences in timelines and service access by ethnicity are present.

Patients with Comorbidity

The interventions put forward as important by informants to improve services for those with comorbidity were:

- Developing the cancer workforce’s knowledge of comorbidity and its impacts on clinical decision making and outcomes.
• Ensuring that cancer nurse specialists have the ability to effectively work with comorbid patients by explicitly including comorbidity in contracts, job descriptions and reporting systems.

• Extending, or developing new, cancer nurse specialist roles that include upper GI cancers was seen as important for a group of patients that are likely to be highly comorbid and thus experience a complex cancer journey.

Mandelblatt: A Framework to Consider Interventions

The interventions within the six themes particular to Māori, along with the key issues and interventions put forward by informants at each step of the stomach cancer treatment pathway, are now summarised according to Mandelblatt et al’s (Mandelblatt et al., 1999) levels of barriers to access to cancer services; health care system, health care process and patient levels. The key findings are presented in Table 39.
### Table 39: Interventions identified by key informants according to the framework of barriers to access; Mandelblatt et al

<table>
<thead>
<tr>
<th>Framework Level</th>
<th>Issue identified</th>
<th>Interventions suggested by key informants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health System Level</td>
<td>Mono-cultural Focus</td>
<td>Stronger mandate for equity accountability and improving health outcomes for Māori</td>
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<tr>
<td></td>
<td></td>
<td>Develop a national-level ethnicity data role</td>
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<td></td>
<td>Develop clinical champions for equity</td>
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<td></td>
<td></td>
<td>Accurate data collection and reporting by ethnicity</td>
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<td></td>
<td></td>
<td>Accommodate a more holistic approach which encompasses whānau</td>
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<td></td>
<td></td>
<td>Improve the cultural friendliness and approachability of services</td>
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<tr>
<td>Fundings, Resourcing, Location and Inconsistent Delivery of Cancer Services</td>
<td></td>
<td>Combine clinics and increase use of tele-clinics</td>
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<td></td>
<td></td>
<td>Formalise shared care across DHBs across the stomach cancer pathway, but especially focussed on surgical management</td>
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<td></td>
<td></td>
<td>All DHBs involved in surgical resection of stomach cancer have a cancer nurse specialist to coordinate care within and across DHBs</td>
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<tr>
<td></td>
<td></td>
<td>Implementation and quality review processes of the upper GI service provision standards</td>
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<td></td>
<td></td>
<td>Standardise clinical pathways, develop evidence based protocols and clear clinical decision-making criteria</td>
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<td></td>
<td></td>
<td>Standardise early detection and diagnostic services nationally</td>
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<td></td>
<td></td>
<td>Standardise MDM including process-dependent feedback loops and MDM monitoring for equity</td>
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<tr>
<td>Health Care Process- Level</td>
<td>Communication between Services</td>
<td>Patient navigation or care coordination for all patients with stomach cancer</td>
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<tr>
<td></td>
<td></td>
<td>Include upper GI and comorbidity in cancer nurse specialist roles</td>
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<tr>
<td></td>
<td></td>
<td>All DHBs involved in surgical resection of stomach cancer have a cancer nurse specialist to coordinate care within and across DHBs</td>
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<tr>
<td></td>
<td></td>
<td>Undertake comparative clinical review or audit across different DHBs - Investigate referral pathways, triage processes, patient flows, timeliness and care coordination</td>
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<td></td>
<td></td>
<td>Consistent use of established tools, including discharge tools</td>
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<td><strong>Patient – Provider Communication</strong></td>
<td><strong>Develop the cancer workforce’s knowledge and increase understanding of their responsibility in effective communication with patients and whānau</strong></td>
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<tr>
<td><strong>Provider Bias</strong></td>
<td><strong>Develop the cancer workforce’s knowledge of inequity and the underlying determinants of health</strong></td>
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<tr>
<td></td>
<td><strong>Clear clinical criteria and consistent use of established tools</strong></td>
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<tr>
<td><strong>Cancer Workforce</strong></td>
<td><strong>Commitment to employing Māori within the cancer sector</strong></td>
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<tr>
<td><strong>Health Literacy - the health care system supporting people to understand their stomach cancer journey</strong></td>
<td><strong>Use MOH organisational health literacy framework and guide</strong></td>
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<td></td>
<td><strong>Review relevant resources from a health literacy viewpoint</strong></td>
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<td></td>
<td><strong>Develop decision-making tools for patients and whānau</strong></td>
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<tr>
<td><strong>Patient- Level</strong></td>
<td><strong>Patient Preference/ Choice</strong></td>
<td><strong>Accommodate a more holistic approach which encompasses whānau</strong></td>
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<tr>
<td><strong>Patient Comorbidity</strong></td>
<td><strong>Explicitly include comorbidity in cancer nurse specialist roles</strong></td>
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<td></td>
<td><strong>Include impacts of comorbidity in workforce development of the cancer sector</strong></td>
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<tr>
<td></td>
<td><strong>Combine clinics, especially for complex patients, and increase use of telehealth clinics</strong></td>
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The complex and multilevel nature of access to, and through, cancer services are highlighted by these findings along with the subsequent need for a broad range of activities or interventions to improve that access. Importantly key informants spoken to largely discussed structural issues and identified systems or process level solutions. They generally did not expect the people, Māori or their whānau, to change in order to get better quality care for stomach cancer. Health literacy provides a good example of this, whereby this could have been framed as the need to improve the health literacy of people. However whenever key informants discussed health literacy it was framed as a health system responsibility to enable patients and their whānau to better understand their journey with stomach cancer and be better equipped for effective decision-making along that journey. The fact that most key informants recognised higher level structural reasons for, and solutions to, inequity is heartening.

Summary of Qualitative Results

Fifteen health professionals were interviewed in this study with the majority stating that overall the health-care system works well for people with stomach cancer in New Zealand.

Informants agreed that the stomach cancer treatment pathway has improved immensely over the five years preceding the interviews, with a lot of activity noted nationally and regionally. Still informants agreed that there was much more that could be done to improve the pathway and quality of care along that pathway. The main issue, which was highlighted by over half of the key informants, was that the delivery of cancer services is not consistent around the country. Patients within smaller DHBs appeared to be impacted to greater levels with lesser access to diagnostic and specialist services, lesser access to multi-disciplinary decision making through the MDM process and longer timeframes through the pathway. Some informants also noted that this inconsistency impacted more on Māori, as Māori more often reside rurally and receive their care within smaller centres.
Six key themes were identified to improve the pathway for all New Zealanders, but especially for Māori: standardisation of care, formalised relationships with shared care across DHBs, cancer workforce training and development, improving health literacy, accurate ethnicity data collection and reporting, and a stronger mandate around equity accountability and improving health outcomes for Māori. It was also thought that the Upper GI Service Provision Standards would improve consistency of service delivery nationally and should impact on equity for Māori in the future. As well a number of interventions were put forward by informants at each step of the stomach cancer treatment pathway. These interventions align to Mandelblatt’s levels of barriers to access to cancer services with the majority of interventions put forward focussed on health system or health care process changes.
Chapter 8: Discussion

This study found both similarities and differences in the presentation, treatment and management of Māori and non-Māori patients with stomach cancer. There were no substantial differences in cancer stage, or grade, at diagnosis and no major differences in proportions of Māori and non-Māori patients who received curative treatments. However, Māori were less likely than non-Māori to have surgery performed by a specialist upper gastrointestinal surgeon or in a main centre. A 30% excess mortality among Māori patients was unexplained by a number of factors, although the study was underpowered to confirm this.

A qualitative phase based on interviews with health professionals, helped to make sense of, and largely supported, the quantitative results. The main finding was that the delivery of cancer services is not consistent around the country; this point was especially relevant for smaller, less well-resourced DHBs and impacted more on Māori patients and those with comorbidity. The qualitative phase also helped to identify interventions that could improve access to, and quality of, stomach cancer services for all New Zealanders but especially for Māori.

This chapter outlines the strengths and weakness of this study and discusses and interprets key findings in relation to existing knowledge on Māori/non-Māori inequity in cancer care. It also makes suggestions and recommendations on interventions to address differential quality of cancer care for New Zealand Māori. It acknowledges that achieving equitable care for Māori will require a variety of interventions along the stomach cancer pathway that combine health system level, health care process level and patient level factors.
Summary of the Study Results

This study made some important observations. Key findings are highlighted below.

Summary of Quantitative Study Results

There were both similarities and differences in the presentation, treatment and survival of stomach cancer for Māori when compared with non-Māori patients in New Zealand.

Presentation

There were no significant differences between Māori and non-Māori in cancer grade or stage at diagnosis. Māori presented with a higher proportion of distally located tumours (43% Māori vs 26% non-Māori, p = <0.05) and non-Māori with a higher proportion of proximally located tumours (25% Māori vs 34% non-Māori, p = <0.05).

Overall 70% of patients had comorbidity, although Māori appeared more likely to have multi-morbidity than non-Māori. A strong deprivation gradient was observed which was more pronounced for Māori (59% of Māori lived within the most deprived quintile vs 29% non-Māori, p=0.01). More Māori than non-Māori lived rurally (16% Māori vs 7% non-Māori, p=0.02).

Treatment and Management

Of stage I–III patients, the proportions of patients that received definitive surgery were similar. Māori appeared more likely to undergo a partial gastrectomy (59% Māori vs 49% non-Māori, p=0.14). Non-Māori appeared more likely to undergo total gastrectomy or Ivor-Lewis oesophagectomy (37% Māori vs 48% non-Māori, p=0.14).
DISCUSSION

Notably, Māori were less likely to have their surgery performed in a main centre (43% Māori vs 83% non-Māori, p<0.01) or have surgery performed by a specialist upper gastrointestinal surgeon (38% Māori vs 79% non-Māori patients, p<0.01). It appears that even when Māori had surgery within a main centre they were 73% less likely than non-Māori to have that surgery performed by a specialist surgeon once age, stage and tumour site were taken into account. Post-operative complications and node harvest both appeared similar between the two groups.

Timeliness through the treatment pathway was similar between the two groups although Māori patients appeared to wait on average 13 days longer between diagnosis and surgery than non-Māori (median 47 days Māori vs 35 days non-Māori, p=0.65). Proportions of patients that received chemotherapy were similar.

Survival

Of the total cohort 78% died during follow-up with the majority of deaths due to stomach cancer. Survival disparities between Māori and non-Māori were unexplained by patient, disease, comorbidity and health care access factors, although the study was underpowered to statistically confirm a 30% excess mortality among Māori (HR 1.30; 95% CI, 0.96 – 1.76).

Summary of Qualitative Study Results

The qualitative phase helped to make practical sense of the quantitative findings, identified what health professionals saw as issues in the management of stomach cancer and considered how to intervene to improve access to, and quality of, stomach cancer treatment services.

The Identification of Key Issues

There was a general view from informants that, once diagnosed, most patients proceed through the treatment pathway relatively quickly and are well linked with the
appropriate clinical and support services. However through the interview process it became apparent that the delivery of cancer services was not consistent around the country. This point was especially relevant for smaller and less well-resourced DHBs.

All informants identified issues particular to Māori, these included the mono-cultural focus of New Zealand’s health care services, along with issues related to rurality and health literacy. Comorbidity was thought to further increase the complexity of stomach cancer care and impact both on timeliness through the treatment pathway and clinical decision-making.

**The Identification of Interventions**

A number of interventions were identified at health system, health care process and patient levels. Of note, a number of informants specifically mentioned the ability of the Service Provision Standards to improve the stomach cancer treatment pathway for all New Zealanders as well as impact on equity for Māori in the future. The standards and other specific interventions are discussed later in this chapter.

**Reflections on the Note Review Data Collection Process**

The use of a research diary allowed critical reflection on the note review process and data gathered, importantly, the diary was summarised before either the quantitative or qualitative findings were generated. The complexity of some patient journeys was apparent, with multiple providers, delays across DHBs and different resources available to different DHBs impacting on the patient journey. The opportunity for patients and whānau to ‘slip through the gaps’ was highlighted. In addition, the impact of comorbidity on clinical decision making and patient pathways was evident. These issues seemed more prevalent among Māori or within DHBs with high Māori populations. The impact of geographical isolation on health professionals, in terms of professional isolation, was also apparent.
Strengths and Limitations of the Study

The validity of any research depends on having the appropriate study design, implementation, and analysis in order to answer the research questions. The research question type and thus study design, activities and analysis differ between quantitative and qualitative research, as do the likely strengths and limitations of each of these research approaches. Thus this section discusses the strengths and limitations of the quantitative and qualitative phases of this study separately. However, three key strengths of the study overall are first identified and discussed, followed by the strengths and limitations of the quantitative phase and then the strengths and limitations of the qualitative phase.

Strengths of the Study Overall

There were three key strengths of this study overall. Firstly this study used a sequential mixed method study design, a quantitative phase followed by a qualitative phase with each phase used to answer related but different research questions. Sequential methods are especially useful when the results from one method help to inform the other method (Creswell, 2003). In the case of this study the quantitative phase was used to audit the stomach cancer pathway in New Zealand. This included determining patient characteristics at presentation, along with treatment, management and survival and whether any of these differed between Māori and non-Māori. The qualitative phase then used data from key informant interviews with health professionals to explore their views on issues for Māori and possible interventions or solutions focussed on those points of the treatment pathway that the quantitative data suggested were inequitable. Qualitative methods of inquiry are said to be especially relevant in health-related research as they can provide insight into health professionals’ perceptions and help to identify barriers to changing healthcare practice (Al-Busaidi, 2008). Qualitative research is also said to be suitable for intervention development and can be useful to policymakers as it describes the
settings in which policies (or interventions) will be implemented (Anderson, 2010). Importantly the qualitative findings supported those of the quantitative phase, namely that the key informants on the whole believe that there are issues that are likely to impact more substantially on Māori with stomach cancer in New Zealand, with a key issue being geographical differences in the treatment and management of people with stomach cancer.

Secondly the study used an analytic framework, that of Mandelblatt et al (Mandelblatt et al., 1999), which allowed the thesis and its recommendations to focus on structural barriers, those at the health system and health care process levels. Just as behaviour that poses health risk can be seen as ‘the problem’ and thus changing one’s lifestyle is seen as ‘the solution’ to decrease disease risk or incidence, so too solutions to improving health care access can be focussed on requiring an individual (or group of individuals) to change their behaviour in order to gain ‘better’ health care (Robson and Harris, 2007a). All researchers should strive to minimise harm to those being researched. This point is even more salient when non-indigenous researchers are studying issues concerning indigenous peoples. Special care must be taken so that the research does not reinforce patterns of colonisation and power imbalances between the researcher and the researched. (Smith, 1990; Smith, 1999) Thus this thesis explicitly chooses not to focus on ‘Māori’ as the problem but rather the health care system itself. Institutionalised racism within the health system is seen as the predominant problem and thus the health system is looked at to provide the solution to equitable access to, and outcomes from, New Zealand’s stomach cancer treatment pathway. Put simply, the explicit rejection of victim blaming ideology is a significant strength of this study.

The third strength of this study overall is that in keeping with a principle of Māori centred research, the thesis moves beyond merely outlining a problem and looks for answers (Cram et al., 2003; Barnes, 2000; Smith, 1999). The thesis sets out to create positive change which will improve the stomach cancer treatment pathway for all New Zealanders, but especially indigenous Māori – who currently experience a greatly increased incidence and poorer survival outcomes from stomach cancer in New
Zealand. This final strength is especially important as, while the study has been primarily undertaken by a Pakeha researcher, it involves Māori patients and data and it tackles an area of great importance to Māori, stomach cancer.

**Strengths of the Quantitative Phase of the Study**

The quantitative phase of this study had a number of important strengths. Its primary strength is that the study is based on rich clinical data collected through manual review of patient medical notes. In addition, this study had a sample that was nationally representative of stomach cancer patients in New Zealand and had equal numbers of Māori and non-Māori giving the study equal explanatory power between the two ethnic groups. Key strengths are further discussed below.

**Good Data Gained From a Manual Clinical Notes Review**

The primary strength of this study is that it is based on a full clinical notes review, which allowed for the collection of comprehensive presentation, treatment and management data on all eligible patients and to conduct a detailed comparison between Māori and non-Māori patients.

The manual review of individual patient files was the most time intensive and costly part of this study however it added great value to the study. The data gathered provided more detailed information than that routinely available from administrative databases. In addition, in depth review of medical notes in a variety of hospitals allowed good understanding of the strengths and limitations of the data, facilitated the visualisation of the patient journey as a whole and provided insight into the context of the delivery of cancer care in the many different facilities of New Zealand.

The most important variables able to be collected through the note review were accurate staging data, accurate data on patient comorbidity and detailed treatment data.
The note review allowed accurate staging of patients diagnosed with stomach cancer in New Zealand within the study timeframes. The New Zealand Cancer Registry (NZCR) uses pathology reporting as the primary source of extent of disease staging and so stomach cancer, which is often staged clinically, for example by CT Scan, only has around 60% complete extent of disease data on the NZCR (Gurney et al., 2013b). Importantly, while the NZCR reported 101 patients within this studies’ cohort as unstaged, we were able to determine stage at diagnosis for all but five patients and thus include this important treatment and prognostic factor in our analysis. Only one previous study on stomach cancer in New Zealand has assessed clinical staging data through clinical notes review. That study was a small study of patients at one health care facility (Biggar et al., 2011). In comparison this study comprised a much larger and nationally representative sample.

Review of medical notes also allowed a comprehensive assessment of patient factors, especially comorbid conditions present at time of diagnosis. Many studies of cancer survival depend on national administrative data to identify comorbid conditions. National administrative data may provide incomplete data on comorbidity as these are derived from clinical coders review of patient discharge summaries or medical notes (Soo et al., 2014; Heng et al., 2011; Sarfati et al., 2010a). Careful review of patient medical notes by a trained oncology nurse, as was carried out in this study, is likely to provide more detailed and accurate assessment of comorbidity relevant to the patients’ cancer diagnosis.

