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Cancer Survivorship

Understanding the Issues Faced by Cancer Survivors

A thesis presented in partial fulfilment of the requirements for the degree of
Master of Arts in Psychology at Massey University,
Palmerston North, New Zealand

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2010

ABSTRACT

International research on cancer survivorship has started to identify a range of issues that affect cancer survivors physically, mentally, emotionally and spiritually. These issues can be present at any time, from diagnosis, throughout treatment and for the rest of the individual's lives. The quality of life and well-being cancer survivors depends on many interacting factors including the type of cancer they are diagnosed with, the type of treatment provided, healthcare utilisation, social support availability and use, employment status, locus of control, ethnicity and socio-economic status.

The objective of this study was to investigate the influence of these factors on cancer survivor's quality of life, health outcomes and support needs within the New Zealand population. Of particular interest is whether ethnicity might affect outcomes. It is hoped that the information provided by this study will help to inform future policy and interventions for cancer survivors.

This study analysed and discussed data from the 2008 Health Work and Retirement Survey. The Health and Work Retirement Survey collected information from over 3000 participants, ranging in age from 57-72 years. This age group has an increased likelihood of cancer diagnosis but also potentially has several more years of active participation in society.

Results from this study were consistent with overseas research and indicates that New Zealand cancer survivors share similar issues to those overseas. Of all the factors, socioeconomic status was found to be the largest contributor to a poorer quality of life in cancer survivors.

ACKNOWLEDGEMENTS

I dedicate this thesis to the memory of my father William J. Walker (Oesophageal cancer) and friends Noel Chapman (Hodgkin's lymphoma), Beverly Greenhead, (Lung cancer), Bobby Tibble, (Liver cancer), Susie Stuart, (Breast cancer) and Anita McPherson, (Breast cancer), all of whom have lost their battles with this disease. With love and encouragement to my cousin Maria Smart (Brainstem Tumour), who has beaten all odds and continues to face cancer with courage, stubborn resistance and her warm sense of humour. Witnessing each of your individual journeys through cancer has ignited my desire to learn more about this disease and the toll it takes on a person's life.

I want to express my heartfelt gratitude to Don Baken for his unwavering guidance and support and to Chris Stephens for her invaluable input. I have truly appreciated the time and energy you have both given me. Special thanks and aroha to Liesje Donkin for your continued help, guidance and belief in me – you have been an inspiration, a teacher and a true friend. And to the girls at Massey from Te Rau Aroha and Tuia Te Mana (you know who you are) – having you as friends has been “he taonga nui”.

Finally thanks and aroha to all my children who have SURVIVED their mother's studying all these years. They have bought me coffee (and wine), dived for cover when the stress levels have threatened to overflow and still managed to come up smiling. And special thanks to my friends Louise, Bill and Kate and extended family who have supported and stood by me through thick and thin and made all this possible.

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CHAPTER ONE: CANCER AND SURVIVORSHIP

1. Introduction

The word *cancer* carries with it connotations of uncertainty, pain, disability, loss and death. The mere suggestion of the possibility of cancer invokes anxiety and distress in most people. Often an insidious, invasive and overwhelming disease, cancer can strike anyone regardless of age, culture, gender or social status on any part of the body. Genetic predisposition, environmental hazards, and an “unhealthy” lifestyle can predispose a person to cancer (Ministry of Health, 2010), however those with a very healthy lifestyle and no genetic predisposition can also find themselves with a cancer diagnosis. Because of these variations and diversities in presentation, each individual’s experience of cancer is varied and can depend on a number of factors. In this chapter, the disease of cancer will be explored, survivorship will be defined, and issues of cancer survivorship will be discussed.

1.1 A Definition of Cancer

“Cancer is a disease that is mysterious, headstrong and makes its own rules. The tabloids will try to destroy your life with bald faced lies in front of the whole world – but this disease chooses instead to destroy life by hiding the microscopic truth about its intent out of sight from human eyes – first in one organ then in another ...” Farrah Fawcett’s description of cancer during her unsuccessful battle with anal cancer (Fawcett & Stewart, 2009).

Although most New Zealanders understand that the term *cancer* refers to a disease, few actually understand the disease itself. The term *cancer* is the collective name given to a complex range of over 100 diseases (New Zealand Cancer Control Trust, 2003). Some cancers are aggressive and spread rapidly, whilst others are slow growing; some are treatable with today's medicine and others are not (New Zealand Cancer Control Trust, 2003). Cancer as a disease is "characterised by abnormal cell growth and spread" (Robson, Cormack, & Purdie, 2006, p. 6), that can affect any organ in the body at any time (Robson et al., 2006; New Zealand Cancer Control Trust, 2003). Many factors are known to cause different forms of cancer, thereby making cancer detection, management and treatment a complex series of procedures that involve a wide range of individuals, medical services and organisations (Robson et al., 2006).

When a cell is damaged and fails to produce healthy replications of itself to replace damaged or dead cells, cancer begins to develop. Cancer cells reproduce more rapidly than healthy cells, resulting in a large number of aberrant cells that develop into a cell mass or tumour, or spread through the blood as the case may be in blood cancers (Kleinsmith, Kerrigan, Kelly, & Hollen, 2006; New Zealand Cancer Society, 2003). These tumours are classified as either *benign* or *malignant*. Benign tumours may interfere with the physiological and mechanical processes of the body, resulting in the need to be removed, but are rarely life-threatening (Kleinsmith et al., 2006). Malignant tumours, however, damage healthy tissue and can spread via the circulatory or lymphatic systems to adjacent tissue, bones and organs through metastasis (Kleinsmith et al., 2006; New Zealand Cancer Society, 2003). This results

in secondary tumour sites or *metastases* (Greenwald, 1992; Kleinsmith et al., 2006; New Zealand Cancer Society, 2003).

Cancer progresses in stages and a favourable prognosis often depends upon three variables: the anatomical site from which the cancer originated, the stage of the cancer at the time of diagnosis, and the histology of the cancerous cells (Greenwald, 1992; Hewitt & Ganz, 2006). Unfortunately, during the initial phases of development, many cancers are asymptomatic and therefore undetectable. This often results in failure to detect the tumour until it is large enough to produce observable symptoms through impairment of physiological functioning (Hewitt & Ganz, 2006; Kleinsmith et al., 2006). Once the tumour affects the normal functioning of the body, the body's ability to fight infection is reduced. This leads to the general debilitation of the body and often results in the cancer patient dying of a secondary illness such as pneumonia (Greenwald, 1992; Kleinsmith et al., 2006; New Zealand Cancer Society, 2003).

The World Cancer Report (2008) estimated that for the year 2008, there were “over 12 million new cases of cancer diagnosed, seven million deaths from cancer and 25 million persons alive with cancer” (p. 9). As the world's population is aging (World Cancer Report 2008), and the incidence of cancer is known to be correlated with age (Balducci & Extermann, 2000; Eakin et al., 2006), it is predicted that the number of patients living with cancer will increase rapidly. So much so that by the year 2030, it is expected that there could be approximately 27 million cases of cancer diagnosed, 17 million cancer related deaths and up to 75 million people living with cancer (World Cancer Report, 2008). Within New Zealand, The Ministry of Health Cancer Control Strategy (2003) estimated that approximately one in three New

Zealanders will experience cancer either personally, or through a relative or friend. In 2005 in New Zealand alone, there were 18,610 new registrations of cancer and 7,971 recorded cancer-related deaths (The New Zealand Cancer Control Trust, 2003). The New Zealand Ministry of Health further predicts that given the prevalence of cancer, the number of new registrations will rise to 22,000 by 2011. Currently, cancer is the second leading cause of death particularly in the elderly and amongst Māori, and a major cause of hospitalisation in New Zealand (New Zealand Cancer Society, 2009).

As mentioned previously, cancer has been found to occur with greater frequency in the older age groups. Several studies from the United States of America (USA) have found that approximately 60% of individuals with a diagnosis of cancer were aged over 65 years (Aziz, 2002; Hewitt & Ganz, 2006). Consistent with such international findings, New Zealand statistics indicate that cancer registrations are considerably higher in the older age groups (New Zealand Cancer Registry, 2005). In New Zealand, a diagnosis of cancer occurs in 18 out of every 100,000 people under the age of 25 years, 371.3 per 100,000 people aged 25 to 64 years, and 2,097.8 per 100,000 people aged 65 years and over (Ministry of Health, 2009). Therefore the chances of being diagnosed with cancer increase significantly with age.

1.2 Definition of a Cancer Survivor

Forty years ago, a diagnosis of cancer was almost certainly a death sentence (Aziz, 2002; Bloom, 2001; Holland, 2003; Hewitt & Ganz, 2006; Lunney & O'Mara, 2001). Now, however, the situation is much improved. As a result of technological advances developing more effective screening tools and treatments, cancer detection

occurs much earlier, thus giving many cancer patients a better prognosis (Bowman, Deimling, Smerglia, Sage, & Boaz, 2003; Holland, 2003; Hewitt & Ganz, 2006). This results in more people not only surviving cancer but living with cancer as a chronic condition.

In 1986, the National Coalition for Cancer Survivorship (NCCS) changed the language used to define a person with a diagnosis of cancer from *cancer patient* to *cancer survivor*. The use of the term *cancer survivor* was developed to encapsulate an individual's experience from the moment of the diagnosis of cancer to the day of the individual's death, regardless of cause (Hewitt & Ganz, 2006). This definition was developed from the description written by Mullan, of his own experiences whilst undergoing cancer treatment. In his journal, Mullan referred to himself as a *survivor* in the battle against cancer, rather than a *victim* or *patient* (Aziz, 2002; Hewitt & Ganz, 2006). The term was adopted by the NCCS as it was thought to give people hope, regardless of the severity of their diagnosis (Ganz, 2006).

The term *cancer survivor* has evolved over the past 30 years and several different definitions have been developed. One definition is that a cancer survivor is an individual who has completed the initial phase of treatment. Another definition is that a survivor is an individual who has survived five years after diagnosis, and still another is that a cancer survivor is an individual who has previously had cancer but is now free of the disease (Hewitt & Ganz, 2006; Reuben, 2004).

The definition of *cancer survivor* has also been extended by some to include not just the individual, but others such as parents, partners, caregivers, and children supporting the individual (Hewitt & Ganz, 2006; Reuben, 2004). This extended

definition has been questioned by Feuerstein (2007), who considers that family and significant others should not be called cancer survivors as they have not experienced cancer biologically or functionally, or in a social or emotional equivalence to the person living biologically with the diagnosis. Whilst the experience of the family and caregivers are important due to their functional and emotional role in supporting the individual, for the purpose of this thesis cancer survivors will be defined as only those individuals with a diagnosis of cancer.

1.3 The Cancer Survivor and Survivorship

For those with a diagnosis of cancer, survivorship begins the day of diagnosis and encompasses the physiological, social, and psychological effects of the cancer (Aziz, 2002; Bloom, 2001; Hewitt & Ganz, 2006). The term cancer survivorship therefore represents the living of life following a diagnosis of cancer and involves a continual, dynamic process that entails much uncertainty (Bowman et al., 2003; Hewitt & Ganz, 2006; Zebrak, 2000). Miller (2009, p. 4) describes the overall experience of cancer and cancer survivorship as a “complex combination and interaction of physical, emotional and social challenges that occur in a series of phases” including:

- “The period prior to diagnosis when symptoms may be developing but are occult
- The time of diagnosis and the trauma associated with it
- A treatment phase of varying duration and intensity
- A longer period of observation during which the frequency of testing and medical care may decrease

- For some, a long period of non-cancer-related life.”

Due to advancements in diagnosis and treatment, millions of cancer survivors now live with cancer as a chronic illness and have to be cared for with this consideration (Aziz, 2002; Miller, 2009). Longer survival rates present medical service providers and support teams with additional challenges of working to extend a cancer survivor’s life whilst at the same time maintaining quality of life for those individuals (Jacobsen & Jim, 1999). Quality of life is often affected by the cancer experience and can be influenced by disease state and treatment variables (Miller & Massie, 2006). Furthermore, the type of treatment prescribed, the presence of comorbidities, and individual psychological characteristics of the cancer survivor influence the experience of survivorship (Miller & Massie, 2006).

Treatment options vary depending on individual characteristics and the pathophysiological indicators of the cancer. At present, the most commonly utilised forms of treatment are chemotherapy, radiation therapy and surgery, each of which has considerable differences in their side effect profile. Depending upon the type of cancer, *systemic adjuvant* therapy can be recommended following the initial treatments for those who have a high risk of recurrence. Systemic adjuvant therapy is often given following surgery in the hope of destroying any remaining cancer cells, particularly those which may have travelled to other parts of the body, thus reducing the chance of recurrence. This can include hormone therapy, chemotherapy, radiation therapy, immunotherapy and targeted therapy or a combination of these. As with initial treatments such as chemotherapy, radiation and surgery, the side effects of systemic adjuvant therapy can be considerable, and equally as destructive (British Columbia Cancer Agency, 2007).

Side effects of therapies can be immediate and short-term, longer lasting or chronic, and can develop later in treatment, sometime after treatment has ended. Table 1 provides details of the side effects of chemotherapy, radiation therapy and surgery as indicated by The Mayo Clinic (2010). Side effects are not limited to these therapies but occur in all cancer therapies, including those not discussed in this thesis.

Table 1.

Type of treatment and long-term and late side effects of cancer

| Treatment | Long-term side effects | Late side effects |
|-------------------|--|--|
| Chemotherapy | Fatigue Menopausal symptoms Neuropathy Chemobrain Heart failure Kidney failure Infertility Liver problems | Cataracts Infertility Liver problems Lung disease Osteoporosis Reduced lung capacity Second primary cancers |
| Radiation therapy | Fatigue Skin sensitivity | Cataracts Cavities and tooth decay Heart problems Hypothyroidism Infertility Lung disease Intestinal problems Memory problems Second primary cancers |
| Surgery | Scars Chronic pain | Lymphedema |

Internal individual characteristics such as coping ability, adaptation skills, emotional development, a history of losses, locus of control, cognitive flexibility and

spiritual beliefs influence how a cancer survivor copes with their diagnosis and the events that follow (Miller & Massie, 2006; Zebrak, 2000). External and social factors also have a role in providing individuals with support and facilitating their coping (Ell et al., 1989; Miller & Massie, 2006; Zebrak, 2000). A large variation in these factors can result in each cancer survivor having quite different experiences of cancer diagnosis and treatment.

Many survivors have difficulty coping with returning to their “pre-cancer life”. For some cancer survivors, reintegrating into society socially, recreationally and through employment can be challenging. Role changes and relationship issues can become prominent concerns (Gotay & Muraoka, 1998; Jefford et al., 2008). Many cancer survivors report that when they rejoined society there was an expectation from others that they were “back to normal” and things would be as they were before; however this was incongruent with their experiences which were that things were not “normal” (Jefford et al., 2008). They described feeling different and isolated and unable to relate emotionally to others (Jefford et al., 2008).

Although many survivors report a negative impact of cancer and ongoing difficulties post-diagnosis, some survivors have reported beneficial changes. These changes have included a greater appreciation of life and/or a sense of purpose that have resulted in a positive change in perspective for the survivor (Alfano & Rowland, 2006). Many have reported a sudden and irrevocable understanding that life is precious but can end at any time (Jefford et al., 2007; Bowman et al., 2003) which can result in revised priorities in life, changes in lifestyles and values, and a greater connection to spiritual aspects such as faith and religion (Alfano & Rowland, 2006, Bowman et al., 2003; Jefford et al., 2007; Reuben, 2004).