The manual review of clinical notes provided the study with detailed data on the treatment and management of patients. National administrative treatment data is shown to undercount receipt of surgery by 13-19% and receipt of chemo- or radiotherapy for cancer patients by 18% and 16% respectively (Gurney et al., 2013a). Collection of data through the clinical note review thus allowed an accurate comparison of the treatment and management of Māori and non-Māori patients throughout the entire treatment pathway.

The manual and in-depth review of medical notes in a variety of hospitals in the North Island of New Zealand had a number of other benefits, key of which was a better
understanding of each patient’s journey as a whole and of the context of cancer care in New Zealand. These benefits were strengthened by the use of a reflective diary which allowed for critical reflection on the note review process, the data gathered and the implications of the data.

**Nationally Representative Sample**

A second key strength of this study is that it comprises a sample that is nationally representative of all patients with stomach cancer in New Zealand. As seen in Chapter 6: Quantitative Results, the final cohort of this study reflects the structure of all patients with stomach cancer in terms of a number of key variables: gender, age, extent of disease, deprivation and rurality. This representativeness was achieved through the inclusion of all Māori patients diagnosed during the study period, except the 5% living with the South Island of New Zealand, along with a randomly selected equal sample of non-Māori patients. As a retrospective cohort study based on clinical note review and national administrative mortality data, once the final cohort was determined no patients were lost to follow up reducing the likelihood of selection bias.

**Equal Explanatory Power**

The inclusion of all Māori along with an equal randomly selected sample of non-Māori means this study has equal explanatory power for Māori and non-Māori (Te Rōpū Rangahau Hauora a Eru Pomare, 2002). Studies with equal explanatory power are able to produce results that have the same precision, or power, for Māori as for non-Māori. This is especially important in equity-based health research. As Māori only comprise 15% of New Zealand’s population a random sample of all New Zealanders would not allow equal depth of information to be produced for both ethnic groups – instead the evidence would favour the numerically dominant. If the research then informs policy or interventions, as is the intent of this study, the needs of non-Māori would again be privileged over those of Māori.
The Treaty of Waitangi provides a rights-based argument for undertaking research involving Māori that is of equal quality as that involving non-Māori; having adequate Māori sample size is then an essential requirement for reporting data in a way that recognises the rights and needs of Māori, rather than those needs being subsumed by those of the non-Māori New Zealand population (Te Rōpū Rangahau Hauora a Eru Pomare, 2002). As noted by Robson and Reid (Robson and Reid, 2001), “the full expression of tino rangatiratanga positions Māori statistical needs as being equally as valid as those of the total population and challenges the Crown to meet those needs as part of its Treaty obligations”.

Limitations of the Quantitative Phase of the Study

The quantitative phase of this study also had a number of limitations, the most important of which is its small sample size and thus limited power to determine some findings. Despite the considerable resource used to undertake a manual review of patient medical notes, data remained missing from some key variables and these were either not used in analyses, were analysed with a missing category or were analysed using imputed data. Another limitation was the potential for misclassification bias, of both the exposure (ethnicity) and outcome (survival or mortality).

Small Sample Size and Limited Power

With 335 patients within the final sample this study had limited power, meaning some of the findings were unable to be estimated with precision, small differences may have been difficult to detect with any certainty and it may have been difficult to identify if some differences actually exist.

The small numbers in this study in part reflects New Zealand’s small population size including the size of the indigenous Māori population. Stomach cancer, while more prevalent in Māori, is a relatively rare disease with less than 400 people diagnosed in
DISCUSSION

New Zealand each year, of whom around 60 are Māori (New Zealand Health Information Service, 2010; New Zealand Health Information Service, 2011).

This current study is part of a larger study (C3 or Cancer, Care and Comorbidity). A full clinical note review was undertaken concurrently for the three cancers within the C3 study with poor staging data: primary liver, rectal and stomach cancers. Initially this study was designed to collect data of people diagnosed over a two-year period. In order to increase the sample and power of the study data of people diagnosed over a three year period were used. Resource constraints meant the sample size could not be increased further.

Firm conclusions were further limited as 46% of patients, i.e. those with stage IV disease at diagnosis, were excluded from some analyses, including the treatment analyses. Limited power caused a lack of precision in effect measure estimates. However importantly while the findings are based on relatively small numbers they are consistent with other research showing disparities in care and outcomes for Māori with cancer.

Missing Data

Complete data for some key variables was unable to be collected. Data on patient characteristics were complete except complete data on patient smoking status was unable to be obtained. This variable was not included in analyses. It is well evidenced that Māori have higher rates of smoking (The Quit Group and the Ministry of Health, 2009; Ministry of Health, 2008) thus it is more likely that Māori patients within this study, compared to the non-Māori patients, were current or ex-smokers. Patient smoking status largely impacts on prognosis indirectly through the impact of smoking on increased comorbidity. It is possible that some of the probable excess morbidity seen within the Māori cohort is explained by higher rates of smoking; however comorbidity was adjusted for within survival analyses and so it is likely that any effect of higher rates of smoking was ameliorated through this.
The disease characteristic variables, stage, grade and tumour site, all had missing data. Stage at diagnosis was the most critical variable to the study with data missing for five non-Māori patients (2%) once all data were collected. This has already been discussed above. However, complete data on the key tumour variables of grade (40% missing overall) and site (35% missing overall) were also unable to be obtained. Māori were more likely to have missing grade data (48% Māori vs 37% non-Māori missing) and less likely to have missing site data (26% Māori vs 36% non-Māori missing). These variables impact on patient prognosis directly though disease effects. Both of these variables were analysed with a missing category. Given the importance that tumour site plays in patient prognosis (McLoughlin, 2004; Abrams and Wang, 2010), it was decided to impute the missing data. The imputation process has been explained in Chapter 5: Methods. Imputed tumour site was then used within survival analyses and was shown to be an important independent prognostic factor within this study.

Data on histological subtype, diffuse or intestinal, were not collected. These data were not always available within the patient notes and currently the NZCR data on histological subtype includes a high percentage of missing or NOS (not otherwise specified) data preventing further investigation of these findings in a larger cohort of patients diagnosed with stomach cancer. Māori have been shown to be more likely to present with diffuse stomach cancer which is thought to negatively impact on prognosis (Biggar et al., 2011; Blair et al., 2012). It is possible that the poorer survival of Māori is partially accounted for by this; however the impact of not including this variable is difficult to ascertain.

Health care access variables, deprivation and rurality, were missing data for 12 patients or 4% of patients overall (n=7 Māori vs n=5 non-Māori missing). These data were imputed, as explained in Chapter 5: Methods, and used within survival analyses.

**Misclassification Bias**

This study used national administrative databases to identify a number of key characteristics of patients and it is possible that misclassification bias was introduced
in either the exposure (ethnicity) or the outcome (survival). Additionally it is possible that misclassification of clinical data gathered through medical note review could have occurred.

Ethnicity for patients in this study was assigned on the basis of NZCR ethnicity data which uses an ‘ever-Māori’ approach. In this approach patients are classified as being Māori if they have identified as Māori on any previous health record. Māori ethnicity has historically been under-counted in health service databases (Robson et al., 2006; Robson et al., 2010; Robson and Purdie, 2007b; Swan et al., 2006), although there is some evidence that this is of smaller magnitude than it once was (Rumball-Smith and Sarfati, 2011). Because of this it is possible that some Māori with stomach cancer were missed during the study selection process and that these patients differ from those that were included in some way (i.e. in patient, disease or health care access factors). Patient ethnicity was checked during the manual review of patient medical notes with no misclassifications noted. Additionally, assigning ethnicity using the ‘ever-Māori’ approach helped to minimize the known under-count of Māori (Robson et al., 2006; Robson et al., 2010). Furthermore, it has been shown empirically that using different methods of assigning ethnicity in a cohort study only results in a very slight variation in results (Simmonds, 2010) and this current study used the same method to assign ethnicity throughout. So while it is possible that ethnicity misclassification bias exists in this study, if present it is likely to be of minimal importance to the results.

This study used data from the National Mortality database to identify the outcome (survival) for patients in order to ascertain the relationship between ethnicity and survival. Misclassification of mortality data could impact estimates of the strength of this relationship in two ways; firstly the fact of death itself, and secondly the cause of death.

Misclassification of the fact of death is unlikely to be a major source of bias in this study. Survival was determined by linking the study cohort to the national mortality database which captures all deaths occurring in New Zealand. All study members who had a death record in this database were classified as having died, with the remainder
assumed to be alive at the end of follow-up. It is highly unlikely that living people would be classified as having died and so misclassification of fact of death would only occur if the patient had died outside of New Zealand. Each of the three patients who were excluded as being non-resident during the note review process (see Chapter 6: Quantitative Results), were in fact, diagnosed with stage IV disease and returned to their original country of residence. Thus these patients were identified and excluded during the clinical note review.

Misclassification of the cause of death can occur if stomach cancer deaths are classified as being due to other causes or if non-cancer deaths are classified as being due to stomach cancer. These forms of misclassification would only alter the hazard ratio if misclassification was different for one group. The three non-Māori study patients whose deaths were classified as malignant neoplasm of lower third of oesophagus (C155) on the National Mortality database but were assumed to have died of stomach cancer (and thus their death attributed to stomach cancer in this study) would have been unlikely to alter the hazard ratio significantly. In this study there was little difference in the proportions of deaths (either stomach cancer or other causes) between the Māori and non-Māori cohorts. It is unlikely that misclassification of cause of death was a major source of error in this study.

There is also potential for misclassification of clinical data gathered through medical note review, including disease factors, patient comorbidity and data related to patient management or treatment. Again these could be misclassified in two ways; firstly during the process of clinical assessment and the writing of medical notes, and secondly during the process of data extraction. As discussed above the collection of clinical data though manual review of patient medical notes was a key strength of this study and provided more robust clinical data than that available within national administrative databases. The potential for misclassification to occur during the second process, that of data extraction was ameliorated through the use of a standardised study proforma for the extraction of clinical data (See Appendix I: Study Proforma), with specific criteria used for key variables.


**Confounding, Mediating and Adjustment**

Treatment, management and survival in Māori and non-Māori patients were adjusted for a range of covariates, some of which are pure confounders and others mediators in the relationship between ethnicity and the outcome.

As discussed in Chapter 5: Methods, age and sex are considered ‘pure’ confounders in this study and all comparisons between the two ethnic groups were adjusted for these two confounders (including prevalence rates and hazard ratios). All other covariates adjusted for in Cox proportional hazards modelling (disease factors: stage at diagnosis and tumour site, patient comorbidity and health care access factors: deprivation and rurality) were considered potential mediators in the relationship between ethnicity and survival (see Figure 6 Direct Acyclic Graph in Chapter 5). In other words they are pathway factors in the causal chain between ethnicity and survival. Sequential adjustment for these factors was undertaken to assess their contribution to any survival disparity between Māori and non-Māori. Biased estimates of the contribution of these factors on survival may arise from misclassification (already discussed), from residual confounding or mediation or from the ordering of mediators in the sequential modelling.

Residual confounding or mediation occurs when a confounder (or mediator) has not been adequately adjusted for in analysis, for example by using poorly measured proxies. In this study age was fitted to the model as a continuous variable so it is unlikely that any residual confounding by age occurred, however residual confounding by comorbidity may have occurred. While review of medical notes is likely to have provided more accurate assessment of comorbidity relevant to the patients’ cancer diagnosis than that able to be gained through administrative databases, it is possible that residual confounding occurred through the imperfect measurement of comorbidity within this study.

The apparent contribution of the factors can also be changed by the ordering of mediators in the modelling. However, in this study the mediators in the sequential modelling were deliberately included in the order chosen to assess the effect of the
pure confounders first, followed by the factors existing at the point of presentation before assessing the impact of factors that lie within the jurisdiction of the health care system.

**Chance**

Finally, as with all research it is not possible to rule out the possibility of chance findings. As noted above, this study had limited power for some analyses causing lack of precision in some effect measure estimates. Limited power also caused an inability to examine outcomes for subgroups. As examples, the study was unable to determine if receipt of curative surgery, or the differences seen in surgical management of patients in this study, impacted on survival for those patients that were diagnosed with potentially curable disease (stage I - III) or to produce meaningful hazard ratio estimates stratified by stage.

It is also not possible to rule out the possibility of chance findings given the multiple numbers of comparisons. However, as the key statistically significant findings (such as Māori having higher levels of comorbidity, more distal cancers and less access to specialised care) are those where we had *a priori* expectation of finding differences, it is unlikely that these are chance findings.

Three further limitations of this study are 1) that 16 Māori diagnosed with stomach cancer and residing within the South island of New Zealand were not able to be included, although it is likely that the issues are similar to those highlighted in this thesis for Māori residing in the North Island of New Zealand 2) that the comparator groups are limited to Māori and non-Māori only; the inclusion of Pacific and Asian peoples, who also have high rates of stomach cancer, with the non-Māori group may have minimised the observed differences, and 2) that patients diagnosed with a gastrointestinal stromal tumour (GIST) are included within the study. Patients with GIST may have a slightly different treatment pathway and different prognosis than those with adenocarcinoma. However patients with GIST comprised only 2.7% of the
total cohort (n=9) and were evenly spread between Māori (N=4) and non-Māori (n=5), thus their inclusion in the study is unlikely to have impacted on the results.

**Strengths of the Qualitative Phase of the Study**

The qualitative study had a number of strengths. Processes were deliberately built into the qualitative phase of the study in order to enhance the trustworthiness of its findings. Such processes are recommended by qualitative researchers (Liamputtong, 2012; Padgett, 2011) and included: purposively selecting a range of informants based on their unique knowledge and taking a systematic, and well documented, approach to the collection and analysis of the data and decisions made during the research process. Additionally feedback was gained on the findings in a number of ways. Firstly emergent ideas were discussed with subsequent informants during the interview process. Secondly, discussions with supervisors with clarification of the findings happened regularly throughout the research process. Thirdly the data and its interpretation were tested through discussion with the groups advising the overarching C3 study and through presentation at specific meetings. Finally this phase of this study followed established research guidance, for example the interview schedule was developed collaboratively and trialled with potential informants before it was used in this study, all key informant interviews were digitally recorded and transcribed as well as field notes taken and consent was gained for all informants.

Another strength of the study was the diversity of the participant sample. It was the intent of this phase of the study to gain a range of views across three key factors of interest: indigeneity, health care professional role type and treatment centre type, thus informants were purposefully selected according to these factors. Using the snowball recruitment method worked well to gain a diversity of informants with in-depth understanding of the stomach cancer treatment pathway and issues for Māori, as informants recommended future informants to meet the maximum variation mix of informants. Importantly recruitment was discontinued once key names began to be repeated and no new names were suggested.
Additionally, key informants offered rich data. The interviews were based on a semi-structured interview schedule with open-ended questions so that informants could share their thoughts and perspectives as fully as possible, and could raise the issues that mattered most to them. As the informants were drawn from the relatively small New Zealand cancer sector, care was taken to ensure that they would feel comfortable speaking freely. As examples a commitment was made to maintain confidentiality and informants were offered the ability to approve direct quotes. Building these processes into the study allowed the informants to discuss, at times sensitive and potentially challenging, issues in depth providing information-rich data to support the quantitative phase of this study.

**Limitations of the Qualitative Phase of the Study**

The qualitative phase also had three key limitations. These relate to the size and diversity of the participant sample and possible biases introduced by the informants themselves or by myself as the researcher.

While the participant sample was diverse it is possible that a larger and more diverse sample would have offered different ideas. However, those interviewed were among the leaders involved in the delivery of care to patients with stomach cancer, at both policy and clinical levels. Thus the findings likely reflect the current situation of stomach cancer care delivery within New Zealand. Also the purpose of these interviews was to determine what key people see as the issues impacting on Māori within the pathway, to present the findings of the quantitative phase and seek expert advice on them and to explore possible interventions to improve the pathway. That the qualitative findings support the quantitative findings (as do my reflections on gathering the quantitative data) is reassuring.

It is possible that bias was introduced to the findings by the informants themselves. Purposefully selected key informants, while able to give information-rich data, may be more likely to express 'politically acceptable' views, or not criticise the system in which they are employed, than people who are not in a key position within the system.
DISCUSSION

Alternatively purposefully selected key informants may have their own agenda which they wish to advance through participation in the study. They are also likely to present their own account of how the system works which may, or may not, differ from how things actually are. Nevertheless, the application of the key informant technique to this study is justified by the significant insight into the delivery of stomach cancer services and issues for Māori along with the generation of intervention ideas grounded in the reality of those working within the health system that were gained in a relatively short period of time.

Finally it is unavoidable that my own personal biases had some impact in the qualitative phase of this study. According to Choy (Choy, 2014: 102) “All researchers’ interpretations are limited. As positioned subjects, personal experience and knowledge influence the observations and conclusions”. As a public health professional committed to improving access to, and quality of, cancer services for Māori it is likely that the gathering, analysis and presentation of the data were undertaken and viewed through an equity lens. However having an awareness of and paying attention to one’s potential biases is important in qualitative methodology; this thesis is explicit in its overarching intent to facilitate positive outcomes for Māori through a systems-based approach whereby solutions to the problem are focussed on changing systems rather than changing individuals or those who participate in the systems. It is however also possible that personal bias I am unaware of may have influenced this study and its interpretations.

External Validity of the of the Study Overall

Whether the findings of this study are able to be applied to other populations depends on two key factors: the characteristics of the cancer patients and the context in which health care is delivered. Both of these factors should be considered when generalising the findings of this study to cancer disparities in other cancers in New Zealand or indigenous people within other countries.
DISCUSSION

The quantitative study population represented all New Zealanders diagnosed with stomach cancer between 2006 and 2008 and this study was intended to inform Māori/non-Māori differences in treatment and management of stomach cancer. The study findings could be in part generalised to other cancers within New Zealand although attention would need to be paid to differences in the characteristics of the cancer and its recommended treatment.

Although the findings of the qualitative phase are pertinent only to New Zealand as they focus on the context of the delivery of cancer services in New Zealand and could not be generalised internationally, they may be of interest to others involved in indigenous cancer research internationally. These findings could well be transferable to other cancers in New Zealand.

Overall the study findings may be relevant to cancer disparities in other indigenous populations; however attention should be paid to differences within the indigenous populations and the contexts in which they live and in which their health care is delivered. Māori in New Zealand are a unique population with a unique history that differs in many respects from indigenous people within other countries - although there are likely to be some similarities, driven by common processes of colonisation, marginalisation and institutionalised racism. Cancer care in New Zealand is delivered primarily within a publicly funded health care system that seeks to provide equal access to all patients based on need. In addition, with New Zealand's small population size, services relevant to stomach cancer are low volume by nature. As long as these factors are taken into consideration the findings of this study may well inform cancer disparities within other countries.

In addition the study overall may contribute to an increased understanding, both nationally and internationally, of institutionalised racism, how it manifests in unequal cancer treatment and outcomes and importantly how it can be addressed.
Interpreting the Study Results

The quantitative phase of this study found a number of key differences in the presentation, treatment and management of stomach cancer for Māori when compared with non-Māori patients in New Zealand. Additionally, there was an apparent survival difference unexplained by a number of patient, disease and health care access factors. There were also some surprising similarities between the two groups. The quantitative findings fall into three main areas:

Quantitative phase

1. Māori and non-Māori patients with stomach cancer differ in terms of patient (age, sex, comorbidity), disease (tumour site only) and health care access (deprivation, rurality) characteristics but have similar disease (stage at diagnosis, grade) characteristics.

2. There are differences in the treatment and management of Māori and non-Māori patients with stomach cancer with Māori appearing to have lesser access to specialist surgical care, although some markers of surgical quality appear similar.

3. These differences could contribute to an apparent 30% poorer survival from stomach cancer seen between Māori and non-Māori in New Zealand.

The qualitative phase of this study helped to make practical sense of the quantitative findings. It identified what key informants working within New Zealand’s health care system see as issues in the management of stomach cancer and considered how to intervene to improve access to, and quality of, stomach cancer treatment services. The qualitative findings fall into three main areas:

Qualitative phase
1. The issues identified along the stomach cancer treatment pathway in New Zealand support the findings of the quantitative phase of this study, as do my reflections on reading 335 patient notes.

2. The delivery of cancer services is not consistent throughout New Zealand which especially impacts on smaller DHBs, Māori and patients with comorbidity.

3. The recently released Upper GI Service Provision Standards have the potential to improve the system for all New Zealanders and impact on equity for Māori however a range of further interventions could be implemented.

The following section explores these findings in more detail. Study results, both quantitative and qualitative, are combined into one with the following interpretation and discussed in relation to existing knowledge of disparities in cancer care and survival among Māori and non-Māori.

**Differences in Presentation between Māori and non-Māori with Stomach Cancer**

There were a number of key differences in the presenting characteristics of Māori and non-Māori New Zealanders with stomach cancer. There were also some surprising similarities.

Māori were found to have higher levels of comorbidity and evidence of poorer access to health care services. These are two important findings. Tumour site was markedly different between Māori and non-Māori patients while other tumour characteristics were fairly similar.
Patient Factors

Age and Sex

Māori patients were on average 10 years younger than the non-Māori patients, reflecting the younger age structure of Māori in New Zealand (Statistics New Zealand, 2014; Robson and Harris, 2007a). Within female patients this ethnic difference was even greater so that Māori women were on average 13 years younger than their non-Māori counterparts. This differential average age at diagnosis may also be a true younger age at onset possibly due to a higher prevalence of known risk factors among Māori, such as H. pylori and smoking (The Quit Group and the Ministry of Health, 2009; Fraser et al., 1996; Ministry of Health, 2008; Biggar et al., 2011). It may also be due in part to the younger age at diagnosis seen in those with hereditary diffuse stomach cancer (mean age at diagnosis: 40 years) as there is a large Māori family in New Zealand who are known to carry the gene mutation for this form of stomach cancer (Blair et al., 2012). However since the discovery of the gene mutation within this family in the 1980’s and subsequent genetic testing, screening and prophylactic gastrectomy it is unlikely that there was high enough incidence within this family to impact significantly on age at diagnosis at a population level.

The primary care guideline (‘Suspected Cancer in Primary Care’) (New Zealand Guidelines Group, 2009) advises primary care practitioners to consider stomach cancer at a younger age, suggesting ten years earlier, when treating Māori patients compared to the general population. This recommendation is supported by the findings of the current study.

Overall the incidence of stomach cancer in this study was higher in males than females which is in keeping with international evidence (Mcloughlin, 2004; World Health Organisation, 2008). The magnitude of this difference internationally is in the ratio of 1.5–2.5 for males to 1 for females (Crew and Neugut, 2006; Ferlay et al., 2010). However, within this study a higher proportion of the Māori cohort were female, with a nearly 1:1 ratio (47% female) compared to the non-Māori cohort who had a nearly 3:1 ratio (35% female). The higher proportion of women within the Māori cohort
remained once the data were age standardised to account for the different age structures within the Māori and non-Māori cohorts. Dockerty also reported a high proportion of Māori women with stomach cancer (Dockerty et al., 1991) as did the New Zealand Cancer Registry between 2000 and 2009 (New Zealand Health Information Service, 2012). Notably no other indigenous population in the world has such a high proportion of women compared to men as do New Zealand Māori. All other indigenous populations have male age-standardised incidence rates (per 100 000) two to three-fold that of their female counterparts (Arnold et al., 2014).

Four key informants in the qualitative phase of this study offered unprompted information on the risk factors of stomach cancer, with each of them stressing that a focus on prevention is vital to improving outcomes of stomach cancer for Māori. Given the extremely high incidence of stomach cancer seen within Māori and the gender anomaly highlighted above further research into the risk factors of stomach cancer for Māori and the significant gender differences suggested by this study is warranted.

All comparative analyses were adjusted for age and sex.

**Comorbidity**

This was a highly comorbid cohort, with 70% of both Māori and non-Māori having at least one comorbidity at the time of their stomach cancer diagnosis. Māori had significantly higher prevalence of congestive heart failure and renal disease, non-significantly higher prevalence of diabetes and appeared more likely to present with multi-morbidity (31% likelihood of three or more comorbidities compared to 17% likelihood in non-Māori). All other comorbidities analysed were similar between Māori and non-Māori patients.

Comorbidity among cancer patients is common with at least half of all New Zealand cancer patients having comorbid conditions (Sarfati et al., 2014a). The observation that Māori were more likely to have comorbidities is consistent with previous studies which have found Māori patients to have higher rates of comorbidity than non-Māori patients with cancer (Stevens et al., 2008b; Hill et al., 2010a). Comorbidity among
Māori is also less likely to be well controlled than that among non-Māori due to the differential access to the underlying determinants of health and lesser access to primary health care, as discussed in Chapters 2 and 4.

As Māori are more likely to be comorbid, comorbidity is of greater importance to Māori. The impact of comorbidity on cancer outcomes could be reduced through measures to prevent disease and improve access to early intervention for all health conditions within the primary health setting for Māori.

**Disease Factors**

**Stage**

Surprisingly, no substantial differences were found in stage at diagnosis between Māori and non-Māori patients. In comparison previous studies that relied on national level data, rather than staging derived from clinical note review, have found that Māori are more likely to be diagnosed with localised disease than non-Māori (Robson et al., 2006) although the authors point out that stage was unknown for about a third of patients overall. However a study at a single New Zealand facility that also utilised more accurate clinical note review data also found no apparent difference in stage at diagnosis between Māori and non-Māori patients (Biggar et al., 2011).

Despite the lack of substantial stage difference between the two ethnic groups within this study, stage overall was poor with nearly half of the total cohort (46% or n=158) diagnosed with metastatic stomach cancer. During the process of gathering the data many examples were seen of complex and lengthy pathways, especially at the beginning of a patient’s cancer journey where early diagnosis matters to improved stage. Key informants also raised the advanced stage of stomach cancer as an issue especially highlighting that access to early detection and staging services, is not consistent throughout New Zealand. There are three points where improvements to stage could occur: within the public in general (or within specific subgroups), within the primary care sector or within secondary services once referred, although there is a general lack of literature related to interventions aimed at promoting earlier diagnosis.
of cancer (Richards, 2009). Clearly though, there is a need to improve the stage profile of stomach cancer overall in New Zealand through systematic improvements to early detection and diagnosis of the disease.

**Grade**

Overall, 42% of the total cohort presented with a poorly differentiated grade of stomach cancer. Although Māori were more likely to have data missing from this variable there was little difference between Māori and non-Māori patients in grade of disease at diagnosis. Little difference between Māori and non-Māori remained when the missing grade data were removed. This variable was not considered further.

**Tumour Site**

There were significant differences in the distribution of tumour site between Māori and non-Māori patients. Māori presented with a much higher proportion of distal stomach cancers, and a corresponding lower proportion of proximal stomach cancers, when compared with non-Māori patients. Stratifying the two main tumour sites (distal and proximal) by sex showed that Māori women were most likely to present with a distally located tumour and least likely to present with a proximally located tumour while non-Māori men were the group most likely to present with a proximally located tumour and least likely to present with a distally located tumour. This is in keep with international evidence that shows proximally located stomach cancers are more likely in white males of more affluent societies (Kelley and Duggan, 2003).

In comparison, high rates of distally located tumours have been reported for other indigenous people (Heise et al., 2009), especially American Indians and Alaskan Natives (Arnold et al., 2014; Wiggins et al., 2008) although differentials by gender are not reported. In the general population internationally non-cardia (distal) stomach cancer has a male-to-female ratio of approximately 2:1 whereas cancer located in the cardia of the stomach has a much higher male to female ratio (Crew and Neugut, 2006; Kelley and Duggan, 2003). In the USA the incidence of adenocarcinoma of the cardia is reported at a 6:1 male to female ratio (Kelley and Duggan, 2003).
The observation of a higher proportion of distal cancer for Māori is also in keeping with previous New Zealand based studies (Biggar et al., 2011; Armstrong and Borman, 1996). This finding suggests that there may be differing aetiological factors driving the high incidence rates of stomach cancer observed for Māori. Infection with H. pylori and smoking have both been shown to be more likely to lead to the development of distal stomach cancer over proximal (McLoughlin, 2004; Crew and Neugut, 2006; Biggar et al., 2011; Kamangar et al., 2006; Forman and Burley, 2006; Martin, 2002). The high proportion of distal stomach cancer among Māori women when compared with non-Māori men and women may be related to their higher rates of H. pylori (McDonald et al., 2015) in combination with a very high smoking prevalence and younger age at initiation (The Quit Group and the Ministry of Health, 2009; Ministry of Health, 2008; Fraser et al.; Biggar et al., 2011). Māori women have one of the highest rates of smoking in the world, more than Māori men and over twice that of non-Māori women (The Quit Group and the Ministry of Health, 2009). These two factors are thought to interact to increase the risk of distal stomach cancer more than would be expected given each risk factor alone (Forman and Burley, 2006; World Health Organisation, 2008).

Again these findings reinforce the need for further research into the risk factors of stomach cancer for Māori. These findings also add weight to a continued emphasis on reducing smoking as well as the development of interventions to prevent the transmission of, and to treat, H. pylori, particularly among Māori as discussed in Chapter 2: Background.

In addition, the New Zealand Cancer Registry (NZCR) does not currently record the sub-site of stomach cancer preventing the verification of these findings to those of the NZCR or over time. Improvements in the reporting of tumour sub-site to the NZCR would enable better monitoring of Māori/non-Māori differences and whether these are changing over time.
Health Care Access Factors

Māori had poorer access to health care services according to both of the factors that were considered markers of health care access within this study.

Deprivation and Rurality

There was a strong socioeconomic gradient for both Māori and non-Māori patients in this study. Over half of the total cohort lived in the most deprived quintiles (7-10) whereas only a quarter resided in the least deprived quintiles (1-4). Previous New Zealand research has also shown evidence of a strong deprivation gradient for stomach cancer (Soeberg et al., 2012; Blakely et al., 2010), with incidence rates in New Zealand at least one-third higher among low income groups when compared to high income groups (Blakely et al., 2010). Despite the strong deprivation gradient overall this association was more pronounced for Māori with 59% of Māori living within the most deprived quintiles compared with 29% of non-Māori patients. The distribution of Māori by deprivation in this cohort is similar to that seen in the general Māori population, which is vastly overrepresented in highly deprived areas (Robson and Harris, 2007a).

Māori with cancer are more likely to live in highly deprived areas (Hill et al., 2010a; Seneviratne et al., 2014c; Stevens et al., 2008b). Previous New Zealand cancer survival studies show poorer cancer survival in patients living in areas of greater deprivation (Soeberg et al., 2012; Haynes et al., 2008; Jeffreys et al., 2009), primarily due to the effect of socioeconomic status on stage and receipt of cancer treatment (Haynes et al., 2008; Jeffreys et al., 2009).

The majority of patients (78%) lived in urban areas. Slightly fewer Māori (68%) than non-Māori (81%) lived in main or satellite urban areas, on the converse it appeared that more Māori lived in rural areas (16% Māori vs 7% non-Māori). This is in accordance with previous reports showing that Māori are most likely to live in Auckland and other major cities (Statistics New Zealand, 2007) and more likely than non-Māori to live in minor urban areas (Robson and Harris, 2007a).
Māori as shown in this study are more likely to live rurally, further from cancer services; thus differential geographical access especially impacts on Māori. Place of residence is viewed as a marker of health care access. Research shows that people living in rural areas experience far greater barriers in accessing health care, and cancer care (Moore et al., 2010; Diaz et al., 2015b; Seneviratne et al., 2014c). The only New Zealand study that has looked at distance travelled and survival for stomach cancer concluded that the relationship between distance and survival was complex. Poorer survival was found for all patients with stomach cancer, regardless of ethnicity, living 51 – 100km from a cancer treatment centre while those living closest and furthest distances fared better, although the study did not assess distance to specialised surgical treatment services. Given that surgery is the mainstay of curative treatment for stomach cancer this would have been a more interesting variable to assess (Gill and Martin, 2002).

Notably only five patients within this current study had their stomach cancer resected in a private hospital (two Māori and three non-Māori) so it appears that little care was delivered within the private sector. It is possible though that some patients received private specialist assessment and diagnostic investigation and then went on to have surgery within the public sector, thus enabling a quicker diagnostic pathway. Although this is speculation, as these data were incomplete and unable to be analysed, it is likely that more non-Māori than Māori would have benefited from an expedited ‘private’ pathway. Non-Māori New Zealanders are more likely than Māori to have private medical insurance (Cumming et al., 2014). Recent research into pathways of care for breast cancer shows more non-Māori women receive their care within the private sector (Seneviratne et al., 2014c).

The findings of the qualitative phase of this study supported those of the quantitative phase; namely that key informants raised issues to do with rurality and receiving care within smaller centres as an issue and one that especially impacts on Māori. The need for patients to travel for multiple appointments with multiple providers and often within a DHB other than that in which they reside was seen as an issue by key informants. The multi-faceted pathway was also clearly seen when gathering the data.
for the quantitative phase of this study. This was viewed as particularly problematic by key informants when the responsibility of navigating these services was left to the patient rather than to the health system supporting the patient and whānau cancer journey or working to improve the navigability of their services.

These findings raise some important questions about the accessibility of cancer services in New Zealand and how to ensure that Māori receive the same access as non-Māori patients.

**Differences in Patient Management and Treatment between Māori and non-Māori with Stomach Cancer**

Comparative management and treatment-based analyses were undertaken on those patients amenable to curative treatment (those diagnosed at stage I-III of disease) only. All were adjusted for age and sex.

**Diagnosis and Staging Investigations**

There was little difference in the proportions of diagnostic and staging investigations received by Māori and non-Māori patients. The majority of patients were diagnosed and staged by gastroscopy and/or computerised tomography (CT) scan while 81 patients also received a laparoscopy. Overall the numbers of patients receiving these diagnostic and staging investigations were similar to those seen in the note review study by Biggar et al (Biggar et al., 2011). Correspondingly, similar proportions of Māori and non-Māori patients received diagnostic investigations in studies on lung cancer (Stevens et al., 2008b) and colon cancer management (Hill et al., 2010b)

A New Zealand study published in 2002 highlighted the need for better staging and treatment planning offered by endoscopic ultrasonography in conjunction with CT scanning (Martin, 2002). This study, using data collected between 1995–1997, found that 10% of patients receiving an operation for a gastro-oesophageal tumour had an unnecessary ‘open and close’ surgical procedure, indicating the need for better
surgical planning information gained by endoscopic ultrasonography prior to surgery. Despite these recommendations, and the fact that endoscopic ultrasonography is considered one of the most valuable tools in the staging of stomach cancer (Dicken et al., 2005) this study’s findings indicate that clinical practice has remained unchanged a decade later, with only four patients receiving an endoscopic ultrasound. Of note, five stage I – III patients (3% Māori vs 2% non-Māori) underwent a potentially avoidable ‘open and close’ surgical procedure.