Despite the heterogeneous experiences of cancer and the influence this has on an individual's perceptions and behaviours, there appear to be stages of survivorship that people with cancer progress through. Three different stages (acute, extended, and permanent) have been described as the *seasons or stages of survival* (Mullan, 1985). Each stage has its own distinct challenges which patients need to overcome, often before progressing through to the next phase. Whilst there is no concrete timeframe for each of these stages, they are hypothesised to occur in parallel with treatment phases.

1.3.1 The Acute Stage of Cancer Survivorship

The *acute stage* of cancer survivorship begins at diagnosis, continues through until the initial phase of treatment is completed, and may last for between one month to a year or more. The main focus during the acute stage is the disease itself (Bloom, 2001). The acute stage is an active, busy time that includes treatment, often in the form of surgery, followed by repeat or additional treatments that may be invasive and painful. Research indicates that while most cancer survivors view their experience of cancer in both negative and positive terms, there is a general agreement that the most stressful stage, physically and psychologically, is the acute stage (Bowman et al., 2003).

Following diagnosis, many cancer survivors experience a period of adjustment during which anxiety, fear, depression, and somatic symptoms of distress such as disruption of sleep and appetite occur (Ell et al., 1989; Miller & Massie, 2006). Grief reactions such as denial, anger, bargaining and depression are often part of the process leading to acceptance of the diagnosis and need for treatment (Cheng, 2009). It is at this time that strong familial and social support, strong bonds of

communication and a strong therapeutic relationship with their physician is important for the psychological wellbeing of the patient (Miller & Massie, 2006).

The development of psychiatric symptoms in cancer survivors is not uncommon. Miller and Massie (2006) reported that in a sample of 215 cancer survivors nearly 90% of the observed psychiatric disorders were reactions to, or manifestations of, the disease or the treatment. Out of the 215 survivors, 53% were adjusting normally to the stress and 47% had clinically-apparent psychiatric disorders. Two thirds (68%) of the 47% had adjustment disorders with depressed or anxious mood and of these, 13% had a major depressive disorder. For many cancer survivors, depressive symptoms are often exacerbated by feelings of helplessness and hopelessness perpetuated by the fear of possible recurrence, and fear of pain of future treatments and side effects (Miller & Massie, 2006; Schroevers, Helgeson, Sanderman & Ranchor, 2009). Even once an individual has completed therapy, there is an increased risk of suicide for those with a poor prognosis, higher levels of pain, delirium, depression, and/or a sense of hopelessness that can continue into the permanent stage of survivorship (Miller & Massie, 2006; Lunney & O'Mara, 2001; Schroevers et al., 2009).

Chemotherapy and radiation therapy occur in the acute phase. During and after these therapies, the survivors often experience acute side effects. Side effects may include skin and hair changes, hair loss, pain, chronic fatigue, nausea, cognitive changes, weight gain or loss, sexual and/or reproductive changes, and damage to other organs of the body not previously affected by the cancer (Balducci & Extermann, 2000). These changes often create further difficulties for the cancer survivor to cope with.

Chemotherapy can also reduce the body's ability to fight infection due to its impact of decreasing red blood cells, further intensifying the survivor's experience of being unwell (Yasko & Greene, 2009). Thus many cancer survivors experience an exacerbation of distress and physical symptoms during treatment and can experience intermittent periods of disability, particularly when treatments are combined (Deimling, Bowman, & Schaefer, 2002). The experience patients may face with regards to chemotherapy can be illustrated by a quote from the late Patrick Swayze. When asked about chemotherapy, his response was, "I'm still fine to work, I haven't changed - oh, I have changed, what am I saying? It's a battle zone I go through. Chemo, no matter how you cut it, is hell on wheels" (Nelson, 2009). This illustrates how, whilst many cancer survivors strive for normality through initially minimising their experiences, they often continue to struggle with the challenges of chemotherapy.

Unlike the systemic approach of chemotherapy, radiation therapy is usually localised to the site of the tumour. Therefore the side effects of radiation therapy are often contained to the site of treatment and can include severe and long lasting burning and tissue damage. The side effects of radiation therapy are often intensified by its combination with chemotherapy, thereby increasing the probability of more severe local and systemic side effects.

In order to facilitate coping, many cancer survivors attempt to work or function in their normal routines for as long as they are able through the acute stage (Harpham, 1999). Being busy appears to provide a link to previous normality and is reportedly a preferential distraction to rumination about the cancer, the therapy and possible outcomes of both the cancer and the therapy (Harpham, 1999). One of the

main obstructions to this, however, is the level of fatigue that most cancer survivors undergoing treatment experience. Fatigue affects between 70 – 100% of cancer survivors and whilst it is a subjective experience, fatigue has a profound effect on the ability for cancer survivors to function normally (Ahlberg, 2003, as cited in Cramp, 2008).

An additional challenge throughout cancer treatments and recovery, are the need to come to terms with the many losses associated with a cancer diagnosis. Research has indicated that the initial stage of cancer carries with it the “critical attributes of a traumatic life event that is characterized by loss and crisis” (Filipp, 1992, as cited in Deimling, Bowman, & Schaefer, 2002, p. 479). Losses experienced can include loss of job, of role (i.e. breadwinner, lover, and home-maker), of physical comfort (i.e. pain, loss of hair and loss of limbs), of personal control (feeling as though life is out of control), of relationships, and of financial security (Harpham, 1999; Bloom, 2001). The previously mentioned side effects such as physical and emotional fatigue can often further exacerbate the sense of loss and helplessness for many survivors (de Boer-Dennett et al., 1997).

1.3.2 The Extended Stage of Cancer Survivorship

The *extended stage* of cancer survivorship begins when the initial treatments have ended. The extended stage is the period in which cancer recurrences are most likely to occur (Bloom, 2001). In addition to the potential threat of recurrences, the extended stage of survivorship is the phase in which interpersonal issues such as changes in relationships, re-employment challenges and sexual dysfunction are most salient (Bloom, 2001; Hewitt & Ganz, 2006) as the patient attempts to return to “life before cancer”.

According to USA figures, 25% of older adult cancer survivors continue to experience clinical levels of depression after the initial treatment has ended (Deimling et al., 2002). Whilst these statistics are consistent with the epidemiology of mood disorders in the general population, it is likely that cancer has contributed significantly to an increased probability of a depressive diagnosis. It is likely that this distress is perpetuated by the losses experienced, the physical effects of cancer, the changes in relationships with the health care practitioners, adjustments in social relationships, isolation, and changes in social support systems (Hoffman, Welch-McCaffrey, Leigh, Loescher, & Meyskens, 1989; Zembrak, 2000) that occur during the extended stage.

For many cancer survivors' medical support is usually reduced during the extended stage, except for those receiving ongoing treatments. As the medical support withdraws, many cancer survivors reportedly find themselves feeling alone during this time with only the support of their closest family members (Jefford et al., 2007). In New Zealand, additional support is available in the form of social services such as the New Zealand Cancer Society, and the numerous individual volunteer cancer support organisations available for advice and assistance. Unfortunately many survivors do not access this support as they are unaware it is available to them and such agencies are unable to contact patients due to patient privacy legislation.

Often, during the extended stage, there is an erroneous assumption made by caregivers that as the cancer is gone the survivor no longer needs support (Jefford et al., 2007; Stanton et al., 2005). However, whilst the initial threat has been removed, late effects and adjustment issues still occur. Late effects, as previously listed in Table 1, are side effects of the different cancer treatments that can appear months and

sometimes years after treatment has been completed. Such effects can include physical problems including fatigue and infertility, psychological issues such as mood disorders and anxiety, and secondary cancers (Bloom, 2001; Hewitt & Ganz, 2006). Late effects are most salient during the extended stage (Bloom, 2001; Mullan, 1985, as cited in National Brain Tumour Society, 1989). The cancer survivor, caregivers and perhaps the local nurse and general practitioner are left to deal with late effects and other issues of health that arise.

During the extended phase of treatment the responsibility of monitoring for recurrence is no longer the ultimate responsibility of the medical team but falls more to the survivor. Being left to largely self manage can exacerbate the fear of recurrence many survivors cope with during the extended stage (Allen, Savadati & Levy, 2009). For many, ongoing health anxiety develops and survivors can become hyper-vigilant for signs of a potential recurrence (Alfano & Rowland, 2006) and can further perpetuate their distress.

Many cancer survivors report the period after treatment is worse than the treatment itself (Hewitt & Ganz, 2006). This is reportedly due to survivors needing to cope with the effects of cancer and then the changes in the support they receive. Many are not aware of these issues until they need to deal with them, as perhaps illustrated in the following quote: *“After my very last radiation treatment for breast cancer, I lay on a cold steel table hairless, half-dressed and astonished by the tears streaming down my face. I thought I would feel happy about finally reaching the end of treatment, but instead I was sobbing. At the time, I wasn’t sure what emotions I was feeling. Looking back, I think I cried because this body had so bravely made it through 18 months of surgery, chemotherapy, and radiation. Ironically, I also cried*

because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned and terrified. This was the rocky beginning of cancer survivorship for me...” (McKinley, 2000, as cited in Rowland et al., 2008, p. 5101). This quote highlights the mixed emotions and feelings of confusion that survivors can experience.

In addition to the emotional distress experienced during the extended phase, chronic fatigue can also become an issue. Fatigue is reported to be one of the most common and longest lasting side effects among cancer survivors. It can be both caused and aggravated by anaemia, the pain and discomfort of treatment processes, and the accumulation of toxicity from cell destruction caused by chemotherapy or radiation treatments. Furthermore, the practical and emotional challenges that accompany cancer also perpetuate feelings of fatigue (Harpham, 1999; Yasko & Greene, 1989). Fatigue further exacerbates the emotional and practical difficulties experienced by a cancer survivor by negatively impacting on concentration, increasing emotional dysregulation, decreasing memory, increasing malaise and reducing sexual desire. Many psychosocial problems, such as difficulty coping with family dynamics, failure to perform job responsibilities, and reduced interest and ability to engage in social interactions, can also occur as a direct result of fatigue or can be perpetuated by it (Harpham, 1999; Yasko & Green, 2009).

While fatigue becomes an issue very early in treatment when the physiologic effects of interventions, medications and everyday stressors are at their peak, it can last well into the permanent stage (Harpham, 1999; New Zealand Cancer Society, 2006). Many survivors report that energy limitations are often more difficult to manage than the other challenges of survivorship. For those survivors that experience

a sense of “time running out” and the need to “finish off unfinished business”, chronic fatigue can diminish their ability to do so, thus intensifying their distress (Harpham, 1999). For many patients there is the added sense of guilt that, because of their lack of energy and the associated problems fatigue creates, they are unable to function as they had before and that they may possibly be adding to the burdens upon their families (Alfano & Rowland, 2006).

Sexual dysfunction and body image issues also become more apparent in the extended stage, particularly for those with breast cancer, gynaecological, colorectal and prostate cancers (Alfano & Rowland, 2006; Bloom, 2001). Hormonal therapies may create early menopause or menopausal symptoms in women such as hot flushes, mood swings and vaginal dryness, and for men a difficulty getting or maintaining an erection. An inability to achieve orgasm and loss of interest in sex are also common in both genders (Alfano & Rowland, 2006; Kattlove & Winn, 2003). These symptoms affect not only the cancer survivor but those that they are in a relationship with (New Zealand Cancer Society, 2007). Infertility may also result as the direct effect of treatment and can impact upon an individual’s self esteem and quality of life during remission (Alfano & Rowland, 2006).

1.3.3 The Permanent Stage of Cancer Survivorship

For those patients that survive their cancer, the *permanent stage* is the final stage of survivorship that begins when the probability of recurrence has diminished and continues for the rest of the survivor’s life (Bloom, 2002). Miller, Merrie and Miller (2008) suggested that cancer survivors within the permanent stage are a heterogeneous group of people comprising four sub-groups which include:

- “Survivors who are cancer-free but are not free of cancer
- Survivors who are cancer-free but continue to experience long-term and late effects of cancer and treatment including psychological, medical, financial and legal sequelae
- Survivors who develop second cancers – either related or unrelated to the first cancer or its treatment; who have a genetic predisposition; or through environmental factors
- Survivors who develop later cancers that are secondary to the initial treatment” (p. 369).

In addition to late effects, long term effects of therapy can occur. Long term effects that can develop but are not limited to this stage, can include the increased probability of secondary cancers developing and the anxiety about the cancer returning, and the development of secondary pathologies such as heart disease and infections. These problems can occur due to reduced immune function and some could have begun in the extended stage (Alfano & Rowland, 2006; Bloom, 2001; Hewitt & Ganz, 2006).

Some of the physical and psychological changes that last well into the permanent stage occur because of long-term effects of treatments including surgeries such as amputations, colostomies, loss of the use of limbs, and permanent loss of hair (Reuben, 2004). Some individuals experience disfiguring scars, which may reduce their self-esteem and inhibit relationships with other people (Alfano & Rowland, 2006; MD Anderson Cancer Centre, 2009; Reuben, 2004) and have been associated with difficulties in psychosocial adjustment (Krouse, Ferrel, Dean, Nelson, & Chu, 2007). Others can develop chronic pain syndromes that seriously affect cancer survivors on levels of physical and psychological quality of life (Portenoy, 2007).

Research on an older cohort of long-term cancer survivors revealed that nearly 25% of respondents reported clinical levels of depression regardless of type of cancer, ethnicity or gender (Deimling et al., 2002), indicating that clinicians should be aware of the increased risk of depression in older cancer survivors.

1.4 Terminal Diagnosis

Cancer survivorship is not just about those who survive for years, for many do not. Cancer survivorship is a process regardless of the outcome, whether there is death by cancer or by some other means (Lunney & O'Mara, 2001). If the definition of a survivor is about an individual's battle from diagnosis throughout treatment until their time of death, then those who have only a terminal or short-term prognosis also need to be considered. Impending death is rarely an openly discussed topic in Western society and many people are uncomfortable around those who are dying or have recently lost someone (Holland, 2003; Kubler-Ross, 1969). For many, it is not that they do not care, but more likely that they do not know what words to say in such an emotional situation, or that fears of their own immortality are triggered (Faulkner, 1995; Kubler Ross, 1969). This often results in reduced support for those with a terminal diagnosis.

Most people who have received a terminal diagnosis experience stages of denial, anger, fear and guilt. These mood states negatively impact upon the quality of an individual's remaining life (Alfano & Rowland, 2006; Lunney & O'Mara, 2001) and have the potential to prevent the individual reaching acceptance. The realisation that they face a progressive deterioration in their physical functioning and an increasing dependence on their families and support groups can weigh heavily

(Lunney & O'Mara, 2001). For those who have been employed, the inability to continue to provide for their family can raise economic, legal and self esteem issues for both the patient and the family (Lunney & O'Mara, 2001). For some there are issues of increasing pain, which further functionally debilitates them and limits physical activities (Ganz, 2001). This can exacerbate the psychological distress that the individual faces. However, if an individual works through these issues and reaches acceptance, they are more likely to experience an improved quality of life for the time they have remaining (Alfano & Rowland, 2006, Holland, 2003).

For many medical professionals a terminal diagnosis means the end of their role with the patient. Care is usually turned over to the palliative medical professionals and caregivers. Other patients, particularly those from a rural area, are often sent home to be with their families. In this situation it is usually the local district nurse or GP that takes over the final weeks or months of care. Those who remain in hospital until the end can often feel isolated and alone and may not have their emotional needs met. The following quote is an example of a person's observation of his father's experience of being in hospital with a terminal diagnosis. This quote highlights the father's difficulties in coping, not only with the effects of the disease but also with his impending death: *"... nor were any ideas offered as to how he could at least improve the quality of life he had left to live, regardless of how short a time that might be. Perhaps most distressingly absent of all were any suggestions of what he might do to deal with the mental, emotional, and spiritual aspects of all that he was experiencing; the tremendous fear and sense of loss associated with losing control of his body; the horrible sense of never being able to feel normal again; the loss of energy and strength; the end of his life as he had*

known it before; and the end of his life altogether. Somehow unbelievably, he was left totally on his own to deal with all these issues...” (Geffen, 2000, p. 3).