Surgical Treatment and Management

There were a number of similarities in the surgical management of patients in this study. Of the 172 patients with stage I-III disease overall, two-thirds (66%) had definitive surgery with similar rates of surgery observed between Māori and non-Māori. Surgery was observed to be the primary treatment modality over our study period, which is consistent with international guidelines in use at the time (Allum et al., 2002; National Health Service Scotland, 2006; Nakajima, 2002). Just over half (55%) of all stage I-III patients had the recommended 15 or more nodes resected during surgery with similar proportions observed between Māori and non-Māori patients, although more non-Māori had missing data for this variable (11% missing Māori vs. 18% missing non-Māori). Overall this is a good finding in international terms but is less than that observed in the United Kingdom where around 76% of patients having curative gastrectomy had 15 or more nodes resected (National Clinical Audit and Patient Outcomes Programme, 2013) or that seen in a single Australian facility where 83% of stage I – III patents had 15 or more nodes resected (Chen et al., 2014). It is though more than the rates of 18% reported in the United States (Dicken et al., 2005). Post-operative complications (within 30 days of definitive surgery) were similar across the two groups and few patients died post-operatively (n=3), another good result in the international context.

There were however a number of key differences in the surgical management of the two groups, namely surgery type, surgical facility type and surgeon type. Māori in this study were more likely to have distal disease and thus more likely to undergo less-
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complex partial gastrectomy. However, our findings suggest that the international guideline recommendations of the time were not being met, particularly for Māori patients. International guidelines, published in 2002 and 2006, recommended that all patients should have treatment planned within the multi-disciplinary context, and that at all stages of disease surgery should be undertaken by experienced surgeons in high-volume specialised units (National Health Service Scotland, 2006; Allum et al., 2002) with appropriate post-operative care available (Allum et al., 2002). While we were unable to accurately measure multi-disciplinary treatment planning, Māori were less likely than non-Māori to have a specialist upper gastrointestinal surgeon perform their surgery (38% Māori vs 79% non-Māori) or to have surgery performed in a main centre (43% Māori vs 83% non-Māori) with specialist post-operative support.

These findings were further explored through stratification. It appears that Māori remained less likely than non-Māori to have their surgery performed by a specialist upper gastrointestinal surgeon whether their surgery was performed within a main or smaller centre or whether a partial gastrectomy or a more complex total gastrectomy was performed. While the results were not conclusive it does appear that even when Māori have their surgery within a main centre they are 73% (95% CI, 0.07 – 1.04) less likely than non-Māori to have that surgery performed by a specialist surgeon once age, stage of disease and tumour site are taken into account. A specialist surgeon is highly likely to be experienced in all potential presentations and problems related to complex upper GI surgery and importantly they are likely to be surrounded by a team of other specialists in upper GI surgery (such as radiologists, anaesthetists, intensivists, dietitians). Specialist surgeons are also likely to audit and publish their results and interact with their peers in a robust and meaningful way, which was highlighted within the qualitative findings as being important to sound clinical practice.

These differences raise serious questions about Māori access to specialist surgical stomach cancer services. This location and resourcing of cancer services may be a factor with more Māori living in minor urban and rural areas (Robson et al., 2010) and so they are more likely to access care from smaller public facilities; indeed this was raised by informants in the qualitative phase of this study as a probable reason for
differences in specialist surgical care between the ethnic groups. However the quantitative findings indicate there is differential access to specialised surgical care for Māori no matter which surgical facility type treatment occurs in. Other studies have shown that Māori receive poorer quality care within New Zealand’s public hospitals than non-Māori (Davis et al., 2006; Grey et al., 2014; Wang et al., 2013; Ellis et al., 2010). Poorer quality care for Māori has also been shown to impact on subsequent cancer survival (Hill et al., 2010a; Seneviratne et al., 2015a; Seneviratne et al., 2014a).

This current study was not able to assess either variation in individual surgeon practice or variation between facilities; it is likely variation within and across different surgical facilities exists. Nor was this study able to assess whether the observed differences in surgical management impacted on treatment outcomes or patient survival. The need for further research in this area is highlighted, especially focussed on the impact of hospital type and surgeon type on patient outcomes in New Zealand. These findings also underscore the need to consider more than absolute intervention rates when monitoring treatment disparity.

**Medical Oncology Treatment**

Of the 172 patients in this study with stage I-III disease, 49% were referred to medical oncology; however few patients received chemotherapy with similar proportions observed between Māori (26%) and non-Māori (30%). Additionally, few patients overall received chemotherapy in conjunction with surgery despite international guidelines of the time recommending both pre and post-operative chemotherapy in patients with curative intent (Allum et al., 2011). Overall 15% of patients with stage I-III disease received pre-operative chemotherapy and 25% received post-operative chemotherapy. The New Zealand study published in 2002 and based on 1995 – 1997 data discussed previously in relation to endoscopic ultrasonography (Martin, 2002) also found that few patients with stomach cancer received multi-modality therapy despite evidence at the time increasingly supporting such treatment. As with endoscopic ultrasonography it appears that clinical practice has remained unchanged a decade later, with little chemotherapy given in this study.
Other studies have found evidence of treatment differences between Māori and non-Māori patients, with Māori less likely to receive potentially curative medical oncology treatment (Seneviratne et al., 2014a; Hill et al., 2010b; Stevens et al., 2008b). Furthermore these disparities were not explained by differences in tumour characteristics, patient comorbidity, deprivation (Seneviratne et al., 2014a; Hill et al., 2010b; Stevens et al., 2008b) or, in the case of lung cancer patients, refusal of treatment (Stevens et al., 2008b).

Informants in the qualitative phase of this study identified the Multi-Disciplinary Meeting (MDM) as the key referral mechanism into medical oncology. However it appears that MDM pathways also differ throughout New Zealand and are especially problematic for patients living within smaller DHB areas or rurally. Again Māori are more likely to be disadvantaged as they are more likely to reside rurally. This warrants further investigation.

**Patient Management**

Waiting times through the treatment pathway were similar for Māori and non-Māori. Māori appeared to wait on average 13 days longer, once diagnosed, for both definitive surgery (median 47 days for Māori compared to 35 days for non-Māori, p=0.65) and before referral to medical oncology (median 34 days for Māori compared to 25 days for non-Māori patients, p=0.31). However, once in the oncology treatment pathway, waiting times were similar for Māori and non-Māori patients.

The following findings were not statistically significant and must be interpreted with caution. However, stratifying waiting times by the two key surgical facility types (main and smaller centres) suggested that Māori who receive their surgery in a main centre have longer delays from diagnosis until both definitive surgical treatment and referral into medical oncology services than either non-Māori treated in main centres or Māori treated within smaller centres. This may be because Māori are more likely to have comorbidity than non-Māori slowing their journey within a main centre. Māori may also be more likely to have their cancer diagnosed within a smaller facility and then be referred onto a main centre for surgical care, again due to comorbidity and the
resources available to smaller centres to adequately care for more complex patients. Certainly my reflections on gathering the data by clinical note review support this hypothesis. Informants in the qualitative phase of this study also spoke of delays in patients’ journeys, especially when dealing with multiple providers across multiple DHBs. In addition, several clinicians highlighted the fact that Māori often wish to discuss treatment options with whānau before finalising their treatment plan. While these clinicians were aware of and tried to accommodate a whānau-based approach to decision making this was not always possible within a busy clinical environment and at times this inability to accommodate a whānau approach slowed the patient journey.

These findings compare with other evidence of disparity in timeliness to cancer treatment. Differences have been shown between Māori and non-Māori New Zealanders across a number of cancers; namely colon (Hill et al., 2010b), lung (Stevens et al., 2008b), breast (Seneviratne et al., 2014a; Seneviratne et al., 2014c) and rectal (Swart et al., 2013) cancers. In the case of breast cancer a high proportion of women did not receive surgical treatment within the Ministry of Health 31 day guideline, especially those women treated within the public sector (in which Māori feature more highly) (Seneviratne et al., 2014c). Public sector treatment was also associated with delays in women receiving adjuvant chemotherapy and radiotherapy, with higher proportions of Māori compared to New Zealand European women, and women residing rurally compared with urban residency, experiencing delays to treatment. Furthermore there is some evidence these delays may be contributing towards the higher breast cancer mortality seen in Māori women (Seneviratne et al., 2014a).

As surgery is the primary curative treatment for stomach cancer, timely access to surgical services is important and potential survival gains could be made for Māori through ensuring timely access to surgery no matter where that surgery is performed.

**Palliative Care**

Referral into a palliative care service (palliative chemotherapy, palliative radiotherapy or other palliative care) was analysed for the 158 patients diagnosed at stage IV
disease only. While similar proportions of Māori and non-Māori were referred to any palliative care service (85% vs 83%) Māori patients are less likely to be referred to (and receive) chemotherapy than are non-Māori patients (28% vs 44%, referred for chemotherapy). On the converse, it does appear that Māori patients are more likely to be referred to (and receive) radiotherapy in the palliative setting (16% vs 7%, referred for radiotherapy) however these latter results are based on very small numbers of patients and are not statistically significant.

Palliative care is a critical part of the treatment pathway for a cohort of patients that are highly likely to be diagnosed with stage IV disease. Indeed a specialist surgeon within the qualitative phase of this study stressed that the health system must maintain focus on palliative patients, and on ensuring that they have the best possible quality of life, in order to make the most difference to the greatest number of people with stomach cancer.

There is evidence of under-treatment with chemotherapy for patients with higher levels of comorbidity (Sarfaty et al., 2009; Sogaard et al., 2013). Thus the lower likelihood of being referred or receiving chemotherapy among Māori patients may be due to the higher levels of comorbidity among Māori. Given the evidence for improved quality of life and up to 10 month median survival benefit of palliative chemotherapy over supportive care alone (Dicken et al., 2005; Allum et al., 2011; Okines et al., 2010) whether (and why) there are ethnic differences as suggested by this study’s findings warrants further investigation.

**Differences in Patient Survival between Māori and non-Māori with Stomach Cancer**

That nearly 80% of the total cohort overall died during follow-up reflects the poor prognosis of stomach cancer. This is an unsurprising finding with most countries reporting five-year survival rates between 10% and 30% (Mercer and Robinson, 2008; Crew and Neugut, 2006; Dicken et al., 2005; Forman and Burley, 2006). Overall there was little difference in the proportions of deaths, either all-cause or stomach cancer
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specific, between the Māori and non-Māori cohorts. Nor was any difference observed in either median all-cause or cancer specific survival times.

However Māori patients appeared to have poorer survival compared with non-Māori, with a probable 30% higher risk of cancer-specific death in Māori although the study was underpowered to statistically confirm this. This does support the finding of 25% excess mortality in Māori with stomach cancer, over that of non-Māori, reported in a large cancer survival trend study that investigated survival from 1991 to 2004 (Soeberg et al., 2012). In this current study the estimated 30% higher mortality in Māori patients was not explained by a number of key factors: patient demographics, disease factors, patient comorbidity, or markers of health care access.

The unadjusted hazard ratio for stomach cancer specific mortality of 1.02 (95% CI 0.79 – 1.31) reflects the similar proportions of deaths overall between Māori and non-Māori in this study. Adjustment for patient demographic factors: age and sex had little impact on the Māori/non-Māori hazard ratio.

Adjustment for disease factors (stage at diagnosis and tumour site), had the biggest impact on the model. Stage alone made the biggest difference to the model with a change in the hazard ratio from 1.08 to 1.21 (95% CI 0.92 – 1.58). Stage in particular is an important mediator between ethnicity and survival among cancer patients; it is a crucial individual measure influencing patient survival and is the most important predictor of stomach cancer survival with a strong association to mortality (McLoughlin, 2004; Crew and Neugut, 2006; Abrams and Wang, 2010). Unsurprisingly stage was a strong independent predictor of survival within this study; with a 13-fold risk of dying observed in stage IV compared with stage I patients. At a population level, stage at diagnosis can indicate levels of access to primary health care and/or cancer screening, along with access to prompt referral and timely diagnostic investigation; differences in stage by ethnicity can reflect differential access to these services. Indigenous Australians (Moore et al., 2014a; Condon et al., 2006; Valery et al., 2006; Chong and Roder, 2010) and Americans (Young et al., 1984; Gilliland et al., 1998; Samet et al., 1987; Jemal et al., 2004) were more likely to be diagnosed with a less favourable stage of stomach cancer than non-Indigenous which played a role in
the poorer survival outcomes seen within them when compared to their non-Indigenous counterparts.

In comparison to other indigenous people, in this study there were no substantial differences in stage between Māori and non-Māori. In fact Māori actually had a slightly better stage profile than non-Māori, with more stage II and less stage III disease, although differences within these stage groups were not determined. Given their slightly better stage profile it could be expected that Māori would be more likely to survive their cancer however we see after adjustment for stage the survival disparity remains.

Patient comorbidity only explained a small amount of the survival disparity seen between Māori and non-Māori in this study. There was a very small, and non-significant change in the hazard ratio from 1.28 to 1.25 (95% CI 0.94 - 1.66) following adjustment for this factor. This is because this was a highly comorbid cohort overall with only small differences in prevalence of comorbidity between the Māori and non-Māori cohorts.

Comorbidity has been shown to mediate ethnic disparities in survival in other cancer survival research (Valery et al., 2006; Hill et al., 2010a; Moore et al., 2014a). Most of the effect of comorbidity seems to be mediated through ethnic differences in receipt of treatment (Hill et al., 2010a). However Moore and colleagues (Moore et al., 2014a) found that Indigenous Australians without comorbidity remained less likely to receive cancer treatment (including surgical treatment) than their non-Indigenous counterparts suggesting factors other than comorbidity play a role in cancer treatment.

While it does not appear that comorbidity plays a large role in the survival disparity seen between Māori and non-Māori in this study, and it is most probably an important driver of survival overall, probably mediated through its effects on treatment decisions. The fact that the group of stage I-III patients in this study who did not receive any treatment had higher levels of comorbidity than those who did receive treatment suggests that comorbidity is playing a role in the decision to treat. The
effect of comorbidity on stomach cancer treatment and survival deserves further investigation.

Additionally adjusting for differences in markers of health care access (deprivation and rurality) was not able to explain the excess mortality in Māori with the final best estimate being a 30% poorer survival for Māori compared with non-Māori (HR 1.30; 95% CI, 0.96 – 1.76). These variables were included as a crude measure of access to, and through, cancer services. There are likely to be other measures of health care access and quality that were unable to be measured within this study. It is important to note that it is possible for a health care system to deliver poorer quality care to one ethnic group even if individuals or individual facilities within that system deliver quality care.

It is likely that treatment type, quality or other non-treatment factors unable to be collected (or analysed) within this study play a role in the observed Māori/non-Māori survival disparity. Further research is needed to better understand the impact of health service access and delivery factors on ethnic disparities in cancer care and survival.
Why might there be ethnic disparities in access to New Zealand’s health system and what can be done about it?

Results from this study align with other research which together provides compelling evidence that Māori are less likely than non-Māori to receive quality, and timely, care for a number of cancers. Importantly these differences in care have been evidenced to contribute to the poorer survival profile of Māori with colon (Sarfaty et al., 2009; Hill et al., 2010a) and breast cancers (Seneviratne et al., 2014a; Seneviratne et al., 2015). This current study supports the Māori/non-Māori stomach cancer survival differences seen in previous research, finding a probable 30% poorer survival in Māori than non-Māori patients. While this apparent survival difference was unexplained by a number of key factors, it is concerning.

The findings of the qualitative phase of this study largely confirmed the quantitative findings. Differential access to stomach cancer treatment services by centre type was apparent as well as specific issues for Māori within the cancer care pathway highlighted. For a number of cancers, including stomach cancer, there may be institutional factors within the health system that privilege non-Māori and discriminate against Māori. Furthermore this privileging of non-Māori over Māori contravenes the Treaty of Waitangi. The Treaty places a responsibility on the New Zealand government to ensure health services are accessible to, and address the health needs of, Māori. The Treaty also requires equity in health outcomes for Māori and non-Māori New Zealanders. Quite clearly Māori with stomach cancer do not have the same access to care as do non-Māori and there appear to be disparate Māori/non-Māori stomach cancer survival outcomes.

New Zealand is however not an isolated case. International evidence suggests that other developed nations have health care systems that do not provide equitable cancer care for their indigenous people (Moore et al., 2014a; Condon et al., 2014; McCramb et al., 2012; Samet et al., 1987; Gilliland et al., 1998). Nor do they seem to provide equitable stomach cancer care for their indigenous people (Morrell et al., 2012; Moore et al., 2010; Condon et al., 2014; Young et al., 1984; Gilliland et al., 1998;
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Samet et al., 1987; Jemal et al., 2004; Heise et al., 2009). Questions about access to, and the quality of, care provided to Māori when compared to non-Māori patients with stomach cancer have been raised by this study. The remainder of this chapter considers explanations for this and offer answers to what can be done to provide more equitable care for Māori.

Mandelblatt et al’s framework of barriers to accessing cancer services (Mandelblatt et al., 1999) provided guidance to this study, its design and analysis. The framework is now used below to structure discussion. In keeping with the intent of this thesis to not require that Māori change their behaviour in order to receive better quality care the most emphasis is placed on discussing health system and health care process levels.

Importantly, there has been considerable work to improve cancer services across New Zealand in the decade preceding this thesis. This work has grown in impetus since 2007 and the advent of Regional Cancer Networks to work towards more equitable access to cancer services across District Health Boards. Still there is much to be done to improve stomach cancer services in New Zealand. As highlighted by one key informant in the qualitative phase of this study ‘... if people really care about it and they make sure a good service is provided, then it’s fine ... but we can always improve”.

The section below outlines some ways in which those improvements can occur to help ensure New Zealand’s health care system provides equitable care to all New Zealanders regardless of their ethnicity, socioeconomic status or place of residence.

Health System Factors

Health system-level factors include the focus, funding and location of cancer services which in turn affect the accessibility of services according to socioeconomic status, geographical location and, as discussed below, by ethnicity. This study raises important questions about the accessibility of specialist stomach cancer services and whether Māori receive the same access to, and quality of care, as non-Māori patients.
The section below considers key health system level factors in relation to these questions.