1.5 Summary

This chapter has discussed the varied nature of cancer, its influence on the survivors and the types of therapy that individuals may undergo. It has also explored the stages of survivorship and the individual challenges faced by cancer survivors. Within each stage, individual and therapeutic challenges have been described, including challenges that are unique to each stage, and challenges that run throughout the experience of survivorship. Whilst each individual experiences cancer survivorship differently, there appear to be common themes of losses, functional disability, and emotional distress.

However, there are factors that play a role in how survivors experience quality of life: such as social support, socio-economic status, and access to healthcare, transportation, employment, cultural differences, financial considerations, ethnic disparities and lifestyle. These variables are therefore important when considering the experience of cancer, and need to be researched further to develop a better understanding of their moderating abilities of the quality of life for the cancer survivor. Given this, these variables will be discussed in more detail in Chapter Two.

CHAPTER TWO: FACTORS THAT AFFECT THE QUALITY OF LIFE OF CANCER SURVIVORS

2. Introduction

The survival rates of patients with cancer have improved dramatically with advances in technology. However, the *quality of life* (QOL) of cancer survivors continues to be influenced by several key individual and socio-demographic factors beyond the disease itself. At an individual level, QOL can be affected by variables such as psychological makeup, locus of control (perceptions about cancer and its therapies), health behaviours and comorbidities. Socio-demographic factors include social support, socioeconomic status, employment status, age, access to healthcare, ethnicity and factors relating to the individual's environment. These factors are varied in their influence on the experience of cancer survivorship, and the complex interplay between them can exacerbate the impact cancer has on an individual. Despite the differences, understanding the effects of these variables is fundamental in understanding the challenges that can arise during cancer survivorship and how these may impact on quality of life.

2.1 Quality of Life (QOL)

According to the World Health Organization's definition of health, QOL relates to the "absence of disease and infirmity", and includes a "positive state of physical, mental, and social well-being" (Whalen & Ferrans, 1998, p. 276). Other studies suggest that QOL is a multidimensional framework consisting of four separate dimensions including physical well-being, psychological well-being, social

well-being and spiritual well-being. There is an interaction effect between each of these dimensions giving each the potential to affect the others (Ferrell & Dow, 1998). Another definition describes QOL for a cancer survivor as subjective, and influenced by individual circumstances, levels of pain, attributions of self, the individual's ability to function 'normally' and their perceptions of themselves and their roles in the world around them (Zebrak, 2000) and that the impact of cancer upon quality of life is likely to vary by cancer site and type of treatment (Gotay & Muraoka, 1998).

Some empirical research has suggested that QOL for many cancer survivors is associated with the ability to integrate the cancer experience into one's self concept. This occurs by drawing meaning from the experience, creating changes in one's life priorities and accepting one's mortality (Zebrak, 1990). Some studies report that the impact of cancer has had a significantly higher positive effect on mental quality of life and a significantly lower effect on physical quality of life (Zebrak et al., 2008). Therefore quality of life for cancer survivors has been measured in this study on two dimensions, Physical QOL and Mental QOL.

Physical QOL for cancer survivors can be defined as the "presence and severity of multiple symptoms and the level of distress caused by symptoms that go untreated or unrelieved" (Burkett & Cleeland, 2007, p. 1). In cancer survivors, untreated symptom burden may have a high detrimental impact on an individual's level of physical functioning thereby reducing quality of life (Vachon, 2001). An example of this is when men who undergo treatment for prostate cancer experience physiological effects of the treatment such as erectile difficulties, loss of muscle mass, bowel and bladder incontinence, breast enlargement and liver dysfunction (Burns & Mahalik, 2006). Research also indicates that Physical QOL may be

influences by low incomes and high comorbidity (Zebrak, Yi, Petersen, & Ganz, 2007) and this may be due to the additional hardships experienced with multiple conditions and low socioeconomic status.

Physical QOL can be complicated by external factors and lifestyle choices such as diet, sedentary habits (lack of exercise), risk taking behaviours (misuse of alcohol and drugs and using unsafe equipment including vehicles), tobacco use and unsafe sexual practices (Durie, 1999). Individually or combined, each of these can reduce quality of life of cancer survivors, intensifying the severity and increasing the risk of secondary cancers. As discussed in Chapter One many cancer survivors live with long-term physical effects from cancer that negatively impact on their Physical QOL and this in turn may impact upon Mental QOL.

Mental QOL is affected by psychological, physiological, social and emotional challenges including depression, physical morbidity and sexual functioning and also existential issues (Bloom et al., 2007). In cancer survivorship mental QOL could be associated with a survivor's ability to come to terms with and accept the changes that have occurred in his or her life due to the diagnosis and treatment of their cancer. Research indicates that mental/psychological well-being involves maintaining a sense of control despite facing a potentially life-threatening illness, emotional distress and a fear of the unknown (Ferrell & Dow, 1997). Many cancer survivors constantly appraise their situation on a psychological level, whether it is assessing each ache or pain as a potential recurrence of the cancer, seeking or re-entering employment, encountering stimuli that reminds them of their own experience, or addressing relationship issues (Yasko & Greene, 2009; Zebrak, 2000). This type of ongoing psychological pressure has the potential to negatively affect quality of life

levels (Zebrak & Zeltzer et al., 2003) and research indicates that this is particularly prevalent in cancer survivors who suffer from anxiety (Whitaker, Watson, & Brewin, 2008).

As previously mentioned there are several key variables that influence a cancer survivor's quality of life. These are now discussed in more detail below.

2.2 Locus of Control

The concept of *locus of control* (LOC), developed by Julian Rotter (1966), describes how an individual perceives events in their lives and how they attribute the causal factors of those events. LOC is a personality trait that falls on a continuum running between high internal LOC (e.g. "I control the outcomes in my world") and high external LOC (e.g. "I have no control over what happens to me"). Based on his observations, Rotter believed that LOC attributions are developed through past experiences but influence the perception of present events (Rotter, 1966; Fournier & Jeanrie, 2003). These expectations of causal outcomes are based upon the individual's perception of a situation, rather than the situation itself. LOC representations have a causal influence on choices, behaviours and outcomes (Rotter, 1966; Fournier & Jeanrie, 2003).

People with a high internal LOC tend to consider events that happen in their lives as being a result of their own choices and behaviours. They actively seek information and learn ways of taking control of situations that arise (Crisson & Keefe, 1988; Chen, Deng, & Chang, 2001). People with a high external LOC are more likely to view events that occur as being controlled by other people or things,

or alternatively tend to attribute blame to others, or to fate or chance. They feel they have little control over their lives and are less likely to seek solutions for issues or problems that arise (Crisson & Keefe, 1988; Chen et al., 2001). For example, following a diagnosis of cancer, a person with a high internal LOC may actively seek treatment and engage in adaptive health behaviours, whilst a person with a high external LOC may wait for their doctor to provide them direction and be passive in their treatment plan.

The Locus of Control construct has been conceptualised as an enduring or stable personality variable that can influence how an individual predicts various health outcomes (Chen et al., 2001; Fournier & Jeanrie, 2003). Despite the hypothesised enduring nature of LOC, research has shown that a traumatic life experience such as a diagnosis of cancer can undermine a person's sense of control (Derks, de Leeuw, Hordijk, & Winnubst, 2005). For example, a previously high internal LOC in cancer survivors who are experiencing chronic pain can be reduced, so that the cancer survivors doubt their ability to cope and become increasingly dependent upon external factors (Chen et al., 2001; Crisson & Keefe, 1988). Therefore the constant stressor of pain influences the individual's sense of control over outcomes.

It was initially hypothesised that an internal LOC was positive and an external LOC was negative. The Powerful Other People Health Locus of Control scale (Watson et al., 1974) measures external control and was administered to prostate cancer patients to assess beliefs that family, friends or peers are important assets in controlling the progression of prostate cancer. The results showed that the men in poor physical health who believed that family, friends and peers had more

control over outcomes in health scored higher positive mental health than those who did not (Burns & Mahalik, 2006). This therefore indicated that the perception that others are in control of their health outcomes leads to greater well being in this population.

Alternatively, research has indicated that there may be a relationship between passive coping, a feature of external LOC, and depression and psychological distress in chronic pain patients (Snow-Turek et al., 1996). Those people who have the ability to actively cope with stressful situations, a feature of high internal LOC, tended to cope better and experience less depression and anxiety than those who cope passively (Chen et al., 2001). In research that tested the coping abilities between a young cohort and an older cohort of cancer survivors, results showed that young people used more internal control than older people, who tended to use religious control (external LOC). Despite the differences in coping and attribution styles, there were no differences in the quality of life or levels of depression between the two groups (Derks et al., 2005). Whilst there is much research about LOC, findings are varied in terms of the influence of LOC on QOL. Further research needs to be conducted to determine the relationship between these two factors.

2.3 Healthcare Behaviours - Physical Activity and Fatigue

It is common knowledge that physical activity is associated with good health, whereas poor life-styles and maladaptive health behaviour can have serious negative effects on health (Baken, 2003). Research shows that increasing physical activity, improving dietary habits, decreasing smoking and alcohol abuse, and reducing sun exposure not only increases a sense of well-being and improves quality of life, but

also may reduce cancer-related morbidity (National Cancer Institute, 2009). Increasing physical activity after a diagnosis of cancer has also been shown to be beneficial in improving quality of life for the cancer survivor by reducing fatigue and balancing energy (Cramp, 2008; National Cancer Institute, 2009).

Research has indicated that the drive to engage in physical activity is dependent upon two factors, (a) *self-efficacy*, defined as the confidence of being able to do specific and desired levels of physical activity, and, (b) *intrinsic motivation* – defined as enjoying physical activity. Both of these factors are reported to be related to differences in physical activity levels and health expectancies (SPARC, 2003). However for many cancer survivors the motivation to engage in physical activity can be hindered by fatigue (National Cancer Institute, 2009) and the loss of confidence that may experience following treatment may impact on self efficacy.

As mentioned previously, fatigue affects between 70–100% of cancer survivors and it has a profound effect on the ability to exercise and perform at functional levels (Ahlberg, 2003, as cited in Cramp, 2008; Harpham, 1999). However if the initial burden of fatigue can be overcome enough to begin exercise, the benefits are reported to improve cancer survivors' quality of life and to have a positive effect on cancer outcomes. In one study with breast cancer patients, participation in an exercise programme resulted in significant improvements in fatigue levels during and after cancer therapy (Cramp, 2008). In another large study of breast cancer survivors, significant positive health outcomes were shown amongst women who had increased exercise, modified their diet and actively engaged in wellness activities (Ganz et al., 2002). In colon cancer research, participants who had

higher levels of physical activity post-diagnosis were less likely to have a second recurrence and had increased survival (Johnston & Abraham, 2000).

2.4 Comorbidities (Total Number of Diagnosed Illnesses)

The Webster's New World Medical Dictionary (WebMD, 2008) defines comorbidity as the coexistence of two or more disease processes present in any one being. The risk of comorbidities increases with age, with those over 70 years having on average three comorbid conditions that affect functioning (Deimling et al, 2009; Extermann, 2007). Age related health issues such as arthritis, osteoarthritis, rheumatism, blood pressure, heart problems and diabetes are commonly found in older adults and are often comorbid with cancer (Extermann, 2007). Comorbid conditions need constant assessment as they affect risk, detection, progression and treatment of cancer, and place the elderly cancer survivors at further risk of developing additional cancers (Deimling et al., 2009; Extermann, 2007; New Zealand Health Information Service, 2005). For instance, diabetic patients have increased incidences of colorectal cancer, a greater risk of breast cancer, and at least a twofold increased risk of pancreatic cancer above patients who do not have diabetes mellitus (Extermann, 2007).

The complexities of comorbid conditions can also create complications when it comes to managing the treatment of the comorbidities in conjunction with the specialized treatment of cancer (Balducci & Extermann, 2000; Extermann, 2007). Several studies have been undertaken to ascertain whether a relationship exists between comorbidity and cancer prognosis. The results have been varied depending

on the type of comorbidity and the type of cancer; however findings indicate that comorbidity modifies the treatment of older patients and therefore may influence survivorship (Balducci & Extermann, 2000; Extermann, 2007; Hewitt et al., 2003; Repetto, 2003). Research indicates that the presence of comorbidities has a detrimental effect on the quality of life and functioning status of cancer survivors, particularly on women and those in ethnic minorities (Deimling et al., 2009).

2.5 Social Support

Social support defines the mechanisms by which interpersonal relationships are assumed to protect people from the damaging effects of stress (Bottomley & Jones, 1997). There are several models of social support that examine both its components, and the effect that these have on the support and the individual receiving the support. One model divides social support into several components that often overlap (Wasserman & Danforth, 1988 as cited in Bottomley & Jones, 1997). These components are:

- a) Informational (e.g. provision of information, accessing of information on behalf of the patient)
- b) Emotional (e.g. validation or agreement with feelings, reassurance of being loved, etc)
- c) Instrumental (e.g. functional support in the form of transport or finances)
- d) Affirmation (e.g. continued engagement in family activities)
- e) Appraisal (e.g. supporting the patient with feedback about a situation).

All of these components have distinct roles in supporting the patient and facilitate coping through different mechanisms. Emotional and instrumental supports have been regarded to be the most important constructs of social support as they have the strongest correlations with positive health outcomes (Wasserman & Danforth, 1988, as cited in Bottomley & Jones, 1997).

Social support theories tend to differentiate between three key variables that influence the usefulness of the social support: “perceived availability of support, actual received amount of support, and the extent to which this amount of received support fits the needs of the person, thus satisfaction with actual received support” (Thoits, 1999, as cited in Schroevers et al., 2009, p. 2). Perceived availability of support and satisfaction with actual support have been shown to have the strongest positive effects on reducing distress and negative affect (Chen et al., 2001; Schroevers et al., 2009) both of which are found throughout all three phases of cancer survivorship.

There has been much research over recent years on the concept of social support and the effect it has on the quality of life of cancer survivors. Although methodologies of this research have been varied, outcomes have consistently indicated that social support has a positive impact on quality of life in cancer survivors and their families. More specifically, for quality long-term cancer survivorship, families that take an active role in the treatment of the survivor report higher levels of optimism towards positive outcomes (Bowman et al., 2005). For example, research by Schroevers, Helgeson, Sanderman and Ranchor (2009) found that support by family and friends in the immediate 3-months following diagnosis, predicted more positive experiences and outcomes when followed up 8-years later.

The social support demonstrated by caregivers included comforting the patient, problem solving and reassurance (Schroevers et al., 2009). Whilst this is appraisal and emotion support, other research has shown that emotional support alone has the strongest positive effect with adjustment to cancer (Chen et al., 2001).

For cancer survivors, social support describes services, usually within the survivors' home environment, by which cancer survivors are supported by family/whānau, friends, social support agencies and others to facilitate adjustment to the challenges of living with cancer (Ministry of Health, 2008). Many family members take instrumental roles in supporting a cancer patient by acting as *health maintenance advocates* (Bowman, Rose, & Deimling, 2005). Health maintenance advocates are normally family members or close friends who are trusted and whom interact with medical teams discussing and interpreting treatment options, side effects and cure as well as providing transport, company, meals and other necessities in the home (Bowman et al., 2005).