In this study we used two variables in quantitative data analyses as proxies for health care access at the health system level - deprivation and rurality. I argue that patient comorbidity should also be considered at the health system level of Mandelblatt et al’s framework as this current study and the work of others clearly shows that level of comorbidity impacts both on treatment and survival from cancer. Yet receipt of curative treatment, even in those patients with higher levels of comorbidity, can improve survival (Sarfati et al., 2009). With this in mind the onus must be on the health care system to better meet the needs of patients with cancer and concomitant comorbid conditions. Thus comorbidity is considered a health system level factor and discussed in the section following.

**Cancer Service Focus on Total Population**

New Zealand’s institutions, including the health care system, were modelled on those of the British (French et al., 2001), these institutions tend to mainstream Pākehā and require non-Pākehā to adapt to their language, culture and protocols. Until recent decades there has been almost no Māori involvement in decision making within the health sector, although recent changes have seen increased Māori representation in health service policy, governance and organisation. Recent decades have also seen the development of Māori health providers although these Māori-led health services are largely confined to services within the primary care sector and represent a small proportion of all health care provided in New Zealand.

In New Zealand cancer treatment services are delivered primarily through the publicly-funded health system (Cormack et al., 2005). Thus most Māori cancer patients receive their care for stomach cancer from a provider that mainstreams Pākehā and requires non-Pākehā to adapt to it, rather than the other way around. So despite New Zealand’s health care system being one of universal access its inherently mono-cultural approach means there are marked differences in access according to ethnicity. Indeed key informants raised the mono-cultural focus of New Zealand’s
health services as an issue for Māori. This was raised in a broad way in terms of how New Zealand’s health care system is designed and organised and how health care services and health outcomes are measured. The mono-cultural focus was also raised more specifically to do with service delivery. Medical clinicians were generally aware of the negative impact of the mono-cultural focus of the health care system on Māori and attempted to mitigate this through measures such as speaking basic te reo (Māori language) or allowing for longer clinic appointment times when seeing Māori patients. However incorporating a more holistic and whānau focussed approach was discussed as not always being possible in the busy clinical environment and so it appears that this is an area in which clinical and cultural needs may conflict. Finding ways to accommodate whānau and whānau-based decision-making while still maintaining timely access through the treatment pathway is important but may be difficult.

Strategies were suggested in the literature to develop a less mono-culturally focussed health care system, one that is more responsive to Māori need. These strategies ranged from developing supportive policy to supporting a focus on Māori in clinical practice, including providing opportunities for whānau participation in patient support and decision-making (Walker et al., 2008; Cormack et al., 2005; Cram, 2014a; Cram, 2014b).

Interventions to develop a less mono-culturally focussed system identified within the literature and those identified by key informants in the qualitative phase of this study are summarised in Table 40 at the end of this section. Synergies between the two are noted within four key areas: Strengthening policy and accountability for equity, leadership, accurate data and monitoring, and accommodating Māori approaches to care.

**Funding, Resourcing and Location of Cancer Services**

The funding, resourcing and location of cancer services influence accessibility, with particular problems noted in New Zealand. New Zealand has a relatively small population with communities spread widely across a diverse geography and despite having a publicly funded and theoretically universally accessible health system in
reality access to health care varies according to a patient’s socioeconomic status and place of residence. Currently 20 regional DHBs are responsible for the bulk of primary, secondary and tertiary care within their geographical boundaries (Ministry of Health, 2013d), but not all DHBs (nor all hospitals) have the same resource available nor can they offer the same level of services (McLeod et al., 2004). Historically in New Zealand, areas with larger non-Māori populations have tended to be advantaged in terms of health system resourcing relative to population size (Gauld, 2001).

In particular, the geographical location of health care services impacts on access to, and through, specialist care. Treatment disparity within specialist cardiac care is shown to be, in part, related to access to and type of treatment facility (Ellis et al., 2013; Ellis et al., 2010; Ellis et al., 2004). Likewise the geographical location of cancer services also impacts on access to, and through, cancer care. Specialist surgical and cancer services tend to be concentrated in major metropolitan areas and so issues such as travel times or transport reduce the accessibility of services for those living further away from providers (Cormack et al., 2005). Distance travelled for treatment plays a role in differential treatment for women with breast cancer (Seneviratne et al., 2014a) and impacts on cancer mortality and survival for a number of cancers (Haynes et al., 2008; Brewer et al., 2012a; Brewer et al., 2012b) including upper GI cancers (Gill and Martin, 2002).

The geographical location of cancer services has the potential to impact more markedly on Māori who in New Zealand are more likely to live in areas further from health care facilities, as shown in this current study and previously (Hill et al., 2010a; Seneviratne et al., 2014c; Robson et al., 2010). In addition, funding and resource structures especially impact on people of lower socio-economic status (in which Māori predominate) who have fewer economic resources and are less able to overcome financial barriers to care. Māori with cancer are more likely to live in highly deprived areas (Hill et al., 2010a; Seneviratne et al., 2014c; Stevens et al., 2008b) while poorer cancer survival is noted in patients living in areas of greater deprivation (Haynes et al., 2008; Jeffreys et al., 2009; Soeberg et al., 2012). Cancer treatment in New Zealand is free to the patient but it can impose many indirect costs, such as time off work, travel
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and accommodation expenses, on a patient and their whānau (Cormack et al., 2005). These costs are likely a greater barrier for Māori than for non-Māori with stomach cancer. Importantly though, while the patterning of socio-economic status of Māori compared to non-Māori plays an important role in explaining ethnic disparities in cancer, socio-economic position alone cannot explain the inequities observed. This is evidenced by the fact that within social strata, Māori/non-Māori inequities remain (Sporle et al., 2002), as they do after adjusting for socio-economic position (Blakely et al., 2007).

The findings of the qualitative phase of this study support those of the quantitative phase. The main issue highlighted by over half the informants in the qualitative phase of this study was that of geographical inconsistency in the delivery of cancer services, with the greatest negative impact appearing to be within smaller (less well-resourced) DHBs. One of the nurse informants from a smaller centre summed up her interview by emphasising what she described as the inequity of a small DHB. Examples of inconsistency between different sized DHBs were given by informants at most points of the treatment pathway. In addition, key informants specifically raised issues to do with rurality and receiving care within smaller centres in relation to Māori. The need for Māori to travel for multiple appointments with multiple providers and often within a DHB other than that in which they reside was seen as an issue by key informants. This was seen as particularly problematic when navigating these services was the responsibility of the patient rather than the health system supporting the patient and whānau cancer journey or working to improve the navigability of their services.

Centralising surgical services into fewer, larger, more specialised centres was raised by both policy and clinical informants of this study, although informants did not commit to a preference. Rather consensus was that the debate on centralising stomach cancer services (or upper GI cancers in combination) needs to happen in New Zealand. Reorganisation of services to a more specialist and centralised model has been carried out within the United Kingdom (Palser et al., 2009) and a number of European countries (Dikken et al., 2013b) however disparity remains in the management of
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patients dependent on the hospital-type of their presentation (Monkhouse et al., 2013; National Clinical Audit and Patient Outcomes Programme, 2013).

While a link has been demonstrated between surgical volume, of both the individual surgeon and the facility, with improved surgical outcomes and patient survival observed when stomach cancer surgeries are performed by surgeons with higher volumes in fully supported institutions (Thrumurthy et al., 2013; Dikken et al., 2013a; Coupland et al., 2013; Mahar et al., 2012; Markar et al., 2012), the context of cancer care is very different in New Zealand to that internationally. With its small population, New Zealand would need to centralise services to a small number of facilities to perform the volumes of surgery needed to attain international-level high volume status (Beenen et al., 2013) often considered to be a minimum of 20 resections annually per facility (Dikken et al., 2013a; Allum et al., 2011; Coupland et al., 2013; Okines et al., 2010; Dikken et al., 2013b). Furthermore, despite having low surgical volumes by international standards, outcomes for upper GI patients comparable to those of tertiary hospitals published internationally have been documented in two non-tertiary New Zealand hospitals (Al-Herz et al., 2012; Beenen et al., 2013). Centralisation could also exacerbate existing inequities in access to care and so would need to be carefully managed with additional support provided. In the meantime equity of access to specialist stomach cancer services could be improved through increased support for regional services and concomitant additional support provided to patients and whānau to access specialist services.

Some informants discussed the future role of the Service Provision Standards in not only assessing but also requiring the level of services necessary within each DHB, with a view that more formalised relationships and shared care across DHBs will occur in the future. This was both in the context of service delivery but also in workforce training, support and development. In terms of surgical services a model of care that enables the provision of care in a facility closer to the patient and whānau’s place of residence, one of specialist support of generalist surgical practice was put forward as the model most likely to gain sector support. Informants also believed that the Upper GI Service Provision Standards, or more specifically the quality improvement review
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The process whereby DHBs are assessing their level of service provision alongside the minimum recommended in the Standards, will help to identify gaps in the system and any differential treatment, providing transparency and impetus for change. The general view seemed to be that this process will help to standardise care throughout New Zealand which has the potential to positively impact on equity for Māori in the future. Certainly there is evidence to show that standardisation of care, though New Zealand’s national breast cancer screening programme, impacts positively on receipt and timeliness of treatment and breast cancer survival in New Zealand (Seneviratne et al., 2015a; Seneviratne et al., 2014c). Thus women diagnosed through the programme are privileged by the programme’s quality standards and associated auditing and monitoring processes. That the screening programme is less accessible for Māori women means that fewer Māori receive the advantage that the quality standards and auditing of the programme confer on those diagnosed in this way.

The interventions regarding funding, resourcing and location of cancer services identified within the literature and by key informants of this study are summarised at the end of this section Table 40. Synergies are seen within two key areas: better addressing regional care and use of guidelines and standardised clinical pathways.

In addition, the literature reviewed for this study calls for better resourcing of Māori health providers to deal with cancer. Māori providers were strongly praised by participants of qualitative studies reviewed previously (Slater et al., 2013; Walker et al., 2008). Māori providers provided practical assistance, such as transport to appointments or helping to understand health literature; they also provided emotional and spiritual support to patients and their whānau through working in a ‘whānau ora’ model of care (Slater et al., 2013; Walker et al., 2008). As concluded by Slater et al (Slater et al., 2013: 313) “Māori health providers are already providing informal cancer navigation. This begs the question of whether they are recognised and resourced appropriately to do this important work”. The Ministry of Health has previously funded three 3-year (2008 – 2010) community based pilots for cancer navigation and support in two urban areas with high Māori populations, and in a rural area of New Zealand (Health Outcomes International, 2011). Evaluation showed these
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Pilots were successful in improving patient and whānau quality of life and in reducing DNAs (Do Not Attends) (Health Outcomes International, 2011). Perhaps now is the time to answer the call to look outside of DHB services and systematically and adequately resource Māori-led cancer support and navigation services in New Zealand.

The literature reviewed for this study also asks the health system to: strengthen networks with other organisations that have commitment to improving Māori access to health care, engage with Māori leaders and communities, locate services in Māori settings where appropriate and, enable partnerships to include culturally competent expertise in teams. While these measures were not specified by key informants of this study they have merit, are recommended and should be investigated.

Comorbidity

Comorbidity is known to impact on the quality of care received by patients. Comorbid patients are less likely to receive curative treatment for their cancer than those without comorbidity (Stevens et al., 2008b; Hill et al., 2010a; Sarfati et al., 2009). When comorbidity is discussed within the multidisciplinary meeting setting, the key mechanism for cancer treatment planning, there is evidence a more conservative treatment pathway is taken (Stairmand et al., 2015). Comorbidity also impacts on the likelihood of survival from cancer (Hill et al., 2010a; Sarfati et al., 2009; Lee et al., 2011; Sogaard et al., 2013) and has been shown to be responsible for a third of the colon cancer survival disparity between Māori and non-Māori (Hill et al., 2010a). However evidence also suggests that patients with comorbidity may well benefit from treatment if given (Hill et al., 2010a; Sarfati et al., 2009; Sogaard et al., 2013; Lee et al., 2011).

Comorbidity is also common, especially in the context of stomach cancer. The risk factors for stomach cancer include poverty, tobacco use, heavy alcohol consumption, obesity, infection with H pylori and chronic gastritis (Layke and Lopez, 2004; NHS Executive, 2001; Allum et al., 2011; Blakely et al., 2010) therefore many patients have significant levels of comorbidity at diagnosis (Palser et al., 2009). This was borne out
DISCUSSION

in this study with 70% of both Māori and non-Māori having at least one comorbidity at the time of their stomach cancer diagnosis. Although Māori had significantly higher prevalence of two key comorbid conditions and appeared more likely to have multimorbidity.

My reflections on the note review process and the views of the key informants both support the need to focus on comorbidity when dealing with patients with stomach cancer. Through the clinical note review the impact of comorbidity on the treatment pathway was visible. It was apparent from reading patient notes in their entirety that comorbidity impacted on clinical decision-making, changed or delayed patient pathways and necessitated care in DHBs away from patients DHB of domicile. Key informants also saw comorbidity as an issue for patients with stomach cancer in New Zealand and emphasised that its presence increases the complexity of an already complex pathway. The impact comorbidity has on both timeliness through the cancer pathway and clinical decision-making were raised. There was also acknowledgement of the impact of comorbidity, not only on the patient, but also of the additional workload the presence of comorbidity places on staff, on services and on health care resources more generally.

Key informants put forward a number of interventions to improve services for those with comorbidity. Interventions such as developing the cancer workforce’s knowledge of comorbidity and its impacts on clinical decision making and outcomes, ensuring that cancer nurse specialists have the ability to effectively work with comorbid patients by explicitly including comorbidity in contracts, job descriptions and reporting systems and extending, or developing new, cancer nurse specialist roles to include upper GI cancers are important for a group of patients that are likely to be highly comorbid and thus experience a complex cancer journey. Interestingly the three key reports on improving access to cancer services for Māori reviewed for this thesis do not focus on comorbidity. Comorbidity is absent within the work of Cormack et al (Cormack et al., 2005) and while comorbidity is considered within the work of Cram (Cram, 2014a; Cram, 2014b) it appears to be considered only as three major diseases were researched at one time. The results appear somewhat silo’ed and the impact of
DISCUSSION

Comorbidity on Māori accessing health care was not emphasised. It is a limitation of these pieces of work.

The effect of comorbidity on the treatment of stomach cancer and subsequent survival requires further investigation. Attention to the optimal management of comorbidity once diagnosed, either through primary health care or as an organised part of cancer management within secondary services, could improve cancer outcomes in all patients with stomach cancer, but especially in Māori patients. The interventions regarding comorbidity identified by key informants in the qualitative phase of this study are summarised below in Table 40.
### Table 40: Health System-Level Interventions identified in the literature and by key informants

<table>
<thead>
<tr>
<th>Framework Level</th>
<th>Issue identified</th>
<th>Literature Interventions</th>
<th>Key Informant Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health System-Level</td>
<td>Total Population or Monocultural focus</td>
<td>Develop cancer control policy for Māori and/or strengthen inequities focus in existing policy</td>
<td>Stronger mandate for equity accountability and improving health outcomes for Māori</td>
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<tr>
<td></td>
<td></td>
<td>Have commitment to, and leadership in, improving equity</td>
<td>Develop a national-level ethnicity data role</td>
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<tr>
<td></td>
<td></td>
<td>Use local and/or relevant data to plan and monitor services</td>
<td>Develop clinical champions for equity</td>
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<td></td>
<td></td>
<td>Incorporate Māori healing interventions and a whānau-based approach to care</td>
<td>Accommodate a more holistic approach which encompasses whānau</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Improved cultural friendliness and approachability of services</td>
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<tr>
<td>Funding, Resourcing, Location and</td>
<td>Address differential access to services and</td>
<td></td>
<td>Combine clinics and increase use of tele-clinics</td>
</tr>
<tr>
<td>inconsistent Services</td>
<td>entitlements by region and provide community</td>
<td></td>
<td>Formalised and shared care across DHBs</td>
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<tr>
<td></td>
<td>based or outreach services</td>
<td></td>
<td>All DHBs involved in surgical resection of SC have a cancer nurse specialist to coordinate care within and across DHBs</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Ensure any guidelines are implemented and monitored</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Implementation and quality review of upper GI service provision standards</td>
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<td></td>
<td></td>
<td></td>
<td>Standardising clinical pathways/evidence based protocols/clear clinical decision-making criteria</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Standardising early detection and diagnostic services nationally</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Standardising MDM including process-dependent feedback loops and MDM monitoring for equity</td>
</tr>
<tr>
<td>Patient Comorbidity</td>
<td>Explicitly include comorbidity in cancer nurse specialist roles</td>
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<td>---------------------------------------------------------------</td>
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<tr>
<td></td>
<td>Extend or develop new cancer nurse specialist roles to include upper GI cancers</td>
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<tr>
<td></td>
<td>Include the impacts of comorbidity in cancer sector workforce development</td>
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<tr>
<td></td>
<td>Combine clinics for complex patients</td>
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</tbody>
</table>
Health Care Process Factors

Health care process-level factors include communication between services and between services or providers of care and patients and their whānau; these in turn may impact on the pathways of care experienced by patients. In this study surgical and medical oncology intervention rates and waiting times are all conceptualised as health care process-level factors as are surgical facility and surgeon type.

While similar rates of both surgical and medical oncology interventions were observed between Māori and non-Māori patients in the quantitative analyses, the differential surgical management of patients and the slightly longer waiting times for Māori point to health care processes that better meets the needs of non-Māori patients.

Health literacy was not measured within the quantitative phase of this study, however it was a theme within the intervention literature and frequently raised by informants of the qualitative phase. As the onus should be on the health system and its services to ensure that patients and whānau understand their cancer journey and are empowered to make informed decisions health literacy is considered as a health care process factor and discussed in the following section.

Communication between Services

Cancer is a complex disease; a number of factors make the management of stomach cancer particularly complex. There have been considerable changes in both the epidemiology and treatment of stomach cancer internationally in the decades preceding this study (Palser et al., 2009; Martin, 2002; Okines et al., 2010; Nakajima, 2002; Allum et al., 2002; Allum et al., 2011; NHS Executive, 2001) thus the management of stomach cancer has been open to variability according to hospital or clinician decision (Nakajima, 2002). Its primary treatment modality, surgery, is major, is demanding on the patient, technically complex for the clinician and places considerable burden on the health system (National Health Service Scotland, 2006;
Allum et al., 2002; Martin, 2002; NHS Executive, 2001). As a result of these factors, and their high levels of comorbidity, patients diagnosed with stomach cancer have diverse and complex clinical needs necessitating care from many different professional groups (Palser et al., 2009; NHS Executive, 2001).

The complexity of the journey for someone with stomach cancer was apparent while gathering the quantitative data by clinical note review and was confirmed qualitatively by key informants. Complexity is thought to contribute to Māori/non-Māori inequities in cancer treatment and outcomes overall (Cormack et al., 2005). Effective and timely communication between, and within, services is vital; this includes ensuring cancer services are easy to navigate. A number of ways to help mitigate the effects of complex patient journeys are discussed below. They are: navigation, the use of clinical guidelines and clinical decision making in the context of MDM.

**Navigation**

Better coordination of care, especially when it necessitates care from services that cross DHB boundaries, may help to improve equity of access through stomach cancer services for different population groups. The 57 new Cancer Nurse Coordinator roles that have been implemented within DHBs across New Zealand since 2012 will undoubtedly help in supporting patients to navigate cancer services. These roles are however operationalised differently in each DHB and few focus on upper GI cancers or explicitly on equity.

There is no consensus definition of patient navigation (Dohan and Schrag, 2005: 1126; Wells et al., 2008) and little literature on navigation specific to indigenous people (Whop et al., 2012). Professional or lay, secondary or primary care based, navigator role type and having an indigenous background or not are all debated (Gilbert et al., 2011; Dohan and Schrag, 2005: 1126; Whop et al., 2012). Despite this debate patient navigation approaches are shown to improve diagnostic attendance and timeliness (Cram, 2014a; Nash et al., 2006; Wells et al., 2008; Gilbert et al., 2011; Gabram et al., 2008; Whop et al., 2012), to improve the patient experience (Nash et al., 2006; Gilbert et al., 2011; Health Outcomes International, 2011), reduce delays in accessing cancer
DISCUSSION

treatment for indigenous peoples (Wells et al., 2008) and enhance the diagnostic process from the clinician viewpoint (Gilbert et al., 2011). There is also evidence that a model which combines hospital and community-based navigators working together improves access to cancer care, and completion of cancer treatment, in indigenous people (Domingo et al., 2011). This adds weight to the point made in the preceding section on better resourcing Māori health providers to attend to cancer.

A number of this study’s key informants discussed navigation as a necessary part of the patient pathway for a complex cancer such as stomach cancer. One had even advocated having their job description changed to accommodate working with upper GI patients alongside lower GI patients, due to perceived patient complexity. Again this is especially relevant to Māori where issues to do with rurality and receiving care within smaller centres are more prevalent. Requiring that all DHBs involved in the surgical resection of stomach cancer appoint a cancer nurse specialist to coordinate care within, and across, DHBs may help to 1) facilitate communication between services and providers, 2) ensure cancer care for all patients meets current clinical guidelines and 3) ensure patients and their whānau do not become lost in the system.

The intervention literature and qualitative key informants were however also clear that the health care system should not rely upon patient navigation alone, rather the system must also work to ensure that their services are easy to navigate. One step towards achieving this put forward by key informants was to audit referral pathways, timeliness and care coordination across different DHBs to investigate any disparity. There is precedent internationally for this approach in a study that found significant differences in the journeys experiences between patients with stomach cancer presenting at two different hospital-types: a local district general hospital and a centralised tertiary hospital (Monkhouse et al., 2013).

Clinical Guidelines

Standardisation of care for all patients with stomach cancer was viewed by informants in the qualitative phase as being vital to improving equity. As mentioned in the previous section the development and implementation of the Upper GI Service
Provision Standards (National HBP/Upper GI Tumour Standards Working Group, 2013) has the potential to standardise care throughout New Zealand and positively impact on equity for Māori in the future. However while they give guidance on the minimum level of service needed by providers wishing to provide care to patients with stomach cancer in New Zealand, they do not provide clinical treatment protocols. As outlined in Chapter 2: Background a number of countries internationally have developed clinical guidelines specifically aimed at standardising treatment. Although these international guidelines do not always reach consensus, there is enough commonality within them to provide some direction on the clinical management of patients in the New Zealand context. It is though imperative that the Service Provision Standards are implemented and monitored with an equity focus that prioritises the needs of Māori.

**Clinical Decision Making**

The MDM is increasing recognised as a key decision-making mechanism for people with cancer, especially a complex cancer such as stomach cancer (Blazeby et al., 2006). Since 2002 international guidelines have recommended that treatment decisions for all patients with upper GI cancer should be made in the MDM context (Allum et al., 2002; Allum et al., 2011). While access to MDMs was not able to be quantified and compared between Māori and non-Māori patients within this study, key informants within the qualitative phase all agreed that the MDM is an important part of the care pathway for patients with stomach cancer. It was apparent through discussions with key informants that access to, and processes of, MDM are inconsistent around the country. Again smaller DHBs appear to be adversely impacted, with their smaller size meaning MDM expertise for their patients is accessed outside of the DHB region, often slowing the patient journey. In addition a recent New Zealand study showed an apparent disadvantage if patients had not been physically seen by one of the MDM team members (Dew et al., 2014). This meant that clinical decisions were made at a distance with difficulties in determining which patient issues were most important and what the MDM recommendations should be. As Māori are more likely to live rurally and to receive their surgery at a smaller centre, it is likely that Māori, more than non-
Māori, are impacted through this mechanism. Key informants also indicated that ethnicity is not often considered within the MDM setting, supporting the research of Dew et al (Dew et al., 2014). Given the inequities in cancer treatment and outcome between ethnic groups in New Zealand, perhaps the impacts of ethnicity should be considered in the future. The ongoing work led by the Ministry of Health aimed at increasing the functionality of MDM is important, including supporting remote video-conferencing within MDMs. Attention to consistent referral criteria and process into, and communication from, MDMs across the country is needed. In addition, it may be useful to audit MDM practice in the future and compare access, decision-making and decision-making coherence by ethnicity. These measures combined could impact on equity for Māori.

Interventions to address the complexity of, and communication between, cancer services identified within the literature and by key informants in the qualitative phase of this study are summarised in Table 41 at the end of this section.

**Communication between Provider and Patient**

Effective communication between health care professionals and patients is also important. At the clinical level the interaction between the health care provider and the patient or whānau is of importance. Betancourt et al (Betancourt et al., 2003: 297) argue that “extensive research shows that patient-provider communication is directly linked to patient satisfaction, adherence to treatment plans and subsequently to health outcomes”. Yet there is evidence that this is of lesser quality for Māori patients than it is for non-Māori patients (Crengle et al., 2005; Jansen et al., 2008) with many Māori reporting poor rapport with health care professionals (Slater et al., 2013; McCreanor and Naim, 2002), including those within the cancer sector (Walker et al., 2008). However the ethnicity of the health care professional is not always important rather the qualities demonstrated are; qualities such as competence, warmth, honesty, respect, a caring attitude and a willingness to engage with and understand Māori (Walker et al., 2008; Cram et al., 2003; Slater et al., 2013).
Māori may also be disadvantaged by individual clinician bias, albeit most likely unconscious bias (Hill et al., 2013; McCreanor and Naim, 2002). When health care professionals do not take social and cultural factors into account they can resort to stereotyping which leads to biased clinical decision making. This bias can then in turn lead to inequitable health outcomes (Betancourt et al., 2003). The quantitative phase of this study did not examine the clinician-patient relationship or clinician decision making and so cannot provide any direct evidence of any differences by ethnicity. However the variation in surgeon-type and surgical treatment type observed between Māori and non-Māori patients in this study possibly provides indirect evidence and suggests different referral patterns for different ethnic groups. Internationally there is evidence of variation in referral patterns to surgical treatment centre type by ethnicity (Chang et al., 2009; Al-Refaie et al., 2012). Further work is needed to better understand whether clinician bias exists and the impact of the health care professional/patient encounter within the context of stomach cancer service delivery in New Zealand. Audit of clinical practice could be valuable in this regard.

**Clinical Audit**

It may be useful for clinicians to audit their own practice against clinical guidelines to see if all patients are receiving the best-practice treatment available. Interestingly surgical expertise was only raised by the surgeons within the qualitative phase of this study, although policy participants did speak of the need for evidence-based and agreed protocols. The Australian and New Zealand Gastric and Oesophageal Surgical Association (ANZGOSA) surgical audit provides an appropriate opportunity for New Zealand surgeons operating on oesophago-gastric cancer or gastrointestinal stromal tumours (Australian and New Zealand Gastric and Oesophageal Surgical Association, 2006). The ANZGOSA audit is a quality improvement tool whereby clinical practice and outcomes are assessed and compared to standards and/or that of peers. Participating in peer-reviewed surgical audit is mandated as part of an upper GI Surgical Fellow’s professional development recertification but is currently not mandatory for all surgeons performing upper GI surgery in New Zealand. Oncology
practice could be evaluated and assessed by ethnicity in the context of the MDM meeting.

**Workforce**

The ethnic composition of the cancer workforce along with the cultural competence or safety of those working within the health sector can also impact on the pathways of care experienced by patients.

Māori are significantly underrepresented in all parts of the health workforce (Durie, 1998; Ministry of Health, 2007) thus most health care encounters take place between Māori patients and non-Māori health care professionals. This underrepresentation can exacerbate health inequity (Boulton et al., 2004) as the more a health worker is able to appreciate the cultural needs of clients the greater the opportunity is for effective health care (Boulton et al., 2004; Durie, 1998). Greater recruitment and retention of Māori within the cancer workforce will likely help to grow a workforce that is responsive to the needs of Māori (Walker et al., 2008; Slater et al., 2013).

Likewise improving the cultural competence or safety of those already working within the cancer sector will help to grow a workforce that is responsive to the needs of Māori. Provider education on cross-cultural issues is identified as one strategy to address inequities in health and health care (Betancourt et al., 2003) and was identified as important both within the intervention literature and by this study’s qualitative key informants. The interventions identified within the intervention literature and by key informants in the qualitative phase of this study are summarised in Table 41 at the end of this section.

**Health Literacy**

Health literacy is defined “as the ability to obtain, process, and understand basic health information and services in order to make informed and appropriate health decisions” (Ministry of Health, 2010c: iii). There is growing awareness that low health literacy can be a significant barrier to accessing health care and that health literacy
impacts on health status (Ministry of Health, 2010c; Kickbusch et al., 2005; Agency for Healthcare Research and Quality, 2014; National Network of Libraries of Medicine, 2014). While on average, New Zealanders have poor health literacy skills Māori have worse health literacy than non-Māori across all indicators measured (Ministry of Health, 2010c). Other indigenous people and minority groups are also likely to have lower levels of health literacy than majority populations (Jiwa et al., 2013; Agency for Healthcare Research and Quality, 2014; National Network of Libraries of Medicine, 2014).

Importantly to this thesis, disparities in health literacy are shown to be an important factor contributing to cancer disparities with minority group patients more likely to be diagnosed with later stage disease and less likely to understand treatment options and thus make suboptimal treatment decisions, all due to ineffective information and communication (Merriman et al., 2002).

Health literacy is not viewed as a knowledge deficit in an individual patient rather it is seen as a systems issue, whereby the onus is on health systems, health care providers and practitioners to support patients to access care, navigate services and manage their own health and wellbeing (Kickbusch, 2001; Kickbusch et al., 2005; Agency for Healthcare Research and Quality, 2014; National Network of Libraries of Medicine, 2014; Ministry of Health, 2015b). According to the Ministry of Health (Ministry of Health, 2015c: 2) “a health-literate organisation makes health literacy part of all aspects of its service planning, design, delivery and performance evaluation to reduce the health literacy demands on consumers”.

Health literacy was not able to be measured quantitatively within this study; still a number of key informants raised health literacy as an issue, especially for Māori patients. Hearteningly key informants’ views on health literacy seemed to be congruent with the systemic-type definitions above. There seemed to be willingness, and effort made, by clinicians to ensure that individual Māori and whānau were supported to see and understand their cancer journey, although some also expressed being unsure of how to best do this. Health literacy was also widely raised in the key informants of Cram (Cram, 2014b) where it was discussed as being about “health
DISCUSSION

providers’ ability to provide culturally responsive information and services to Māori patients and their whānau” again in keeping with a systems-type approach. Two interventions noted in Cram’s literature review focussed on improving health professional ability to communicate effectively with minority group populations. Both improved the health care provider’s self-rated efficacy in working with minority groups (Cram, 2014a). Attention to the health literacy framework (Ministry of Health, 2015b) and organisational health literacy review guide (Ministry of Health, 2015c) recently released by the Ministry of Health may be helpful.
Table 41: Health Care Process-Level Interventions identified in the literature and by key informants

<table>
<thead>
<tr>
<th>Framework Level</th>
<th>Issue identified</th>
<th>Literature Interventions</th>
<th>Key Informant Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Care Process</td>
<td>Communication between services</td>
<td>Patient navigation or care coordination</td>
<td>Patient navigation or care coordination for all patients with stomach cancer</td>
</tr>
<tr>
<td></td>
<td>Change health workforce roles and funding formulas to</td>
<td>Patient navigators or care coordination</td>
<td>Include upper GI and comorbidity in cancer nurse specialist roles</td>
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<td></td>
<td>support an increased nursing workforce</td>
<td></td>
<td>All DHBs involved in surgical resection of stomach cancer have a cancer nurse specialist roles</td>
</tr>
<tr>
<td></td>
<td>Make services easier to navigate alongside the use of</td>
<td>Patient navigators or nursing care coordinators</td>
<td>Undertake comparative clinical review or audit across DHBs</td>
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<td></td>
<td>Investigate referral pathways, triage processes, patient flows, timeliness and care coordination across different DHBs</td>
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<td></td>
<td>Care plans and comprehensive discharge planning</td>
<td>Consistent use of established tools, including discharge tools</td>
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<tr>
<td>Patient – provider</td>
<td>Build a culturally competent and health literate</td>
<td>Develop the cancer workforce’s knowledge and increase understanding of</td>
<td>Develop the cancer workforce’s knowledge of inequity and determinants of health</td>
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<td></td>
<td>communication and provider bias i.e. through training of</td>
<td>their responsibility in effective communication with patients and whānau</td>
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<tr>
<td></td>
<td></td>
<td>Use clear clinical criteria with consistent use of established tools</td>
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<tr>
<td>Cancer workforce</td>
<td>Debunk health practitioner stereotypes of Māori</td>
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<td>Commitment to employing Māori within the cancer sector</td>
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<td></td>
<td>Employ more Māori within cancer care including in</td>
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<td></td>
<td>governance roles</td>
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</tbody>
</table>
**DISCUSSION**

<table>
<thead>
<tr>
<th>Health literacy - the health system and services supports people to understand their stomach cancer journey</th>
<th>Provide culturally tailored and responsive information and services</th>
<th>Use MOH organisational health literacy framework and guide</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Review relevant resources from a health literacy viewpoint</td>
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<tr>
<td></td>
<td>Develop decision-making tools for patients and whānau</td>
<td></td>
</tr>
</tbody>
</table>
**DISCUSSION**

**Patient Factors**

Patient-level factors are factors existing at presentation to secondary services and so lie outside of the dominion of the secondary and tertiary cancer care system. In this study patient (age, sex and comorbidity) and disease factors (grade and site) are conceptualised as patient-level factors. These factors have been discussed at the patient level in descriptive analyses and have already been attended to earlier in this discussion. As argued earlier in this discussion patient comorbidity could also be thought of as a health system factor whereby the onus on the health system to better manage comorbidity in patients both at the primary and secondary or tertiary levels of care. Patient choice alone is discussed below in relation to the Mandelblatt et al framework.

**Patient Choice**

This study was unable to measure patient treatment choice. Previous studies that have investigated cancer treatment decline have reported both higher rates (Stevens et al., 2008b) and no difference (Hill et al., 2010b) in declining treatment in Māori compared with non-Māori patients. Research by Mandelblatt and colleagues described a fatalistic view of, and fears and misconceptions about, cancer within minority groups (Mandelblatt et al., 1999). Although recent New Zealand research with Māori cancer patients refutes these views. Māori are concerned about their health and they do not want to be unwell (Dew et al., 2015; Walker et al., 2008; Slater et al., 2013; Cram et al., 2003). To the contrary Māori want to receive good health care that is mindful of their needs as Māori. These needs include whānau involvement in the cancer journey and taking a holistic approach to health which includes emotional and spiritual support from within Māori culture (Dew et al., 2015; Walker et al., 2008; Slater et al., 2013). A longstanding relationship with a primary care provider, either a Māori health provider (Slater et al., 2013; Walker et al., 2008) or ‘mainstream’ (Slater et al., 2013), also help to mitigate the impact of a complex cancer
journey. Māori health providers in particular help to provide both practical assistance and emotional and spiritual support alongside that provided by whānau members (Slater et al., 2013; Walker et al., 2008).

As seen in Table 42 below, the intervention literature and key informants of this study both identified whānau and holistic health views as important patient level factors. However while the clinicians spoken to in this study were aware of the needs of Māori patients and took steps to meet these needs this was not always possible in the busy clinical environment. Investigating ways to better accommodate the needs of Māori and to incorporate Māori ways of attending to their health within cancer service delivery is important.