A loss of social support as can occur in the extended stage of survivorship can result in a limiting of communication between the medical services and the cancer survivors, particularly for those who have depended upon advocates to speak for them. This can result in survivors and their families leaving cancer treatment without knowledge as to the treatments and care received while they were ill, without information on what follow-up care they should receive and what to expect in terms of late or long term effects (Reuben, 2006). Research indicates that a lack of information can significantly increase anxiety and impact on the quality of life the survivor experiences (Jefford et al., 2007).

Family and friends often have their own distress to cope with and many are unable to give the cancer survivor the attention they may need (Bottomley & Jones, 2009). This can be particularly distressing for the patient, who may feel abandoned or resentful and as though they are not emotionally supported when his or her need is greatest (Galinsky & Schopler, 1994, as cited in Bottomley & Jones, 2009). Consistent with this, research has indicated that for many cancer survivors the perceptions of family distress following diagnosis are related directly to their own negative appraisals of cancer, and indirectly to decreased well-being in long-term survivorship (Bowman et al., 2003).

2.6 Socio Economic Status (SES)

According to the American Cancer Society (2007) the primary cause of disparities in cancer incidence and death amongst the United States of America (USA) population (particularly between African American and Anglo Americans) is poverty. International research indicates that access to medical care and appropriate cancer treatments are major determinants to health outcomes, and that the quality of treatment patients receive is often dependent upon socio-economic status factors (SES) such as income levels, availability and affordability of insurance, ethnicity and race (Singh, Miller, Hankey, & Edwards, 2003; Jack, Gulliford, Ferguson, & Moller, 2006). This is supported by recent studies that have identified disparities in the stage at diagnoses of cancers amongst cancer survivors from lower SES areas, and variances in the treatments offered, resulting in significantly higher mortality rates, higher numbers of recurrence and poorer outcomes (Greenwald et al., 1998; Haynes et al., 2008; Shavers & Brown, 2002; Singh et al., 2003).

Shavers and Brown (2002) identified racial disparities for patients in the UK indicating institutionalised bias in the provision of definitive treatments, conservative and adjuvant therapies for cancer survivors from different ethnic backgrounds and lower SES. This is supported by research indicating that women diagnosed with breast cancer in low socio-economic areas were more likely to have a later diagnosis, and to receive less aggressive cancer treatment, than their counterparts in higher socio-economic areas (Singh et al., 2003). In another study low SES was a strong predictor of mortality among individuals from racial/ethnic minority groups and for those aged over 65 years (Byers et al., 2008). Further research in USA suggests that lower SES has a more significant influence on the treatments and outcomes of cancer than ethnicity (Bradley, Givens & Roberts, 2002; Byers et al., 2008) and was associated with a more advanced disease stage and less aggressive treatment (Byers et al., 2008). Other factors that have been found to be linked to low SES that may influence health outcomes include a greater exposure to occupational hazards, maladaptive sexual practises, and late cancer screening (Singh et al., 2003).

In New Zealand there are disparities in the incidence, mortality and survival among cancer patients across ethnic and socioeconomic groups, highlighting the relationship between ethnicity and socioeconomic position and the outcomes of cancer (Jeffreys, Sarfati, Tobias, Lewis, Ellison-Loschmann, & Pearce et al., 2005). Using the New Zealand Deprivation Index to identify aspects of material and social deprivation, Jeffreys et al., (2005) reported that for the majority of cancers there was good evidence of a deprivation gap between low and high socioeconomic status participants. They state that in New Zealand late-stage diagnoses account for some of the disparities; however they suggest that a lack of access to specialised cancer

services and poorer quality of care could contribute to these outcomes (Jeffreys et al., 2005).

Smoking, alcohol and other high risk behaviours may also explain some of the difference of rates on cancer in lower SES. For example, the prevalence of smoking is approximately three times higher among those in deprived living areas and smoking is shown to adversely affect cancer survival (Jeffreys et al, 2005). Comorbidity is also another factor that affects the outcomes of cancer and those in more deprived areas of New Zealand have a higher rate of ischemic heart disease, diabetes and chronic respiratory disease than those living in less deprived areas (Ministry of Health, 2008). While the presence of comorbidities is not directly related to higher mortality, it makes treatment of cancer more difficult and can account for some of the disparities in survival rates (Jeffreys et.al, 2005).

2.7 Employment

For cancer survivors, ongoing employment depends upon the prognosis of cancer, the type of treatment, attributes of the actual job, the work environment, levels of support, and communication with employers and fellow employees (Steiner, Nowels & Main, 2009). For many cancer survivors, returning to work can be imperative, and research indicates they regard returning to work as a sign of having attained complete recovery (Kennedy, Haslam, Munir, & Pryce, 2007; Peteet, 2000; Spelten, Sprangers, & Verbeek, 2002). Working helps to maintain a semblance of normality and health and provides emotional and financial support for the cancer survivor (Kennedy et al., 2007; Peteet, 2000; Rasmussen & Elverdam, 2008).

Being able to continue or return to work is thought to be important for a person's identity and feelings of control in a situation that appears to be out of personal control (Petee, 2007). By working, individuals integrate themselves into society on a social level through which relationships are formed. Work can provide a form of structure and order in everyday life, and provides a sense of identity and companionship for an individual (Rasmussen & Elverdam, 2008).

Many cancer survivors face challenges such as the discrimination of employers, and fatigue and physical or mental limitations that may affect their chances of regaining pre-cancer status within the workplace (Rasmussen & Elverdam, 2008; Steiner, Nowels & Main, 2009). Research indicates that at least one in five cancer survivors have experienced cancer related discrimination, whether subtle or blatant, up to five years after diagnosis and treatment (Hewitt & Ganz, 2006; Rasmussen & Elverdam, 2008). As previously mentioned side effects can substantially affect a particular individual's ability to work and can impact on the individual's immediate ability to perform a job. Conversely, emotional problems related to cancer are not as obvious to the onlooker and therefore are less easily recognised or tolerated by co-workers and employers. This often results in even less understanding and accommodation of the survivor into the work place (Rasmussen & Elverdam, 2008).

Difficulties in establishing or re-establishing relationships at work often arise as many cancer survivors suffer poor self-esteem, depression, resentment and feelings of isolation (Hewitt, Breen, & Devesa, 1999). Employment issues may also vary according to gender. Survivors of breast cancer and cancer of the female reproductive organs appear to have a higher risk of unemployment as opposed to

those surviving blood cancers, testicular and prostate cancers (de Boer, Taskila, Okakarvi, van Dijk, Verbeek, 2009). Despite these findings, research in USA indicates that most cancer survivors who were employed before they were diagnosed with cancer continued to work; however many required some form of accommodation by the employer to do so (Hewitt & Ganz, 2006).

Some cancer survivors report that once they have returned to work they find their priorities have changed. Being able to return to work gives them a sense of well-being and they are more interested in job satisfaction than they were before they became ill (Rasmussen & Elverdam, 2008). Salary and hours of work can become less important than 'quality of life through work.' Some choose to work shorter hours, others change the type of employment to something more meaningful, and others begin to consider their retirement where previously they had not thought about it at all (Rasmussen & Elverdam, 2008).

2.8 Age

According to research, age is the most significant risk factor for developing cancer (Aziz, 2002; Extermann, 2007) with approximately 60% of American cancer registrations occurring in people aged 65 and over (Avis & Deimling, 2008; Aziz, 2002; Hewitt et al., 2003). These statistics are similar in New Zealand also. The New Zealand Health Information Service (Ministry of Health, 2005) indicates that New Zealand cancer registrations are higher in the older age groups, with those in the 65-74 years age-group accounting for 25.7% of all new cancer registrations and 24.2% of all cancer deaths in 2005.

With aging comes the natural progressive decline of the body's physical functioning and organs systems (Balducci & Extermann, 2000), with the incidence of malignancy in older patients is known to increase progressively with age (Ershler, 2003). This may be related to a prolonged exposure to carcinogens over the lifetime or because age related changes in the organism produce a more favourable environment for latent malignant cells (Anisimov, 2007). Another theory is that age related cancers could be attributed to the length of time that some tumours take to develop, reflecting the complexity of certain carcinogenic steps required for tumour growth (Ershler, 2003).

Ganz (1997) stated that the older patient's life goals and concerns must be considered when deciding the course of possible treatment, primarily because cancer therapies are toxic, especially to the older patient, and "trade-offs must be weighed between the serious toxicities and the length of life remaining" (p. 1323). This is supported by Balducci & Extermann (2000), who suggested that the benefits of treatment must outweigh the damage that specific treatments can cause. Ganz (1997) described the special requirements that many older cancer survivors need to experience a good quality of life. These include social support to combat the increased dependence and social isolation which occurs for many elderly, as well as support with existential and spiritual issues that older people often face regardless of having cancer or not. Such factors are likely to impact on the quality of life an older cancer survivor experiences.

Research has indicated that age is a predictor of quality of life outcomes. In a study of older adults by Zebrak, Yi, Petersen, and Ganz (2008), investigating the impact of cancer on long-term cancer survivors, results showed that while older

cancer survivors reported poorer physical health than their younger counterparts, they reported better mental health. This indicates that older cancer survivors appeared to cope better psychologically with their diagnosis. Ganz (1997) suggests this could be a result of older adults having a lifetime of experience in dealing with serious life events or perhaps having less responsibilities in life compared to younger cancer survivors. However, research suggests that older cancer survivors are often unlikely to challenge the doctor's decisions preferring to let the doctor make the decisions on their behalf (Ganz, 1997) thus they run the risk of reducing their own sense of well-being.

2.9 Healthcare Utilisation and Access to Healthcare

A diagnosis of cancer and its proceeding treatment results in a greater need for access and utilisation of healthcare resources. However, some cancer survivors in New Zealand do not have immediate access to the healthcare services they require, and others do not utilise the services available to them. Many factors contribute to this, including transportation issues, geographical isolation, difficulties with negotiating healthcare services, and a lack of awareness of what services are required or available.

In New Zealand cancer treatment is largely centred in the six main centres, Auckland, Hamilton, Palmerston North, Wellington, Christchurch and Dunedin (Haynes et al., 2008). In rural areas such as the East Coast of the North Island, Bay of Plenty region and the Far North, treatment centres and pharmacies are minimal and cancer survivors are required to travel long distances to receive treatment and medication. This makes access to specialists and medication difficult for many,

especially those who depend upon costly public transport, should it be available, or others to transport them. Although General Practice surgeries in more deprived areas may have lower consultation charges, they are less likely to offer payment plans or deferred payments, which also results in fewer patients accessing their care (Barnett & Barnett, 2001).

A recent survey in Auckland medical centres have shown that at least one third of their patients visited less often in recent years, with the most cited reason for non-attendance being the cost of medical visits (Barnett & Kearns, 1996). It was discovered that people with the least ability to pay for a consultation were most likely to have the poorest health and be the least likely to attend a doctor's appointment despite their need (Ministry of Health, 1999). Of those that do seek medical attention, many have switched GPs seeking lower costs or because credit was not available with their current GP. Failure to present early for assessment due to the cost of the medical consultation significantly reduces the likelihood of early detection of cancers, and therefore reduces the chances of survival.

As the *pay-for-service* charge has increased, the availability of good health care to many families in the primary care environment has decreased. Primary care is an essential component of health care and higher use leads to a higher chance of earlier diagnosis of cancer (Parchmand & Culler, 1999, as cited in Hiscock, Pearce, Blakely, & Witten, 2008). Research into *survival strategies* (Barnett & Barnett, 2001), found that people who face financial difficulties usually delay seeking care and delay obtaining medication unless the care is for their children. The costs of transport, medications and support care can overwhelm cancer survivors to the point that they do not take advantage of all the care available (Haynes, Pearce, & Barnett,

2008). This is particularly disturbing for many New Zealand cancer survivors as research confirms that people with lower incomes have a poorer prognosis for cancer (Haynes et al., 2008).

2.10 Ethnicity

Ethnicity is a construct that includes history, language, cultural orientation and behaviours, spiritual beliefs, religion, lifestyle and biology, all of which have an individual and combined effect on lifestyles, socioeconomic factors and access to health care for indigenous people (Pearce, Foliaki, Sporle & Cunningham, 2004). According to Durie (2005) ethnicity is a distinctive factor that can be explained by describing two major categories. The first includes the characteristics of the indigenous groups themselves such as ‘genetic predisposition, customary beliefs and cultural practices’ and the second relates to ‘explanations outside the ethnic groups such as discriminatory behavior in the provisions of services, access to economic opportunities, stereotypical preconceptions towards people of other cultures and rejection of ethnic and cultural values and aspirations, all of which influence social outcomes’ (Durie, 2005, p. 43).

There are some theories that cancer presents in a more aggressive phenotype amongst minority ethnic groups. Thus, “biologic differences could explain some of the associations between low SES and both stage and mortality” (Byers et al., 2008, p. 586). While this could explain some associations, Pearce et al., (2004) suggest that ethnic disparity could be more a result of environmental factors such as housing, employment and lifestyle behaviours that have a direct effect on health and increased

risk factors of cancer. Ibrahim, Thomas and Fine (2003) suggest that characteristics and practice of some health care professionals including racism, bias, discrimination, stereotyping and cultural incompetence is another explanation for disparities in health for minority ethnic groups through an inability to successfully engage and therefore treat ethnic minorities.

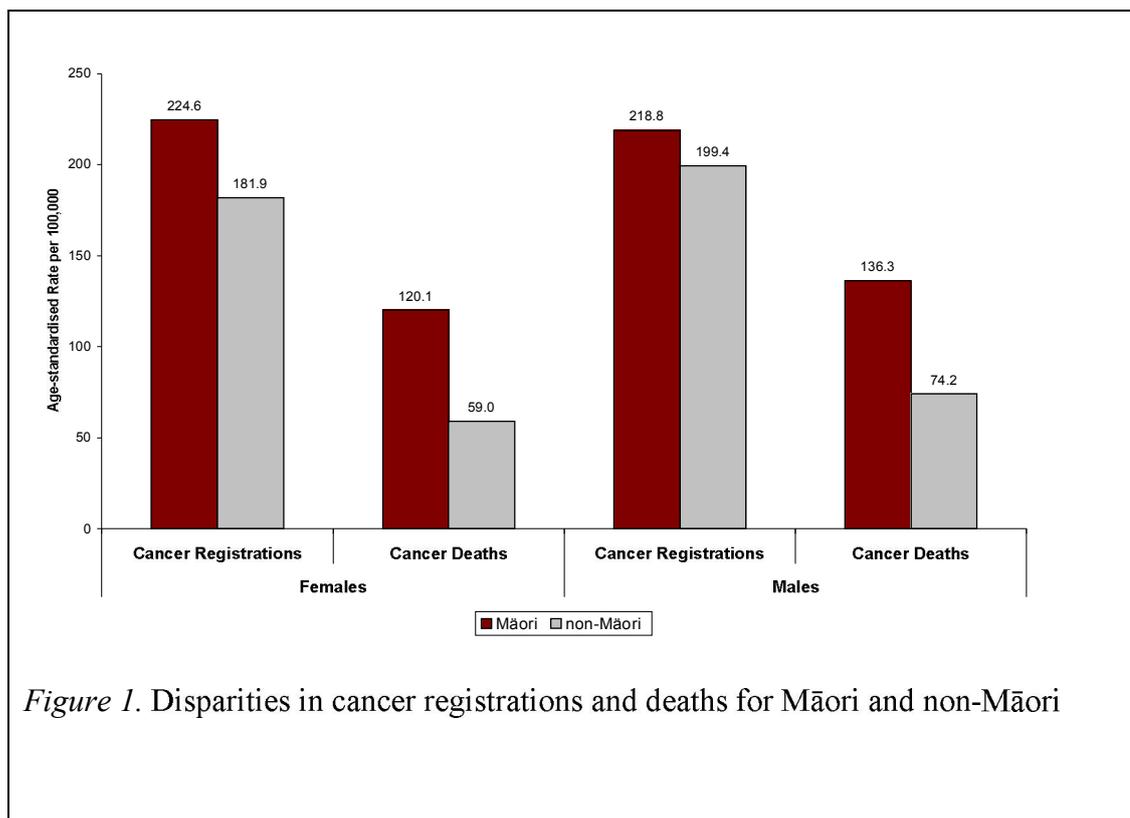
A further theory for explaining the larger racial disparities in cancer mortality in USA also came from Byers et al., (2008), who reported that medical care is ultimately dependent upon economic status. It was therefore hypothesised that the disparity was due to a larger proportion of minor racial groupings found in lower SES areas where people cannot afford the higher quality treatments. This has been supported by findings, that in an organised health setting such as Department of Defence and Veterans Administration where healthcare inequalities are smaller, racial minorities experience better outcomes (Jeffrey's et al., 2009).

Overseas research indicates that indigenous cultures and displaced ethnic groups all over the world experience health disparities and poor health outcomes. People of indigenous cultures, particularly those that have been colonised, suffer poorer levels of health than those of the dominant culture (Aishing-Giwa, 2004; Boffa, 2008; Byers et al., 2008; Cancer Control Taskforce, 2005; Coory et al., 2008; Durie, 2005; Gill & Martin, 2002; Pearce et al., 2004). For instance, research in Australia suggests that the Aboriginal population have a lower cancer survival rate than non-Aboriginals, are less likely to be offered diagnostic or therapeutic procedures, or receive adequate cancer management (Boffa, 2008; Coory, Green, Stirling, Valery, 2008). In a large study of breast cancer survivors in USA including African American, Asian American, Latina and Caucasian women, results showed

that disparities in stage of diagnosis, survival, morbidity and mortality exist for ethnic minority women, many of whom are diagnosed at more advanced stages than other American women (Ashing-Giwa, 2004). Native American Indians and Alaskan Natives also experience less screening for cancer, higher degrees of late stage prognosis and higher mortality rates (Wiggins et al., 2008).

New Zealand is an ethnically diverse country of approximately four million people. According to Statistics New Zealand (2006), 14.6% of the population identifies as Māori, 6.9% as Pacific Islanders, 9.2% as Asian. The remaining 69.3% consists of mostly European (Pākehā). However, Māori are the tangata whenua (people of the land) as affirmed by the Treaty of Waitangi and represent the indigenous/ethnic group of New Zealand. Statistics suggest that there are three main patterns of inequities for Māori; (a) Māori are overly represented in the more deprived neighbourhoods (deciles 8-10), (b) Māori health outcomes are worse despite controls for deprivation and (c) there is a gradient gap in which Māori are more seriously affected by socioeconomic status than other ethnic groups in New Zealand (Reid, Robson, & Jones, 2000). These disparities are displayed in Figure 1 below (Cormack et al., 2005, p. 17).

Other research indicates that “Māori have a poorer health status mentally and physically than non-Māori, regardless of their level of education, income or occupation” (Cancer Control Taskforce, 2005, p. 5; Durie, 2005), and approximately twice the cancer mortality rate of non-Māori (Blakely, Kiro & Woodward, 2002).



Perceived social support is recognized as an important factor in Mental QOL. However the 2006 preliminary results of the HWR study indicated that Māori reported lower levels of perceived social support than non-Māori and that these levels reduced with age, socioeconomic status, income and levels of educational qualifications (Stephens & Noone, 2008).

Socioeconomic status may provide some explanation as to why Māori are reported to be disproportionately represented in cancer statistics, with inequalities apparent in risk, incidence and outcomes (Cormack et al., 2005). However, research has indicated that Māori do not always take advantage of healthcare offered, for reasons such as rurality, transport costs, and perceived cultural safety (Barnett & Kearns, 1996; Jeffrey’s et al., 2005; Pearce et al., 2004). Whether or not these are

the reasons for poor Māori health statistics, research supports the fact that Māori are medically underserved in New Zealand, (Cormack et al., 2005; Durie, 2005; Robson, Purdie & Cormack, 2006), and that Māori health care utilization is not proportional to the expected need (Jeffreys et al., 2005).

Another issue related to ethnicity and socioeconomic status is employment. According to the Labour Department (2009) Māori are over-represented in lower skilled jobs within at-risk industries, which largely involve physical work. This could imply that for Māori who develop cancer, the chance of returning to work following treatment is substantially reduced because of the nature of the employment and inability to continue to be employed in physical work. Furthermore leave entitlements and the flexibility of working hours could impact upon access to cancer services, time available for treatment plans particularly for those who may depend upon others for transport (Robson, 2004).

However, other research has found that in rural districts where local iwi based health organisations function, Māori utilisation of health services is higher than that of Pākehā for all age groups (Crampton et al., 2000). This could be due to an improved cultural fit of services provided, or the availability of health services, however the fact remains that Māori are still underserved. Whilst there is a strong move towards Māori-led healthcare and services, there is still a lack of qualified Māori employed in the health workforce meaning that for Māori the disparities will continue until the status quo improves. Such disparities impact significantly on both QOL and cancer survivorship through failing to access adequate healthcare and lacking the support networks within and the knowledge of healthcare resources to gain assistance as required.

2.11 Summary and Research Goals

The previous two chapters have discussed the challenges cancer survivors face in their battle for health and quality of life and the factors that may influence their survivorship. This thesis proposes to investigate and provide some understanding of the issues that New Zealand cancer survivors face.

By investigating the quality of life differences between those with cancer and those without cancer in variables of social support, locus of control, socioeconomic status, health utilisation, health behaviours, ethnicity and quality of life it is hoped that this information will assist policy makers and funding agencies. This will allow them to plan and provide more appropriate services to improve the health and quality of life of cancer survivors in the areas of greatest influence. From the review of literature the following research questions were developed:

1. Is there a difference in perceived Physical QOL between Cancer Survivors (CS) and those without cancer (NC)?
2. Is there a difference in perceived Physical QOL between Māori and non-Māori?
3. Is there a difference in perceived Mental QOL between CS and NC?
4. Is there a difference in perceived Mental QOL between Māori and non-Māori?
5. Is there a difference in Healthcare Behaviour (HB) between CS and NC?
6. Is there a difference in HB between Māori and non-Māori?

7. Is there a difference in perceived Locus of Control (LOC) between CS and NC?
8. Is there a difference in perceived LOC between Māori and non-Māori?
9. Is there a difference in levels of comorbidities between CS and NC?
10. Is there a difference in levels of comorbidities between Māori and non-Māori?
11. Is there a difference in perceived Social Support (SS) between CS and NC?
12. Is there a difference in perceived SS between Māori and non-Māori?
13. Is there a difference in socioeconomic status (SES) between CS and NC?
14. Is there a difference in SES between Māori and non-Māori?
15. Is there a difference in Job Satisfaction (JS) between CS and NC?
16. Is there a difference in JS between Māori and non-Māori?
17. Is there a difference in Healthcare Utilisation (HU) between CS and NC?
18. Is there a difference in HU between Māori and non-Māori?
19. What are the variables that contribute to Physical QOL and Mental QOL for cancer survivors? Does this differ between Māori and non-Māori?

The methodology used to answer these questions is described in the next chapter.

CHAPTER THREE: METHODOLOGY

3. Introduction

The raw data for this study was taken from the 2008 Health Work and Retirement (HWR) Study conducted in cooperation by the School of Psychology, Massey University; The Health Research Council of New Zealand; The New Zealand Institute for Research on Aging, and The Centre for Māori Health Research and Development, School of Māori Studies, Te Putahi-a-Toi, Massey University. The HWR study is a longitudinal project (three biennial data collections beginning 2006 ending 2010) that was designed to identify and investigate the influences on health and wellbeing in adults aged 55 to 70 years. These are considered the years that lay the basis for community participation and health in later life, and ultimately a more independent retirement. Information was collected on the physical and mental health of older workers and retirees including socioeconomic and demographic status and the changes in these as people move from work to retirement. The HWR study deliberately over-sampled Māori participants to enable the researchers to explore issues that may be affecting Māori workers as they transition to retirement.

3.1 Procedure

3.1.1 Survey Design.

The HWR questionnaire is a postal survey based on Dillman's (2000) Tailored Design Method (TDM). Dillman's TDM provides a framework for creating surveys and implementation which has been shown to consistently provide at least a

70% return rate in studies outside of a clinical setting. This structured approach creates survey instruments that are both attractive to a particular audience and minimizes the burden placed on the respondent as described in Table 2 (Dillman, 2000, as cited in Towers, 2007). This design incorporates modern technology implementing optical imaging to gain the attention of the respondents and maximise response and participation rates.

Table 2.

The Dillman Structured Approach to Survey Design

| Point of Contact | Posting procedure and content | Weeks after initial contact |
|-------------------------|--|------------------------------------|
| 1 | A brief pre-notice letter was sent to potential participants informing them that they had been randomly selected from the electoral roll to participate in the current study, that a questionnaire would be arriving soon and that their participation in the research would be greatly appreciated. | - |
| 2 | The questionnaire and a free-post return envelope were sent to participants. This was accompanied by a detailed cover letter explaining the premise of the study, who was involved, participants rights and expectations, and points of contact in case they had queries. Finally, all questionnaires also contained a consent form on which participants could provide their consent to participate in the longitudinal study and be involved in face-to-face interviews. | 1 |
| 3 | A postcard was sent to everyone in the sample, thanking those who had responded and encouraging those who had not responded to do so. | 3 |
| 4 | A replacement questionnaire was sent to all non-respondents to encourage participation. | 6 |
| 5 | A final contact (postcard) was sent to all non-respondents again encouraging non-respondents to complete the questionnaire and return it. | 11 |

3.1.3 Population of Interest

The population of interest for the HWR study was New Zealanders between the ages of 55 to 70 years of age as they represent the population who are transitioning from work to retirement yet still of an age that gives them several years of potentially active participation in society (Towers, 2007). According to the New Zealand Statistics Department there are approximately 609,000 older adults aged from 55 – 70 years living in New Zealand. Of those, 47,500 identify themselves as Māori. It was decided that the HWR study was appropriate for the present study as it provided a large nationally representative sample of people who are most susceptible to cancer and are still active. It therefore provided a sizeable sample of cancer survivors that could be compared with those without cancer.

3.1.3 Recruitment of Survey Participants

Potential participants for the first wave of the HWR study in 2006 were randomly drawn from the 55-70 year old age group on the New Zealand Electoral Roll. The Electoral Roll was considered to provide a nationally representative sample because although voting is not compulsory in New Zealand, it is mandatory that all people eligible to vote in a New Zealand election (that is New Zealand citizens over the age of 18) are registered on the New Zealand Electoral Roll. The Electoral Roll thereby provides researchers with a database that reflects the most accurate source of information of the New Zealand adult population.

Equal probability sampling procedures were used to select both the general and Māori sub-samples which were then treated independently (Towers, 2007). In using this process it was considered likely that those who identified themselves as

Māori on the Electoral Roll would be willing to be identified as Māori in this survey and the remainder could be classed as being from the general population. Excluded potential participants were individuals currently incarcerated in prisons, residents of nursing homes and those under dependent care. These individuals did not fit the criteria for the HWR study on retirement as they were deemed to be not independent in their health care decision making (Towers, 2007).

For the general population sub-sample 5260 older adults were randomly selected. Using the same exclusions as for the general sub-sample and given the possibility of higher attrition rates 7,881 Māori participants were randomly selected for the Māori sub-sample (Towers, 2007). Therefore the HWR study not only had a representative sample of the general public but also a large sample of Māori who represented the key indigenous population of New Zealand (Towers and Noone, 2007).

3.1.4 Survey Participants

There were 3200 surveys sent out to older New Zealanders between the ages of 57 and 72. (These were the respondents of the 2006 HWR survey who had indicated that they would be available for the 2008 posting). There were 2495 responses. Of these, 279 reported a diagnosis of cancer and they would be compared against the remainder of the sample which would serve as a comparison group.

3.1.5 Questionnaire

The 2008 questionnaire comprised of questions concerning six different areas of the participants' lives, specifically designed to gather information on factors central to retirement, independence, health and well-being. The structure of the

questionnaire was by section and subtopic for six specific topics with an added section intended for Māori participants (Towers, 2007) (refer to Appendix I, for a detailed outline of the sections, subtopics and measures used in the HWR study).

The first page of the questionnaire provided instructions on how to complete the survey, the participant's rights, and the contact details for anyone needing further help with completing the survey. The body of the questionnaire comprised of seven sections covering the six areas of the participants' lives; (1) Health – state of health, health concerns and the impact these have on daily life, (2) Physical Activity – the frequency of and level of exercise, (3) Social Support – sense of social support and social networks and social activities, (4) Work – questions relating to work relationships, desire for work and satisfaction with work, (5) Retirement – planning for retirement and different aspects of retirement, (6) General information – demographic questions, ethnicity, employment status, and household composition. The seventh section was aimed specifically at Māori participants and was labelled Whakapapa/Whanaungatanga which is translated as History and Family. The last page of the questionnaire advised the participants that the study was longitudinal in nature and asked them to complete contact details for follow-up (See Appendix II for a complete copy of the HWR survey which includes the questions for the present study).

Each participant was assigned a unique code in the initial posting which was carried forward to the 2008 wave of follow-up postings. This code provided confidentiality for the participants but also assisted the researcher to identify a specific questionnaire to allow identification if necessary of those who had responded and those who had not. This enabled the researchers to narrow down the

posting of the procedures four and five listed in Dillman's Structured Approach (Towers, 2007).

The questions relating to cancer (Questions 15 and 16 in Section One - Health) comprised a small subset of the questionnaire and included type of cancer, date of diagnosis, current treatment status and whether or not the participant had experienced secondary cancers.

3.2 Measures

This study selected specific measures from the HWR study due to their relevance to cancer survivorship based on the literature and also the reported reliability and validity of the measure for the sample population. As the HWR study covered many aspects of health and retirement that were beyond the scope of this study, specific measures pertinent to the study of cancer survivors were selected from the available question pool of the HWR study and based on literature indicators of important variables for cancer survivorship. These measures covered a range of areas including Quality of Life (mental and physical health), Social Support, Socio-economic Status and Employment/Job Satisfaction, Health Care Utilisation, Comorbidities, and Health Behaviours.

3.2.1 Quality of Life.

Quality of life was assessed by using the Australian and New Zealand version of the Short Form (36) Health Survey (SF-36) which is a self reporting survey. As previous longitudinal research has indicated that self reported health is a reliable method to predict mortality (Stephens and Noone, 2008), this measure was chosen

for the present study. The SF - 36 measures physical and mental health status and is widely used in both New Zealand and international research. The SF – 36 includes 36 items measuring nine health scales: general health perception (self assessment of overall health); mental health; role emotional (the level to which emotional health affects daily activities); physical functioning (activity levels); role physical (the level to which physical health has affected daily activities); social functioning (the level to which health has affected social activities); health transition (perceived health changes); bodily pain and vitality. Questions are presented using a five point Likert scale and scores for each of these 9 concepts are transformed linearly to produce scores ranging from 0 to 100, with higher scores indicating more positive perceptions of health. The sub-scales of the SF-36 are combined to provide summary scores for both Physical Quality of Life and Mental Quality of Life. These summary scores have been additionally normed and standardized to give a population mean of 50 (Gandek, 2000; Stephens & Noone, 2008; Ware, Snow, Kosinski, Gandek, 1993).