Table 42: Patient-Level Interventions identified in the literature and by key informants

<table>
<thead>
<tr>
<th>Framework Level</th>
<th>Issue identified</th>
<th>Literature Interventions</th>
<th>Key Informant Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-Level</td>
<td>Patient Preference or Choice</td>
<td>Support whānau-based and holistic self management</td>
<td>Accommodate a more holistic approach which encompasses whānau</td>
</tr>
</tbody>
</table>

Summary and Key Messages

The section above on why the health system might deliver less quality care to Māori and what can be done to change it has provided detailed discussion and raised a large number of possible interventions. However as previously highlighted In order to optimise the responsiveness of cancer services and effectively address equity multiple issues must be addressed and multi-faceted interventions implements. The key take-home messages with respect to what needs to change within New Zealand’s health care system are provided below.

- Strengthen policy, leadership, monitoring and accountability for equity.
- Standardise and address regional variations in cancer care.
- Improve services for those with comorbidity, either through primary health care or as an organised part of cancer management within secondary services.
DISCUSSION

- Ensure cancer services are easy to navigate through the investigation of current patient flows across DHBs and the use of enhanced patient navigation approaches, consistently applied clinical guidelines and effective clinical decision making in the context of MDM.
- Consistently use clinical audit tools such as the ANZGOSA surgical audit.
- Implement the health literacy tools recently released by the Ministry of Health and upskill the cancer workforce.
- Better accommodate Māori approaches to care.
- Finally, partner with and better resource Māori health providers to attend to the needs of their clients, and whānau, with cancer.

Conclusion

The findings of this study add to the literature on Māori/non-Māori inequities in cancer treatment and survival in New Zealand. They also add to the literature on the role of the health system in contributing to those inequities and how the health system can intervene to improve access to, and quality of, cancer care for all New Zealanders, but especially for Māori.

The specific objectives of this study were to investigate:

Quantitative phase

1. Patient (age, sex, comorbidity), disease (stage at diagnosis, tumour site, grade), treatment (receipt and timing of surgery, chemo and radiotherapy), health care access (deprivation, rurality) and outcome (survival) characteristics of a cohort of patients with stomach cancer in New Zealand.

2. Whether there were Māori/non-Māori differences in treatment timeliness, quality and quantity.
DISCUSSION

3. If differences exist, how these differences contribute to Māori/non-Māori stomach cancer survival.

Qualitative phase

4. What key informants identify as issues for stomach cancer treatment in New Zealand, with a focus on Māori.

5. The interventions key informants identify that may improve access to, and quality of, stomach cancer treatment in New Zealand, with a focus on Māori.

Despite the fact that New Zealand’s indigenous Māori are much more likely to be diagnosed with stomach cancer than non-Māori, have worse mortality and poorer survival once diagnosed, no previous studies have examined Māori/non-Māori differences in treatment and management of stomach cancer and whether this impacts on survival for Māori. This study’s key strengths are that it is based on rich clinical data gathered by manual clinical note review and that it included a qualitative phase that in effect validated the quantitative findings and allowed the thesis to move beyond merely describing the problem and into investigating how and where to intervene to improve access to, and the quality of, stomach cancer services. Its main limitation was its small sample size (n= 335) which meant it had limited power to detect some associations or differences.

Specifically what this study’s findings add to the literature are, that it;

- Confirms the differential tumour site between Māori and non-Māori, most probably related to higher rates of infection by H. pylori in Māori.
- Shows that there are no difference in stage at diagnosis, treatment intervention rates and some markers of surgical quality between Māori and non-Māori.
- Shows differential access to specialist surgical care for Māori and non-Māori, both by centre type and surgeon type.
- Supports the differential survival for Māori, which remains unexplained by a number of factors.
DISCUSSION

- Supports the proposal that in order to optimise cancer services responsiveness to priority groups and effectively address equity the health system must address multiple issues and implement multi-faceted interventions.

- In addition, key informants confirmed the differential access to stomach cancer treatment services by centre type and that there are specific issues for Māori along the cancer care pathway.

Importantly this study helps to give transparency to the issue of institutionalised racism within New Zealand’s health care system. As a policy-based participant of this study stated “You know, the only way to address these problems is by getting transparency. If you don’t know the problem exists, you can’t really address it”. Addressing the disparities highlighted within this study will take effort. Access to, and through, cancer services is complex; especially when you are dealing with a particularly complex cancer like stomach cancer. Achieving equitable care and outcomes for Māori will require a variety of interventions along the stomach cancer pathway that combine health system, health care process and patient-level factors. It will also require commitment, leadership, and engagement with Māori at all levels of the health care system.

It must be noted that even a well-designed, fully functioning and equitable health system is only intervening at the level of health services. The broader underlying determinants of health also need to be addressed. This is particularly salient for a cancer with incidence rates that are driven by underlying poverty and differential access to the resources of society. Addressing stomach cancer inequity will require a broad approach to health that extends beyond the health sector.

Over recent years substantial work has been carried out in New Zealand to improve the access to, and the quality of, cancer services generally. This work should continue, however it is imperative that emphasis continues on ensuring there are improvements to Māori health and reducing inequities for Māori. Māori with stomach cancer deserve excellence in cancer care, including equitable and timely access to high quality cancer services.
References


Australian and New Zealand Gastric and Oesophageal Surgery Association (ANZGOSA). (2013) Guidelines for hospitals and/or health services to assist in credentialing of surgeons performing gastric cancer resection in Australia and New Zealand 2013.

Australian and New Zealand Gastric and Oesophageal Surgical Association. (2006) ANZGOSA: Australian and New Zealand Gastric and Oesophageal Surgery Association Available at: http://www.anzgosoa.org/.

REFERENCES


REFERENCES


REFERENCES


Ellis C, Devlin G, Elliott J, et al. (2010) ACS patients in New Zealand experience significant delays to access cardiac investigations and revascularisation treatment especially when admitted to non-interventional centres: results of the second comprehensive national audit of ACS patients. New Zealand Medical Journal (Online) 123: 44-60.


REFERENCES


REFERENCES


REFERENCES


REFERENCES


New Zealand Familial Gastrointestinal Cancer Service. (2009) **New Zealand Familial Gastrointestinal Cancer Service**. Available at: www.nzfgcs.co.nz.


REFERENCES


Padgett DK. (2011) Qualitative and mixed methods in public health: SAGE Publications.


REFERENCES


Appendix 1: Quantitative Proforma

<table>
<thead>
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<th>3 1st presentation to health system</th>
<th>4 Referral for specialist review</th>
<th>5 First seen by specialist</th>
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<td>Date ............................</td>
<td>Date ........................</td>
</tr>
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<td>○ Date unknown</td>
<td>○ Date unknown</td>
</tr>
<tr>
<td>Seen by (type i.e. GP)</td>
<td>Referred from</td>
<td>Seen by (type i.e. GI)</td>
</tr>
<tr>
<td>Data source</td>
<td>Data source</td>
<td>Data source</td>
</tr>
<tr>
<td>○ 1. GP letter</td>
<td>○ 1. GP letter</td>
<td>○ 1. GP letter</td>
</tr>
<tr>
<td>○ 2. Specialist letter</td>
<td>○ 2. Specialist letter</td>
<td>○ 2. Specialist letter</td>
</tr>
<tr>
<td>○ 4. Other.........................</td>
<td>○ 4. Other.......................</td>
<td>○ 4. Other...................</td>
</tr>
</tbody>
</table>

Signs & symptoms noted at presentation

| 6 Any signs & symptoms noted? | | |
|-------------------------------|----------------------|
| ○ 1. Yes                      | ○ 2. No              | ○ 3. Unknown           |
| If yes, for how long?         | | |
| ○ 1. < 1 month                | ○ 2. 1-3 months      | | |
| ○ 3. 3 – 6 months             | ○ 4. > 6 months      | | |
| On surveillance               | | |

| 7 If signs & symptoms noted, which? | | |
|-------------------------------------|----------------------|
| ○ 1. Abdominal Pain                | ○ 2. Anorexia        |
| ○ 3. Nausea                         | ○ 4. Dysphagia       |
| ○ 5. Fatigue                        | ○ 6. Unintentional weight loss |
| ○ 7. Bloating                       | ○ 8. Changes on bowel habits |
## APPENDICES

### 11. Anaemia
- [ ] Yes
- [ ] No

### 12. Other (specify):

### Comorbidities recorded up to and including date at diagnosis

<table>
<thead>
<tr>
<th>8</th>
<th>Any comorbidities documented?</th>
</tr>
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<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

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<thead>
<tr>
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<th>CVS</th>
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</thead>
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<tr>
<td></td>
<td>(1=history noted but not currently active; 2=currently on medication, controlled; 3=currently active/on medication and not well controlled)</td>
</tr>
<tr>
<td></td>
<td>1. Angina</td>
</tr>
<tr>
<td></td>
<td>1 2 3</td>
</tr>
<tr>
<td></td>
<td>3. Myocardial infarction</td>
</tr>
<tr>
<td></td>
<td>1 2 3</td>
</tr>
<tr>
<td></td>
<td>5. Valvular disease</td>
</tr>
<tr>
<td></td>
<td>1 2 3</td>
</tr>
<tr>
<td></td>
<td>7. PVD</td>
</tr>
<tr>
<td></td>
<td>1 2 3</td>
</tr>
<tr>
<td></td>
<td>9. Other CVS</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>10</th>
<th>Resp</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Mild chronic pulm disease</td>
</tr>
<tr>
<td></td>
<td>3. Other resp</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>11</th>
<th>Haematological</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Blood loss anaemia</td>
</tr>
<tr>
<td></td>
<td>3. Other haem</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>12</th>
<th>GI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Ulcer disease</td>
</tr>
<tr>
<td></td>
<td>3. Inflammatory bowel disease</td>
</tr>
<tr>
<td></td>
<td>5. Mod/severe liver disease</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>13</th>
<th>Neuro</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Cerebrovascular disease</td>
</tr>
<tr>
<td></td>
<td>3. Dementia</td>
</tr>
<tr>
<td></td>
<td>5. Other neuro</td>
</tr>
</tbody>
</table>
### Endocrine

(1=history noted but not currently active; 2=currently on medication, controlled; 3=currently active and not well controlled)

- 1. Diabetes (uncomplicated)
- 2. Diabetes (end organ damage)
- 3. Hypothyroidism
- 4. Other endo

### Malig

- 1. Leukaemia
- 2. Lymphoma
- 3. Tumour
- 4. Metastatic tumour

Define (if available):

### Other mental health disorder (see also Psychoses below)

- 1. Substance dependence/abuse
- 2. Alcohol dependence/abuse
- 3. Other

### Psychoses

(1= history noted, 2= on medication, 3= under care of secondary or tertiary mental health services (+/- meds)

- 1. Major depression
- 2. Anxiety disorders
- 3. Bipolar disorder
- 4. Schizophrenia and other psychoses
- 5. Other

### Other

- 1. Connective tissue disease
- 2. Mild renal disease
- 3. Moderate/severe renal disease
- 4. AIDS
- 5. Coagulopathy
- 6. Weight loss
- 7. Obesity
- 8. Other

### Other behaviours/comorbidity recorded up to and including date at diagnosis

### Smoking

- 1. Current smoker?
- 2. Ex-smoker. Years smoked? .........
- 3. Non Smoker
- 4. Unknown
## Investigations and Diagnosis

### 25 Diagnostic and staging investigations:

1. **Gastroscopy (all)**
   - Date: ________
2. **CT scan (all)**
   - Date: ________
3. **Endo ultrasound (some, new pathway)**
   - Date: ________
4. **Laparoscopy (some, new pathway)**
   - Date: ________
5. **Biopsy**
   - Date: ________
6. **MRI**
   - Date: ________

### 26 Alcohol use

- 1. **Yes**
- 2. **No**
- 3. **Unknown**

### 27 Cirrhosis?

- 1. **Yes**
- 2. **No**
- 3. **Unknown**

### 28 Histology noted?

## Surgery

### 29a Surgery?

- 1. **Yes**
- 2. **No**
- 3. **Unknown**

### 31 Date of initial surgery

### 32 Hospital where surgery undertaken

### 35 Nature of surgery:

- 1. **Elective**
- 2. **Acute**
- 3. **Unknown**
29b If no surgery -> reason:

- 1. Not offered
- 2. Declined
- 3. Other ...................
- 4. Unknown

33 Type of operation:

- 1. EMR
- 2. Partial gastrectomy
- 3. Total gastrectomy
- 4. Other .................

36 Obstruction at surgery?

- 1. Yes
- 2. No
- 3. Unknown

37 Perforation at surgery?

- 1. Yes
- 2. No

38 Surgeon type:

- 1. Specialist/Upper GI
- 2. General
- 3. Unknown
- 4. Unknown

39a Resection of liver metastases?

- 1. Yes Date: .................
- 2. No
- 3. Unknown

39b Other treatment for liver mets?

- 1. Yes Specify: ................. Date: .................

Postoperative complications (within 30 days post-op)

40 Postoperative complications?

- 1. Yes
- 2. No
- 3. Unknown

373
### Nature of complications:

<table>
<thead>
<tr>
<th>Reoperation for:</th>
<th>Date:</th>
<th>Other complications:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bleeding</td>
<td></td>
<td>6. Pneumonia</td>
</tr>
<tr>
<td>2. Other</td>
<td></td>
<td>7. Sepsis</td>
</tr>
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</table>

### Organ failure:

<table>
<thead>
<tr>
<th>Date:</th>
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<tr>
<td>3. Cardiac</td>
</tr>
<tr>
<td>4. Respiratory</td>
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<tr>
<td>5. Renal</td>
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</table>

### Other complications:

<table>
<thead>
<tr>
<th>Date:</th>
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<tbody>
<tr>
<td>6. Pneumonia</td>
</tr>
<tr>
<td>7. Sepsis</td>
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</tbody>
</table>

### Other treatment

<table>
<thead>
<tr>
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<th>Date:</th>
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<tbody>
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<td>1. Yes</td>
<td></td>
</tr>
<tr>
<td>2. No</td>
<td></td>
</tr>
<tr>
<td>3. Unknown</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
</tr>
<tr>
<td>3.</td>
</tr>
</tbody>
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### Definitive Staging (at time of definitive diagnosis) OR to probable staging

<table>
<thead>
<tr>
<th>Tumour site:</th>
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<tbody>
<tr>
<td>1. Proximal</td>
</tr>
<tr>
<td>2. Distal</td>
</tr>
<tr>
<td>3. Unknown</td>
</tr>
<tr>
<td>4. Other description</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tumour size</th>
<th>Tumour depth</th>
</tr>
</thead>
<tbody>
<tr>
<td>mm</td>
<td>mm</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Tumour at resection margins?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Yes/+ve</td>
</tr>
<tr>
<td>2. No/-ve/clear</td>
</tr>
<tr>
<td>3. Unknown</td>
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</table>

<table>
<thead>
<tr>
<th>Lympho/Vascular invasion?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Yes</td>
</tr>
<tr>
<td>2. No</td>
</tr>
<tr>
<td>3. Unknown</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Tumour grade?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Well-differentiated</td>
</tr>
<tr>
<td>2. Moderately differentiated</td>
</tr>
<tr>
<td>3. Poorly differentiated</td>
</tr>
<tr>
<td>4. Unknown</td>
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</table>

<table>
<thead>
<tr>
<th>Number of nodes resected?</th>
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<tbody>
<tr>
<td>&lt; 15</td>
</tr>
<tr>
<td>&gt; 15</td>
</tr>
<tr>
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</table>

<table>
<thead>
<tr>
<th>Total number resected</th>
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</thead>
<tbody>
<tr>
<td>Total number involved</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>TNM staging possible?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Yes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TNM reported (pathology):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>
### Tumour
- **T1**: Tumour invades submucosa
- **T2**: Tumour invades muscularis propria
- **T3**: Tumour is growing into the subserosa layer
- **T4**: Tumour has grown through the stomach wall and into the serosa and may be growing into a nearby organ or other structures/major blood vessels

### Nodes
- **N0**: Nodes not involved
- **N1**: 1-2 regional lymph nodes involved
- **N2**: 3 - 6 regional lymph nodes
- **N3**: 7+ regional lymph nodes

### Metastases
- **M0**: No distant metastases
- **M1**: Distant metastases
- **Mx**: Clinical metastases

### Stomach Stage Groupings
- **Stage 0**: Tis, N0, M0
- **Stage 1a**: T1, N0, M0
- **Stage 1b**: Any of the following - T1, N1, M0 or T2, N0, M0
- **Stage 2a**: Any of the following - T1, N2, M0 or T2, N1, M0 or T3, N0, M0
- **Stage 2b**: Any of - T1, N3, M0 or T2, N2, M0 or T3, N1, M0 or T4a, N0, M0
- **Stage 3a**: Any of the following - T2, N3, M0 or T3, N2, M0 or T4a, N1, M0
- **Stage 3b**: Any of - T3, N3, M0 or T4a, N2, M0 or T4b, N0 or N1, M0
- **Stage 3c**: Any of the following - T4a, N3, M0 or T4b, N2 or N3, M0
- **Stage 4**: Any T, any N, M1

### Probable Staging a (if definitive diagnosis not available) OR

<table>
<thead>
<tr>
<th>55a TNM staging possible?</th>
<th>1. No</th>
<th>TNM reviewed (notes):</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>From:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Date:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>56a Tumour</th>
</tr>
</thead>
<tbody>
<tr>
<td>T ……… N ……… M ………..</td>
</tr>
<tr>
<td>(if known)</td>
</tr>
<tr>
<td>Stage 1</td>
</tr>
<tr>
<td>Stage 2</td>
</tr>
</tbody>
</table>
## Probable Staging b (at time of probable diagnosis)

### 55b TNM staging possible?
- No
- From: 
  - Date: 

### 56b Tumour
- Stage 1
- Stage 2
- Stage 3
- Stage 4

## Oncology

### 57 Referred to Medical Onc ?
- Yes Date 
- No
- Unknown

### 61 Offered chemo?
- Yes
- No
- Unknown

### 64 Offered chemo?
- Yes
- No
- Unknown

### 58 If YES -> oncology review?
- Yes Date 
- No
- Unknown

### 62 If YES -> received chemo?
- Yes start date: 
- No
- Unknown

### 65 If YES -> received chemo?
- Yes start date: 
- No
- Unknown

### 59 If not reviewed -> reason:
- Died before appointment
- Declined
- DNA

### 63 If not received -> reason:
- Died before appointment
- Declined
- DNA

### 66 If not received -> reason:
- Died before appointment
- Declined
- DNA
### APPENDICES

<table>
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<tr>
<th>67</th>
<th>Treatment Intent</th>
<th>1</th>
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<th>2</th>
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<td>5. Unknown</td>
<td></td>
<td></td>
<td>5. Unknown</td>
<td></td>
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<td>5. Unknown</td>
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</table>

#### 68 Completed Pre op Chemotherapy?
- **1. Yes**
- **2. No**
- **3. Unknown**

If No, Reason noted?
- **1. Died before completion**
- **2. Declined**
- **3. Patient DNA**
- **4. Other**
- **5. Reason unknown**

#### 69 Completed Post op Chemotherapy?
- **1. Yes**
- **2. No**
- **3. Unknown**

If No, Reason noted?
- **1. Died before completion**
- **2. Declined**
- **3. Patient DNA**
- **4. Other**
- **5. Reason unknown**

### Referred to Palliative Care

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<tr>
<th>70</th>
<th>1. Referred to Palliative care, treatment unknown</th>
<th>Date referred</th>
<th></th>
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</table>
Appendix 2: Reflections on the Data Collection Process

Manual review of individual patient files added immense value to the study. Not only did it provide more detailed information than that routinely available from administrative databases, it allowed a good understanding of the strengths and limitations of the data gathered. It also allowed the visualization of the patient journey as a whole, better engagement with the health system and those who work within it and provided insight into the context of the delivery of cancer care in the many different facilities of New Zealand. A reflective diary was kept daily during the data collection process. Of note, the diary was written and summarised before the quantitative findings were generated or the key informants interviewed to gather their views on the stomach cancer treatment pathway, yet it appears to support the findings of this study. Key reflections from that diary are presented below.