3.2.2 Locus of Control.

Levenson’s brief version of the Locus of Control Scale was used to measure Locus of Control. The scale measured “the extent to which people believe they exercise control over their lives” (Handler, Hynes, & Nease, 1997, p. 54) on three dimensions; internal (internal control and choices in life), chance (fate) and powerful others (external control and little choice over events in life) (Sapp & Harrod, 1993). This scale has 9 items presented on a 5-point Likert scale that goes from -2 (strongly agree) to +2 (strongly disagree). Higher levels of LOC indicated higher levels of internal LOC therefore there was less dependence upon chance or significant others. The three scores were expressed as a total score in this study. The Levenson’s brief

scale was evaluated by using principal components analysis and simultaneous second order factor analysis and structural equation analysis (Sapp & Harrod, 1993). Evaluation of the Levenson's brief scale showed coefficients of 0.58 for Internal, 0.65 for Chance, and 0.72 for Powerful Others dimensions.

3.2.3 Healthcare Behaviours - Physical Activity

The New Zealand Sport and Physical Activity Questionnaire – Short form (NZPAQ-SF) was used to measure physical activity. SPARC is the New Zealand government agency that has responsibility for promoting physical activity amongst New Zealanders. The NZPAQ-SF is a specifically designed self reporting questionnaire used to assess the frequency, duration and intensity of an individual's physical activity in all contexts such as organised sport, transportation, occupation, informal leisure time, recreation and domestic work. Although the validity of many self report questionnaires is limited due to the tendency of individuals to over-report perceived positive behaviours, this questionnaire has been validated by the University of Auckland in collaboration with the Ministry of Health, thus providing a reliable and valid measure for the present study (Moy, 2005). The short form version was created specifically to be included in other health surveys such as the current HWR survey. However for the purpose of the present study, two questions were used to assess 'time spent on physical exercise'. This was to gain an idea on levels of exercise, (at the same time distinguishing exercise from organised sport) that older adults and cancer survivors may be involved in.

3.2.4 Total Number of Diagnosed Illnesses - Comorbidities

The Comorbidities variable was measured by using question 15 on the 2008 HWR study. This question lists 26 different illnesses that are common in older adults and the participants were asked to tick any they may have been diagnosed with and put the year of diagnosis alongside it. As the presence of other diseases or illnesses influence cancer treatment, treatment outcomes and quality of life for many cancer survivors, it was considered an important issue for the present study. The results of this question formed the variable ‘Total number of Diagnosed Illnesses’ which was used to measure comorbidities, thus giving an overall total of comorbidities per group (Cancer/no Cancer – Māori/non-Māori).

3.2.5 Social Support

Social Support was assessed using the Social Provisions Scale developed by Weiss (1974). Weiss identified six individual social functions or provisions that can be gained from relationships with other people. These provisions allow an individual to feel supported and this helps to reduce self reported loneliness. The provisions are divided into two broad conceptual categories; assistance related and non-assistance related (Cutrona and Russell, 1987). The assistance related category includes functions that relate directly to problem solving specifically in the context of stress such as *guidance* (information and advice – usually from doctors, teachers, mentors or parental figures) and *reliable alliance* (the knowledge that there are others one can count upon for tangible assistance – in particular family members and loved ones) (Cutrona and Russell, 1987).

To measure the participant's levels of Social Support, participants were asked to respond to 24 questions relating to their relationships with other people. The instrument included four questions for each of the six provisions: Attachment, Social Integration, Reassurance of Worth, Reliable Alliance, Guidance and Opportunity. Half of the items covered the type of support and the other half covered absence of a type of support (Cutrona & Russell, 1987). These questions were presented using a four point Likert scale ranging from; *strongly disagree – disagree – agree and strongly agree*.

The Social Provisions Scale has been tested extensively and has been found to be reliable. For example internal consistency figures across all provisions were over .70 on a sample of 100 older adults (Cutrona, Russell & Rose, 1984, as cited in Cutrona & Russell, 1987) and over .60 on a cohort of 300 school teachers (Russell, Altwater & Van Velzen, 1984, as cited in Cutrona & Russell, 1987). The present study will be using the overall summary score of the Social Provisions score.

3.2.6 Socioeconomic Status.

Socio-economic status (SES) was assessed by using the *Economic Living Standards Index-Short Form (ELSI_{SF})* (Jensen, Spittal, Jensen, 2003). The ELSI_{SF} provides a valid and reliable survey tool for measuring people's economic standard of living, in particular the material aspect of wellbeing that is reflected in a person's consumption and personal possessions – including such items as household durables, clothing, recreations or access to medical services (Jensen et al., 2005). The ELSI_{SF} provides a score from a set of items by combining the information from specific questions. The reliability of this measure, as assessed by coefficient alpha, is 0.88, which represents excellent internal reliability (Jensen et al., 2000).

3.2.7 *Job Satisfaction.*

The Job Satisfaction Index was used to measure levels of Job Satisfaction (Brayfield, Rothe, 1951). The scale was developed using a combination of Thurston and Likert's scaling methods in response to the need of a reliable and valid scale to measure attitudes towards employment. The questionnaire has 18 statements based on Thurston's instructions for creating survey's and the scoring system is based on Likert's scale which consists of five categories ranging from Strongly disagree – Strongly Agree with a high score indicating Job Satisfaction and a low scale indicating dissatisfaction (Brayfield & Rothe, 1951). A reliability co-efficient score of 0.87 was found in a test trial for a large group (N = 231). Testing of the measure between a sample of employees N = 91 (Personnel/non-Personnel) provided evidence of validity which Brayfield and Rothe (1951) claim comes from the nature of the items, the method of construction, and its discriminant power between two groups.

3.2.8 *Age*

Because age is known to influence health status, 'Age' was controlled for in the present study. Using the method endorsed by Statistics New Zealand for the New Zealand Census, the date, month and year of birth were obtained and this was subtracted from the year the questionnaire was administered. The ages were sorted into three groups 57-61, 62-66 and 67-75 for the present study 2008.

3.2.9 *Healthcare Utilisation*

Healthcare Utilisation was measured using one question from the Taking the Pulse survey (TTP), (Sarfarti, Scott, Haslett, Johnston, Hedges, 1999) was used to

measure Healthcare Utilisation. The TTP is a nationally representative survey of New Zealand residents and is a key component of the Ministry of Health's population health monitoring function that provides information on (a) selected health risk behaviours, (b) the self reported physical and mental health status of New Zealanders and prevalence of certain conditions such as asthma or diabetes and accidents, (c) health service utilisation and (d) individual experiences and knowledge of health services, satisfaction with health services and barriers to access' (Sarfarti et al., 1999; Ministry of Health, 1999). One question was selected for the present study relating to 'frequency of contact with healthcare services' as it provides the best indication for the present study of how often each individual might visit his/her GP per year.

3.2.10 Ethnicity

Ethnicity was assessed using the Te Hoe Nuku Roa (THNR) framework (Durie, Cunningham, Fitzgerald, Stevenson, Ngata, 2004) as the basis for gaining information regarding the Māori population in this study. The THNR was designed to contribute positively in the facilitation of appropriate policies and programmes for Māori and to promote Māori research by providing a basis from which other researchers could develop studies to bring about new knowledge (Durie et al., 2004).

The THNR provides an empirical database that is sound and reflects cultural, economic and social indicators that are indicative of contemporary Māori lifestyles. As many of the participants in the HWR study affiliated with more than one ethnic group, a single ethnic affiliation was permitted per person, for the purpose of comparison to national data. This was managed according to guidelines given by the Ministry of Health in the New Zealand Health Survey report (2004) for those with a

single ethnicity and when more than one ethnicity was reported priority rules were applied to narrow the selection down to one ethnicity. The first rule was applied and subsequent rules apply to those not assigned to a specific group based on prior rules (Towers, 2007).

3.3 Data Analysis

Data from this research was analysed using SPSS computer software package version 17. Assumptions of distributions for analysis were checked to ensure that the most accurate analysis could be performed. Correlations, Two-Way Between Groups ANOVA's, Mann Whitney U Tests and Multiple Regression analyses were used.

CHAPTER FOUR: RESULTS

4. Introduction

This chapter presents the results of the statistical analyses used for this study. All statistical analyses were performed using version 17.0 of SPSS. The results are divided into six sections; 4.1 describes the characteristics of the participants; 4.2 describes the descriptive statistics for the variables of interest; 4.3 describes the initial exploratory data analysis; 4.4 contains Two-Way Between Groups Analysis of Variance testing; 4.5 describes the Two-Way Independent Samples test: The Mann Whitney U Tests and 4.6 describes the Multiple Regression testing to determine the significance of the effect of the independent variables on the dependent variables.

4.1 Participants

Of the 3,200 surveys that were posted out for the 2008 wave of the HWR study, a total of 2,495 were returned yielding a response rate of 77% of older New Zealanders. The ages of participants ranged from 57 to 72 years old ($M = 63.27$, $SD = 4.59$). The sample comprised 1,146 (46%) males and 1,307 (52%) females, with 42 participants not stating their gender (2%). This sample comprised 1,069 (43%) who identified themselves as Māori and 1,418 (57%) non-Māori; 8 participants (0.3%) did not respond to the question of ethnicity and were not included in the analyses. Of the overall sample, there were 279 participants who reported having a diagnosis of cancer, 104 (37%) of which were Māori and 175 (63%) were non-Māori.

4.2 Initial Exploratory Data

4.2.1 Descriptive analysis and frequencies of variables

The means and standard deviations for the variable scale scores for each of the subgroups of cancer/no cancer and Māori/non-Māori are presented in Table 3.

Table 3.

Means and standard deviations for variables

| Variable | Cancer Status | Ethnicity | N | Mean | SD |
|---|----------------------|------------------|----------|-------------|-----------|
| SF36 - QOL Physical | Cancer | Māori | 97 | 44.88 | 9.50 |
| | | Non-Māori | 162 | 47.30 | 10.47 |
| | No Cancer | Māori | 880 | 48.69 | 9.78 |
| | | Non-Māori | 1160 | 51.05 | 8.61 |
| SF36 - QOL Mental | Cancer | Māori | 97 | 44.88 | 9.50 |
| | | Non-Māori | 162 | 47.31 | 10.47 |
| | No Cancer | Māori | 880 | 49.69 | 9.84 |
| | | Non-Māori | 1160 | 51.66 | 8.63 |
| Social Provisions – Social Support | Cancer | Māori | 89 | 77.44 | 8.59 |
| | | Non-Māori | 160 | 79.44 | 9.06 |
| | No Cancer | Māori | 792 | 77.67 | 9.28 |
| | | Non-Māori | 1113 | 78.41 | 9.41 |
| Locus of Control | Cancer | Māori | 99 | 27.84 | 5.34 |
| | | Non-Māori | 174 | 28.67 | 4.82 |
| | No Cancer | Māori | 929 | 28.22 | 5.13 |
| | | Non-Māori | 1215 | 28.84 | 4.40 |
| ELSFsf – SES | Cancer | Māori | 85 | 4.42 | 1.80 |
| | | Non-Māori | 156 | 5.22 | 1.43 |
| | No Cancer | Māori | 810 | 4.84 | 1.64 |
| | | Non-Māori | 1120 | 5.29 | 1.41 |
| Job Satisfaction | Cancer | Māori | 49 | 67.26 | 10.17 |
| | | Non-Māori | 90 | 68.65 | 9.27 |
| | No Cancer | Māori | 579 | 67.52 | 8.31 |
| | | Non-Māori | 759 | 67.57 | 9.28 |
| Comorbidity | Cancer | Māori | 104 | 4.47 | 3.04 |
| | | Non-Māori | 174 | 3.20 | 2.23 |
| | No Cancer | Māori | 965 | 2.47 | 2.21 |
| | | Non-Māori | 1244 | 1.73 | 1.66 |
| Healthcare Utilisation | Cancer | Māori | 92 | 3.22 | 1.06 |
| | | Non-Māori | 158 | 2.91 | .989 |
| | No Cancer | Māori | 833 | 2.71 | 1.04 |
| | | Non-Māori | 1075 | 2.60 | .944 |
| Physical Activity | Cancer | Māori | 90 | 3.64 | 2.36 |
| | | Non-Māori | 160 | 4.08 | 2.40 |
| | No Cancer | Māori | 888 | 4.09 | 2.37 |
| | | Non-Māori | 1177 | 4.34 | 2.26 |

Table 3 suggests that non-Māori with cancer reported better levels of Physical and Mental QOL, Locus of Control, SES, Physical Activity and Job Satisfaction than Māori with cancer. Māori with cancer reported higher levels of Comorbidity and Healthcare Utilisation than non-Māori with cancer. On the whole the means and standard deviations were generally lower for Māori than non-Māori with or without cancer indicating that Māori experience a poorer level of health overall when compared to non-Māori.

4.3 Correlations

4.3.1 Intercorrelations with the whole sample

Correlation coefficients were computed on the whole sample to examine the relationships between the variables Physical QOL, Mental QOL, Social Provisions Scale (Social Support), Locus of Control Scale, ELSIsf – Socioeconomic Status (SES), Job Satisfaction and Total of Diagnosed Illnesses (Comorbidity). This was used to provide information concerning whether the scales were independent or if they were capable of predicting scores on another scale. The results of these analyses are presented in Table 4. There were significant inter-correlations between all measures. The greatest correlations involved Mental QOL and ELSIsf – SES, $r = 0.40$. The correlations also showed that ELSIsf was significantly linked to Physical QOL, $r = 0.33$, indicating that individuals reporting low levels of SES also report poorer QOL mentally and physically. The inter-correlations also show that Social Support was significantly linked to Mental QOL, $r = 0.30$. The variable Total Number of Diagnosed Illnesses (Comorbidities) was significantly negatively correlated to Mental QOL, $r = -0.52$, and to Physical QOL, $r = -0.33$.

Table 4.

Correlations between dependent and independent variables and total sample of participants

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--------------------------------------|---------|---------|---------|---------|---------|---------|---|
| 1 SF36_PCS: Physical QOL | 1 | | | | | | |
| 2 SF36_MCS: Mental QOL | .201** | 1 | | | | | |
| 3 Social Provisions: Social Support | .123** | .300** | 1 | | | | |
| 4 ELSIsf: Socioeconomic Status - SES | .326** | .403** | .309** | 1 | | | |
| 5 Locus of Control: LOC | .132** | .269** | .229** | .249** | 1 | | |
| 6 Total Number of Diagnosed Illness | -.517** | -.331** | -.123** | -.312** | -.147** | 0.096** | 1 |

** Correlation is significant at the 0.01 level (two-tailed)

* Correlation is significant at the 0.05 level (two-tailed)

Locus of Control was significantly linked to Mental QOL, $r = 0.27$ and to Physical QOL, $r = 0.13$.

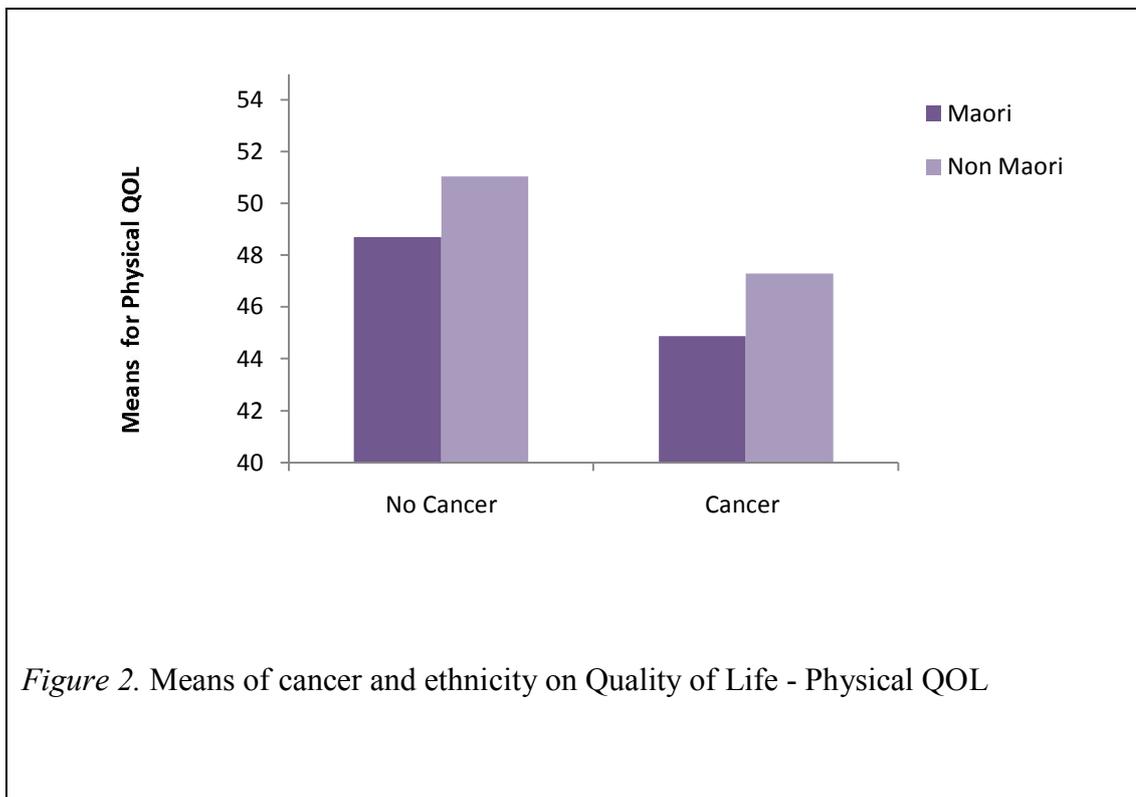
4.4 Analysis of Variance

Two-Way Between Groups Analysis of Variance (BGANOVA) tests were conducted to explore the differences between the groups, Cancer/no-Cancer and Māori/non-Māori, and to test the impact of ethnicity and cancer as independent variables on the Physical QOL, Mental QOL, Social Support, Locus of Control, Job Satisfaction, and Comorbidities variables as dependent variables. These analyses were conducted using the whole sample. Each analysis met the assumptions required except for the Levene's tests on some which resulted in the significance levels changing from $p = 0.05$ to $p = 0.01$.

4.4.1 Physical Health - Quality of Life (Physical QOL)

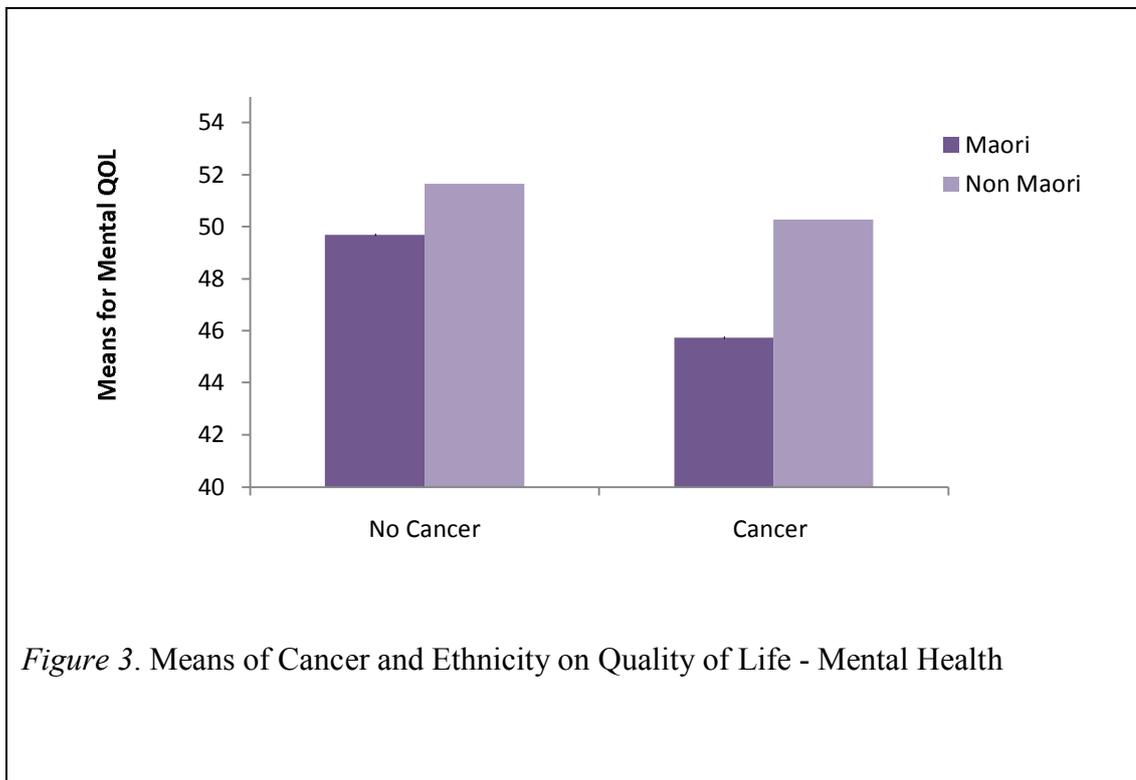
The Levene's test indicated that the assumption of Equality of Error Variances of the Physical QOL variable across the groups was not met therefore the significance level was set at $p = 0.01$ rather than $p = 0.05$. For the Cancer group, the mean Physical QOL score was $M = 47.31$ for non-Māori and $M = 44.88$ for Māori. Figure 2 shows the means for Cancer/No Cancer and Māori /non-Māori on Physical QOL. For the No Cancer group, the mean Physical QOL score was $M = 51.05$ for non-Māori and $M = 48.69$ for Māori.

There was a significant main effect of Cancer on Physical QOL, $F(1, 2413) = 36.11$, $p = 0.00$; however the effect size was small (partial eta squared = .015). There was also a significant main effect of Ethnicity on Physical QOL, $F(1, 2295) = 14.45$, $p = 0.00$; but again the effect size was small (partial eta squared = 0.01). These results indicate that cancer and ethnicity do have a significant but small effect on levels of Physical QOL with the Cancer group having a lower Physical QOL mean score than the No Cancer group and the Māori group reporting a lower Physical QOL mean score than the non-Māori group. The interaction effect for Ethnicity and Cancer together on Physical QOL was not statistically significant $F(1,2413) = .003$, $p = .957$).



4.4.2 Mental Health Quality of Life - Mental QOL

The Levene's test indicated that the assumption of Equality of Error Variances of the Mental QOL variable across the groups was not met therefore the significance level was set at $p = 0.01$ rather than $p = 0.05$. Figure 3 shows the means of Cancer/No Cancer and Māori /non-Māori on Mental QOL. For the Cancer group, the mean Mental QOL score was $M = 50.29$ for non-Māori and $M = 45.75$ for Māori. For the No Cancer group, the mean Mental QOL score was $M = 51.66$ for non-Māori and $M = 49.70$ for Māori.



There was a significant main effect of Cancer on Mental QOL, $F(1, 2295)=17.89$, $p = 0.00$), however, the effect size was small (partial eta squared = 0.01). There was also a significant main effect of Ethnicity on Mental QOL, $F(1,$

2295) = 26.73, $p = 0.00$), however again, the effect size was small (partial eta squared = .01). These results indicate that cancer and ethnicity do have a significant effect on levels of Mental QOL with the Cancer group having a lower Mental QOL mean score than the No Cancer group and the Māori group reporting a lower Mental QOL mean score than the non-Māori group. The interaction effect for Ethnicity and Cancer on Mental QOL was not statistically significant, $F(1,2295) = 4.26, p = 0.04$).

4.4.4 Locus of Control Scale

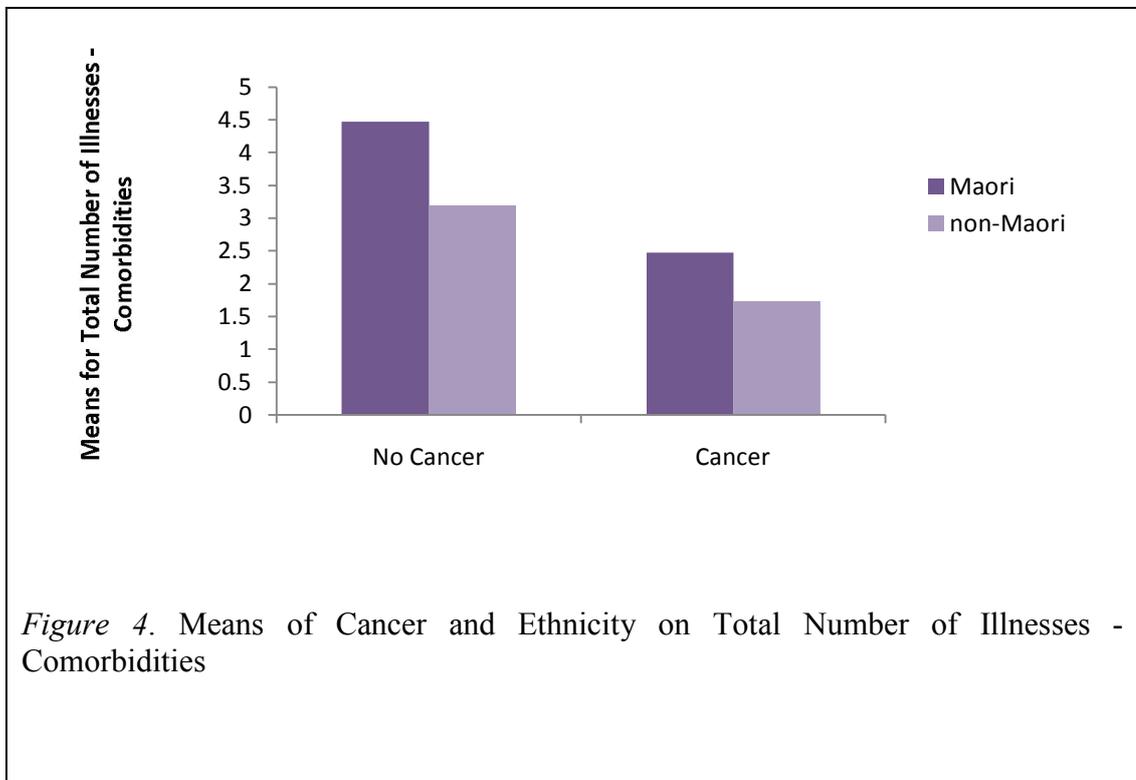
The Levene's test indicated that the assumption of Equality of Error Variances of the Locus of control scale variable across the groups was not met therefore the significance level was set at $p = 0.01$ rather than $p = 0.05$. Figure 4 shows the means for Cancer/No Cancer and Māori/non-Māori on the Locus of Control scale. For the Cancer group, the mean Locus of Control score for was $M = 28.67$ for non-Māori and $M = 27.84$ for Māori. For the No Cancer group, the mean Locus of Control score was $M = 28.85$ for non-Māori and $M = 28.22$ for Māori.

The effect of Cancer on Locus of Control $F(1,2413) = 0.77, p = 0.38$ and Ethnicity on Locus of Control, $F(1,2413) = 5.32, p = 0.02$ were not significant although the Cancer group did report a lower Locus of Control mean score than the No Cancer group and the Māori group reporting a lower Locus of Control mean score than the non-Māori group. The interaction effect for Ethnicity and Cancer on Locus of Control was also not statistically significant, $F(1,2413) = 0.11, p = 0.74$.

4.4.7 Total Number of Diagnosed Illnesses (Comorbidities)

The Levene's Test of Equality of Error Variances for Comorbidities was not met therefore the significance level was set at $p = 0.01$ rather than $p = 0.05$. Figure 5

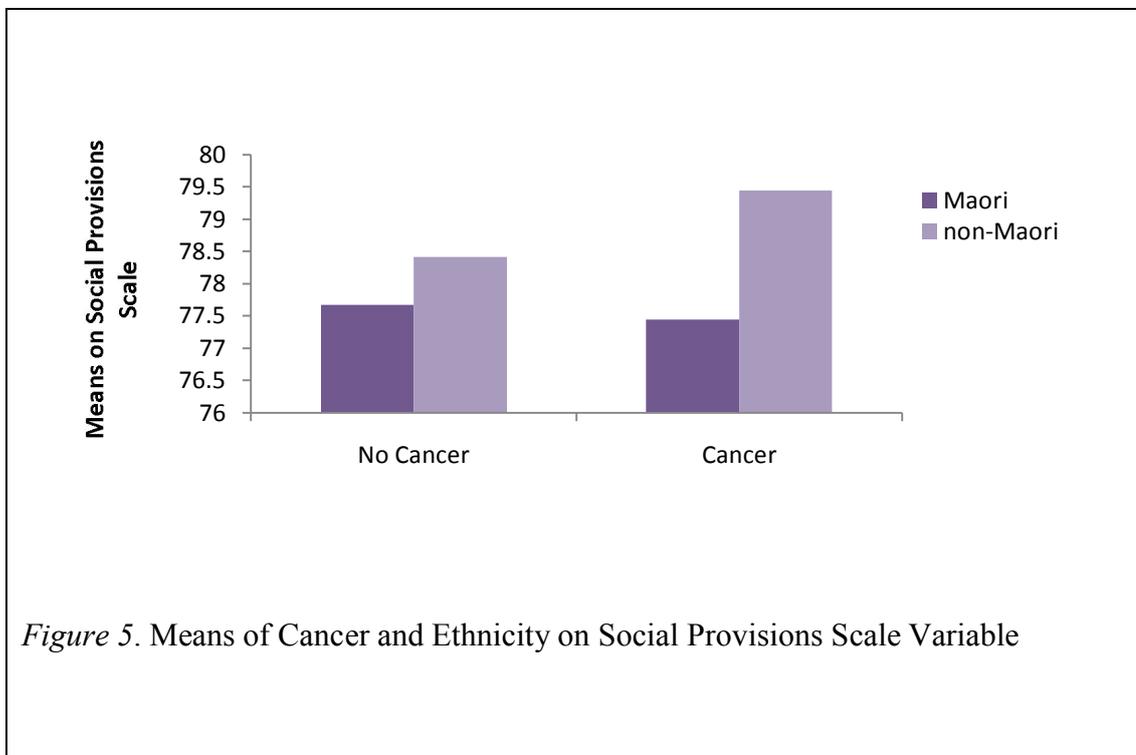
shows the means for Cancer/No Cancer and Māori /non-Māori on Comorbidity. For the Cancer group, the mean Comorbidity score was $M = 3.20$ for non-Māori and $M = 4.47$ for Māori. For the No Cancer group, the mean Comorbidity score was $M = 1.72$ for non-Māori and $M = 2.47$ for Māori.



There was a significant main effect of Cancer on Comorbidity, $F(1,2486) = 175.27, p = 0.00$; however, the effect size was small (partial eta squared = 0.07) with the Cancer group having a higher Comorbidity mean score than the No Cancer group. There was also a significant main effect of Ethnicity on Comorbidity, $F(1,2486) = 58.68, p = 0.00$; however again, the effect size was small (partial eta squared = 0.02) with the Māori group reporting a higher Comorbidity mean score than the non-Māori group. The interaction effect for Ethnicity and Cancer on Comorbidity was not statistically significant, $F(1,2483) = 4.03, p = 0.04$.