In-Depth Understanding of the Data

The process of reviewing individual patient medical notes allowed for an awareness of the data and its limitations. Firstly, the medical notes had an incomplete perspective. They were written from a clinician perspective with no real patient voice within them; patients were often labelled: feisty, lovely, large whānau, non-compliant or DNA (did not attend). Yet these labels were given without explanation or context and information on patient ‘non-compliance’, refusal of treatment or wish to involve whānau in decision making was confined to what was documented by the clinician in the medical notes. Secondly, an appreciation was gained of why some variables had incomplete data. At times medical notes can be sketchy or contradictory, with, for example, different medical disciplines writing different dates for key events. The most comprehensive information was written within the oncology new patient histories (both medical and radiation oncology). If patients were seen within oncology these histories provided a good overall review of the patient’s journey, otherwise gathering data on all variables within each patient’s individual proforma required patience, time and detective work.
The manual review of medical notes also allowed an in-depth understanding of the data implications that might not have otherwise been possible. The presence of comorbid conditions and their impact on treatment is exemplified below.

There appeared to be few patients in the study that did not have any comorbid condition and multi-morbidity was common. Even multiple cancer diagnoses were not uncommon. I was astounded by the level of morbidity that many people have, with multiple medical and often severe chronic conditions. It seemed to me that the presence of multi-morbidity was more prevalent within District Health Boards (DHB) with high Māori populations. The impact of comorbidity, or multi-morbidity, on the treatment pathway was also evident. Patients were often not referred, referred but treatment not offered, referred but a lesser or different treatment offered or sent to a larger hospital for treatment. As highlighted in one patient’s notes “our ICU would not cope with them post-surgery”. Delays in treatment were inevitable and evident.

**The Patient Journey**

The manual review of patient medical notes also allowed the visualisation of each patient’s cancer journey as a complete journey, certainly a more complete journey than that previously seen as a nurse providing episodic care during patient visits to hospital based cancer treatment. I was struck by the pathways some patients take through the system; seeing multiple health practitioners, in multiple facilities, in multiple towns and in some cases multiple DHBs. I also realised that cancer is a complex issue and medicine not an exact science. Biopsies miss tumours, often multiple times. At times variables were difficult to determine, for example to which specialist people first presented, the date of diagnosis (in the case of multiple gastroscopy for example) or the date the patient first saw a specialist relevant to the cancer diagnosis. These examples are all at the beginning of the pathway, where early diagnosis matters. I reflected that if I - a trained oncology nurse - found reading patient medical notes complex, and often confusing, then how do the patient and whānau fare and how easy would it be for patients to ‘slip through the gaps’?
Engagement with the Health System

Engagement with the health system in a way not previously possible in my capacity as an oncology nurse was also possible. I gained better appreciation for all who work within it. The staff within medical records departments in particular left a lasting impression. They appeared to be an undervalued workforce doing a highly efficient, highly organised and physically demanding role which the health system arguably would not be able to operate without. The physical environment of the medical record department in itself was often challenging. Many patient notes were stored in underground, musty, cluttered and quite frankly scary dungeons, yet staff were able to maintain order and be quickly responsive to the needs of the facility in which they work.

The Context of Cancer Care in Aotearoa/New Zealand

Undertaking a clinical note review was also a journey I experienced, both physically and reflectively. Of note, it allowed insight into the context in which cancer care is delivered in New Zealand. This is important to understanding the implications of this study.

The different resources available to various DHBs were evident. This was apparent not only in the resource allocated to housing and maintaining clinical records but was evident when reading about the patients within these records. For example Auckland hospital, a facility within a large and relatively well-resourced DHB, has converted all clinical records into electronic form with all information: clinic letters, medical and nursing notes and referral letters, scanned into individual electronic records. Pathology and investigation results were linked to each patient and available electronically. Auckland hospital had a purpose built medical records department with dedicated space for research purposes. As well, they had a staff member specifically allocated to assisting researchers and auditors. On the converse smaller facilities, such as Gisborne or Thames hospitals, still operated a paper-based system and while they had a medical records department, staff felt these were not suitable
for a researcher to operate within. Instead staff chose to seat me in professional offices.

Geography also appeared to make a difference to the services available with access to specialist services differing by DHB. Auckland hospital provides many specialised cancer services, such as New Zealand’s only dedicated Hepatobiliary/Upper GI Cancer Unit, a Familial Gastrointestinal Cancer Service and has specialist Upper GI surgeons. For Auckland based patients these services are reasonably accessible. As an example of this accessibility Auckland based people with suspected stomach cancer were at times referred directly from primary care to a specialist upper GI surgeon, potentially shortening the waiting time until diagnosis. On the converse there were many instances in smaller facilities, in which Māori patients seemed to predominate, where opinions on patients were sought from outside the DHB and/or patients were sent to another DHB. This was apparent in particular for treatment where the DHB either did not have the specialist service available or the patient had comorbidities that necessitated specialised intensive care post-operatively.

New Zealand has six regional cancer treatment centres servicing the entire country and one specialist upper GI cancer unit based in Auckland. The distance covered by regional cancer treatment centres, for example holding regular clinics in peripheral centres, appears a large amount of work. However my observation is that it seems to work well. Doctors based regionally know when peripheral clinics are being held and communication seems collegial and fairly prompt between the doctors within different DHBs. Relationships between the Auckland Upper GI Unit and the rest of the North Island also seem to work well, with prompt communication and a regular Auckland MDM which regional doctors are aware of and use to obtain specialist opinions on their patients. Despite these reflections the impacts of geographical isolation and fewer resources within smaller DHBs were evident for the health professional and for the patient and whānau. In the latter case this often translates into longer journeys through the cancer treatment pathway and the necessity of care at times far from home.
Appendix 3: Qualitative Information Sheet

**Inequities and Interventions: The Case of Stomach Cancer in Aotearoa/New Zealand**

**PARTICIPANT INFORMATION SHEET**

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

**Who is doing this study?**

This study is being led by researchers at the University of Otago, Victoria University and Waitemata DHB. It is being undertaken as part of a PhD by Virginia Signal. It is part of a larger group of studies, called the *C3: Cancer, Comorbidity and Care* studies, which are investigating the effects of ethnicity and comorbidity on cancer survival at a population level and are funded by the Health Research Council.

**What is the aim of the study?**

In Phase One of this study, we have investigated stomach cancer presentation, treatment and survival in New Zealand using data from a clinical note review of 335 newly diagnosed patients. In Phase Two of the study, we aim to use these findings to identify, investigate and recommend interventions that will help to improve the stomach cancer pathway in New Zealand.

**Who are we looking for?**

This study is interested in the health systems response to improving the stomach cancer pathway so we are seeking the opinion of health care professionals and policy makers in Phase Two of this study. We aim to conduct up to 20 key informant interviews, and would like to draw participants from the wider community of Clinicians, Specialist GI Nurses, Upper GI Cancer Coordinators, Regional Cancer Networks, District Health Board Planning and Funding, Ministry of Health Cancer Team, Māori Cancer Coordinators and the C3 Māori/Community and Clinical advisory groups.
What does your participation in the study involve?

If you decide to take part you will be asked to participate in a 30 minute telephone interview which will be recorded. The interview will be held with the PhD candidate (Virginia Signal) and arranged at a time which suits you. Your verbal consent will be gained at the beginning of the telephone interview. Following the interview, some email contact may be necessary to follow up and clarify points of discussion. You will be given the opportunity to review the transcript of the interview once it has been typed and to approve any quotes used in the thesis or resulting publications (if you choose to do so).

Participation in this study is voluntary. You may withdraw from this study at any time during the period of data collection. If you withdraw the information from the interview you participated in will not be used in the research. If you do participate the data gained will be used in a PhD thesis, there may also be resulting publications. Every effort will be made to ensure that you are not identified in any reported data or publications. You will not be named but information about your role and ethnicity will be used to describe the people who participated in the research. Transcripts and audio recordings will be kept on password protected computers and in locked filing cabinets for five years, at which time they will be destroyed. You can to request a copy of the results of the research should you wish.

Ethics approval

This study has received Otago University Level B ethical approval from the Department of Public Health, Wellington.

If you have any concerns about the ethical conduct of the research you may contact the University of Otago Human Ethics Committee through the Human Ethics Committee Administrator (ph 03 479-8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

If you have any questions about the study please contact:

Virginia Signal PhD Candidate, Ph (06) 918-6188 Department of Public Health, University of Otago, Wellington, email virginia.signal@otago.ac.nz

or Associate Professor Diana Sarfati Ph (04) 918-6042, Department of Public Health, University of Otago, Wellington, email diana.sarfati@otago.ac.nz
Appendix 4: Qualitative Consent Form

PARTICIPANT CONSENT FORM

- I have read and understood the Information Sheet about this study.
- I have had the opportunity to discuss this study and all my questions have been answered to my satisfaction.

I understand that:

1. I will be asked to take part in a 30 minute telephone interview;
2. My consent to participate in this study will be verbally obtained at the beginning of the telephone interview;
3. The telephone interview will be recorded;
4. My participation in the study is entirely voluntary;
5. I am free to withdraw from the study at any time without any disadvantage;
6. I am free to request further information at any stage;
7. I have the opportunity to review the transcript of my interview and any direct quotes used;
8. I will not be named and that every effort will be made to ensure that I am not identified in any reported data;
9. Personal identifying information [audio-tapes] will be destroyed at the conclusion of the study but any raw data on which the results of the project depend will be retained in secure storage for at least five years;
10. The results of the study may be published and will be available in the University of Otago Library (Wellington, New Zealand) but every attempt will be made to preserve my anonymity.

I will be asked at the beginning of the telephone interview whether I:

- agree to take part in this research
- wish to review the transcript of my interview
- wish to approve any direct quotes used in the PhD thesis and resulting publications.
Appendix 5: Qualitative Interview Schedule

Inequities and Interventions: The Case of Stomach Cancer in Aotearoa/New Zealand

INTERVIEW QUESTIONS

1. RESEARCH QUESTIONS FOR PHASE TWO
   Which interventions will facilitate changes in health care process and systems factors and will help to ensure equal access to, and quality of, stomach cancer treatment for Māori?
   Which interventions will be the most feasible in New Zealand and should be recommended to reduce stomach cancer inequalities?

2. INTERVIEWER INTRODUCTIONS
   Mihimihi as appropriate to the participant
   Reconfirm the amount of time the participant has available for the interview
   Check that they are happy to be recorded and remind that they can request a copy of the transcript

3. INTERVIEWER TO REVISE THE STUDY WITH PARTICIPANTS
   Ask if the participant had time to read the Information sheet and consent form previously sent to them – any questions?
   Explain that I am about to turn on the tape recorder and that I will need to record names, date & time and gain verbal consent first
   Ask and revise the study if needed
   This study is by researchers at the Wellington campus of the University of Otago, Victoria University and Waitemata DHB.
   This is phase two of a two phase study. The study has already investigated the stomach cancer treatment pathway for 335 patients diagnosed between 2006 and 2008. It has used data from a clinical note review and compared patient factors, treatment factors and survival between Māori and non-Māori.
   We are now interested in the health systems response to the inequities we have seen and so we are seeking the opinion of health care professionals and policy makers for this phase of the study.

4. INTERVIEWER TO RECORD (turn on recorder & check numbers moving)
   Date and time, Name of researcher, Name of Participant, Participants organisation.
   Obtain Consent for Interview: Participant agrees to take part in this study, agrees to the interview being recorded, knows they are free to withdraw from the study at any time without any disadvantage.
   Remind: Participant that their confidentiality will be maintained – they will not be identified personally but their role and ethnicity will be recorded
   Check whether: Participant wants to review the transcript of the interview, or approve any direct quotes used in the PhD thesis and resulting publications.
5. PARTICIPANT QUESTIONS

A. Opening
   - Can you briefly tell me about your role in relation to the stomach cancer treatment pathway?

B. Stomach Cancer Treatment Pathway for Māori
   - Thinking about the pathway of care for patients with stomach cancer, what do you think NZ health services do really well?
   - What do you think NZ health services do not do really well? Prompts below:
     - **Health System level** - funding policies, resources, service organisation and configuration, physical accessibility of services, waiting times, cost and the cultural appropriateness of services.
     - **Health Care Process level** - the way in which services and providers operate and how they work together and communicate with each other, the characteristics of physicians or providers themselves, such as age, gender, training and competence, communication skills, values, attitudes and biases and clinician/patient communication
     - **Patient level** – socioeconomic position, transportation, knowledge, attitudes and beliefs and patient decision-making/preferences
   - Are these issues the same for Māori patients? *(if not covered above)*
   - Are these issues the same for complex patients? Comorbid/multimorbid? *(if not covered above)*

C. Treatment decision making
   - How often are treatment decisions made in the context of an MDM? Prompts below:
     - Are all stomach cancer patients discussed at MDM?
     - Are MDM operating and functioning well, if not how could they improve?
     - Is ethnicity considered when discussing patients?
     - Is comorbidity considered when discussing patients?
   - Has anything changed in the last five years that has improved the SC treatment pathway for all NZers?
   - Has anything changed in the last five years that has improved the SC treatment pathway for Māori?

D. The National Upper GI Tumour or Treatment Standards
As you may be aware the Ministry of Health (and a working group) has recently developed national upper GI tumour standards intended to ensure best-practice management of patients with stomach cancer (and a range of other cancers). How do you think these standards will impact on the SC treatment pathway?

What is needed to ensure that these are implemented? Facilitators and barriers?

Do you think the standards will impact on equity? What is needed to ensure that they do?

E. VS to revise key findings of the quantitative data. Prompts below:

- Started with equal numbers of Māori and non-Māori, final cohort 335, high numbers of Māori women, roughly half overall stage 4 at diagnosis.
- No differences in: stage at diagnosis, diagnostic investigations, timeliness through the pathway, numbers who had curative surgery
- Statistically significant differences in: age at diagnosis by 10 years, level of comorbidity, tumour site, surgery type, access to specialist surgical care, access to major treatment centres – some differences in nodal harvest but not significant
- Few patients overall referred to or received chemotherapy – 15% pre-op, 25% post-op. Some differences between Māori and non-Māori but not statistically significant
- Probable differences in: survival by 27%, adjusted for age, stage, tumour site, comorbidity

F. Referral pathways into specialist care

- Can you tell me about the mechanisms of access to specialised surgical services? The referral process, who refers and how? Who makes the decisions about patient flows between DHBs?
- How could the surgical referral process improve?
- Can you tell me about mechanisms of access and referral to medical oncology?
- How could the oncology referral process improve?

G. How to improve the Treatment Pathway for all, but especially for Māori

- Do you have any other thoughts on what needs to change in the SC Treatment pathway in the future? In relation to Māori? In relation to complex patients? Prompts below:
  - Look for health system and process levels answers

H. Other Possible Interventions
I. Anything else?
   • Can you think of anything else relevant that we have not discussed
   • Is there anybody else you think I should speak with? Why is it important
     I speak with them?
   • What is the best way to contact you if there are any follow up questions
     or points of clarification afterwards?

J. Collect Demographics
   • Finally, I just need to ask a few quick demographic questions
     o Gender
     o Ethnicity – which ethnicity do you identify as?
     o Age bracket – up to 25, 25 - 49, 50 – 64, 64 plus

6. THANK PARTICIPANT FOR THEIR TIME
Appendix 6: Survival Analyses for Stage I – III Patients

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<tr>
<th>Adjusted for:</th>
<th>HR</th>
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<td>0.56 to 1.32</td>
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<td><strong>Disease Factors</strong></td>
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<td>Stage and Tumour site</td>
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<td>0.79 to 2.00</td>
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<td><strong>Comorbidity</strong></td>
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<td>0.79 to 2.02</td>
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<td><strong>Health Care Access Factors</strong></td>
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<td>NZDep and Rurality</td>
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