4.4.3 Social Provisions Scale - Social Support

The Levene's Test of Equality of Error Variances for the Social Provisions Scale variable was met therefore the significance level remained at $p = 0.05$. Figure 6 shows the means of Cancer/No Cancer and Māori /non-Māori on the Social Provisions Scale variable. For the Cancer group, the mean Social Provisions score was $M = 79.44$ for non-Māori and $M = 77.44$ for Māori. For the No Cancer group the mean Social Provisions score was $M = 78.41$ for non-Māori and $M = 77.67$ for Māori.



There was no significant main effect of the Cancer variable on the Social Provisions scale $F(1,2153) = 0.38, p = 0.54$. There was a significant main effect of

Ethnicity on the Social Provisions scale variable $F(1,2153) = 4.45, p = 0.03$; however the effect size was small (partial eta squared = 0.00) with the Māori group having a lower Social Provisions mean score than non-Māori in both the Cancer and No Cancer groups. The interaction effect for Ethnicity and Cancer on Social Provisions was not statistically significant, $F(1,2153) = 0.94, p = 0.33$.

4.4.5 *ELSI_f - Socioeconomic Status (ELSI_f-SES)*

The Levene's test indicated that the assumption of Equality of Error Variances of the ELSI_f variable across the groups was not equal therefore the significance level was set at $p = 0.01$ rather than $p = 0.05$. Figure 7 shows the means for Cancer/No Cancer and Māori /non-Māori on ELSI_f-SES. For the Cancer group, the mean ELSI_f-SES score was $M = 5.22$ for non-Māori and $M = 4.42$ for Māori. For the No Cancer group, the mean ELSI_f-SES score was $M = 5.29$ for non-Māori and $M = 4.84$ for Māori.

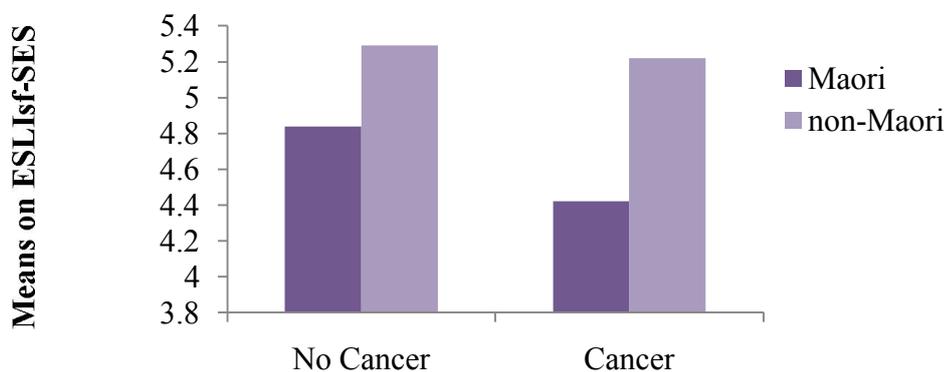
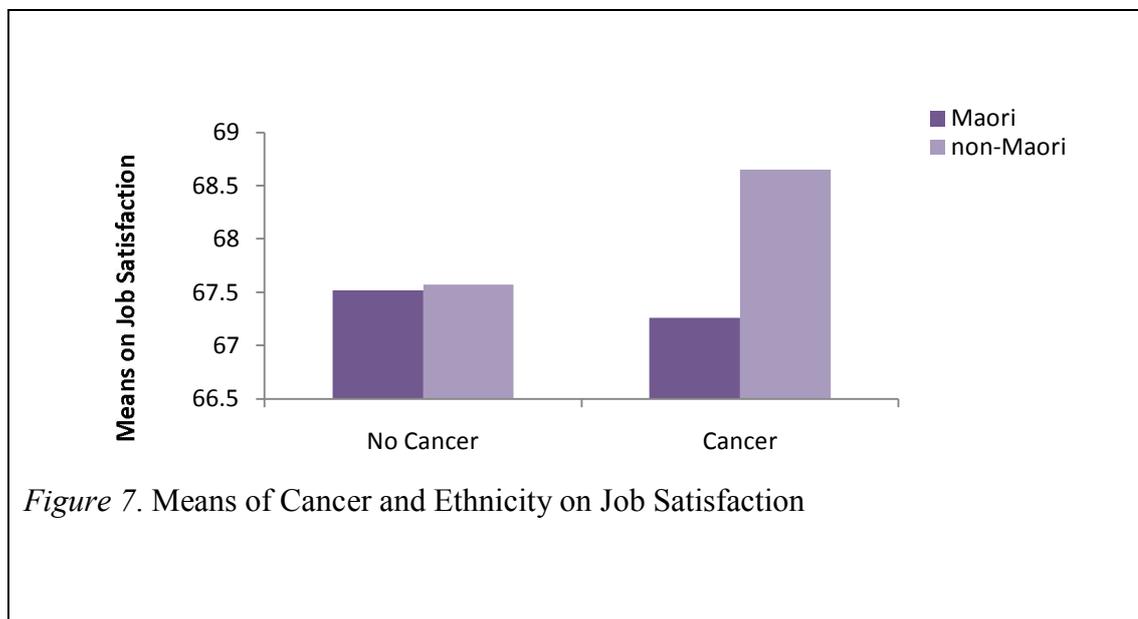


Figure 6. Means of Cancer and Ethnicity on ELSI_f-SES

There was no significant main effect of Cancer on ELSIsf-SES, $F(1,2175) = 5.12, p = 0.02$. There was a significant main effect of Ethnicity on ELSIsf-SES, $F(1,2175) = 33.53, p = 0.00$; however the effect size was small (partial eta squared = .015). Māori reported a lower ELSIsf-SES mean score than non-Māori on both the Cancer and No Cancer groups. The interaction effect for Ethnicity and Cancer on ELSIsf-SES was not statistically significant, $F(1,2175) = 2.63, p = 0.10$.

4.4.6 Job Satisfaction Index (Employment)

The Levene's Test of Equality of Error Variances for the Job Satisfaction variable was equal (.178) therefore the significance level was left at $p = 0.05$. Figure 8 shows the means for Cancer/No Cancer and Māori /non-Māori on Job Satisfaction. For the Cancer group, the mean Job Satisfaction Index score was $M = 68.65$ for non-Māori and $M = 67.26$ for Māori. For the No Cancer group, the mean Job Satisfaction Index score was $M = 67.57$ for non-Māori and $M = 67.52$ for Māori.



There was no significant main effect of Cancer on the Job Satisfaction Index, $F(1,1476) = .24, p = 0.62$, and also no significant main effect of Ethnicity on the Job Satisfaction Index, $F(1,1476) = .75, p = 0.39$, however the Cancer group reported a marginally lower Job Satisfaction mean score than the No Cancer group and Māori reported a lower Job Satisfaction mean score than non-Māori. The interaction effect for Ethnicity and Cancer on the Job Satisfaction Index was also not statistically significant, $F(1,1476) = .64, p = 0.42$.

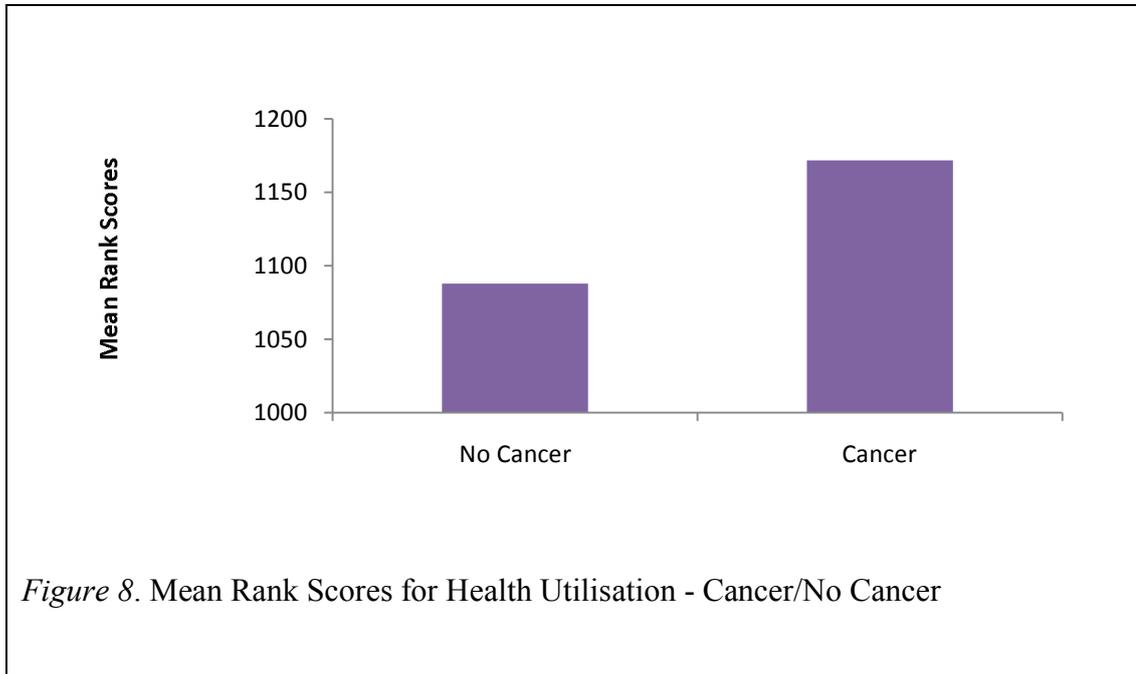
4.5 Two-Way Independent Samples Test: Mann Whitney U Test

A Mann Whitney U Test was conducted to identify difference in scores, on average, between the Cancer group and the no-Cancer group and the scores, on average, between the Māori group and the non-Māori group on Healthcare Utilisation and Health Behaviours-Physical Activity variables. All assumptions for these tests were met.

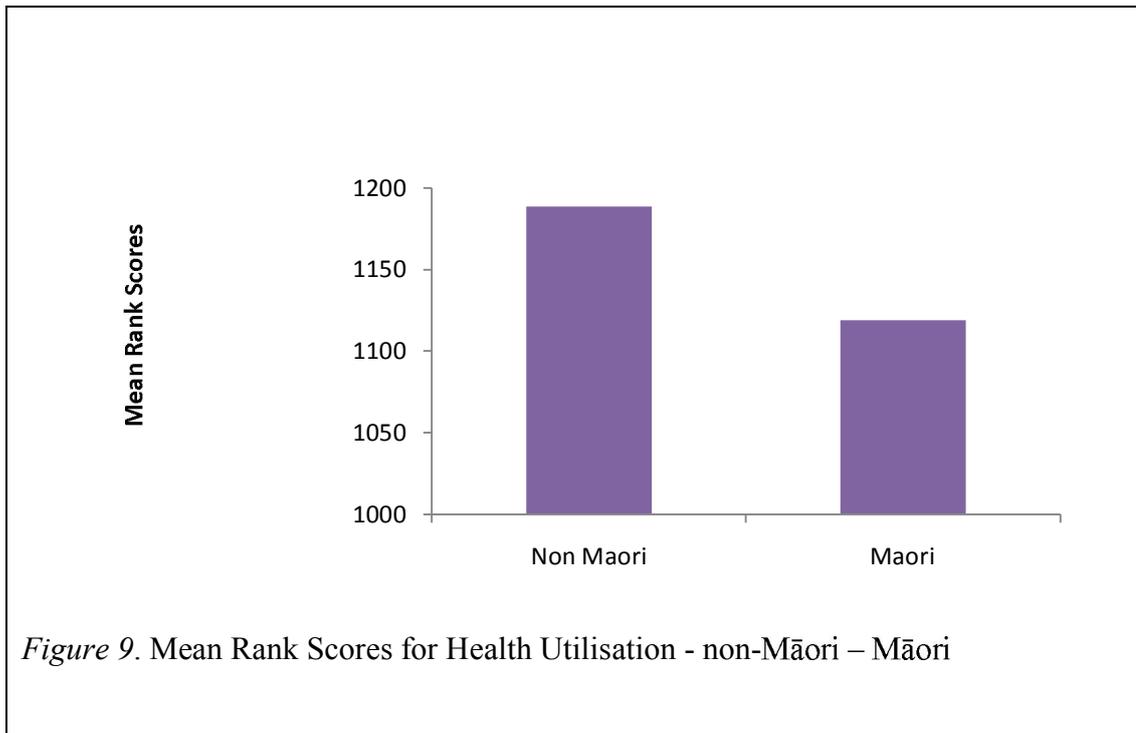
4.5.1 Healthcare Utilisation – Cancer – No Cancer

The mean Healthcare Utilisation score for the Cancer group was $M = 2.91$ for non-Māori and $M = 3.22$ for Māori. For the No Cancer group, the mean Healthcare Utilisation score was $M = 2.60$ for non-Māori and $M = 2.71$ for Māori. The results showed the differences for the Cancer/no-Cancer groups on Healthcare Utilisation were significant $z = -5.27, p = 0.00$. Cancer survivors had an average rank of 1266.14, while the no-cancer group had an average rank of 1057.58. Figure 8 shows the distributions of the scores on the Healthcare Utilisation measure for cancer/no-

cancer groups indicating that cancer survivors utilised healthcare services more than those without cancer.

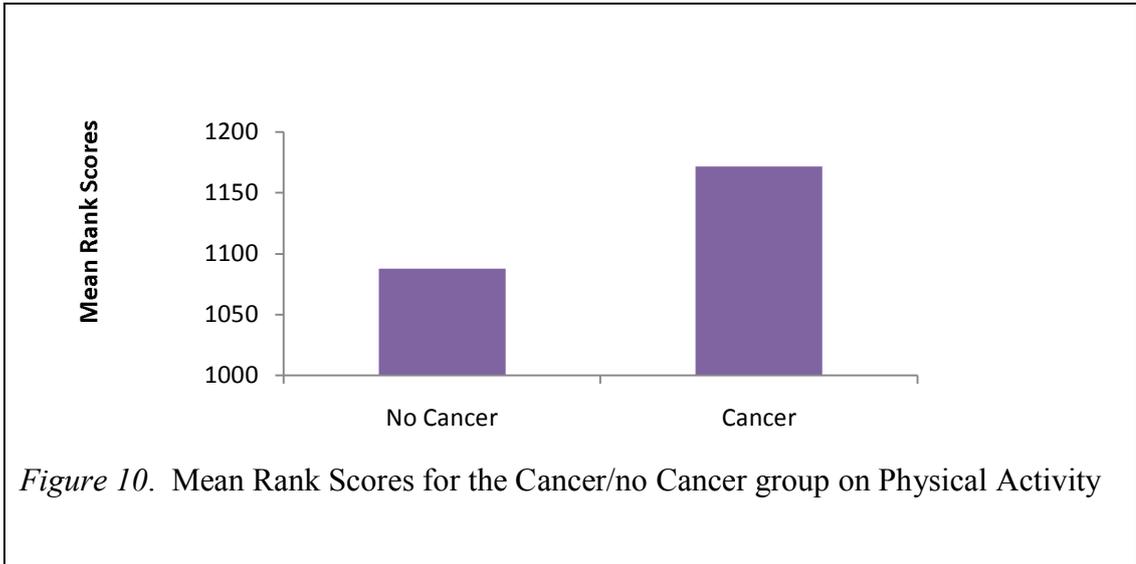


The mean scores for Māori on Healthcare Utilisation were $M = 2.76$ and for non-Māori $M = 2.65$. The results for the differences in the Māori /non-Māori groups on Healthcare Utilisation were also significant $z = -2.52, p = .01$. Māori had an average rank of 1051.01 and non-Māori had an average rank of 1115.23. Figure 10 shows the distributions of the scores on the Healthcare Utilisation measure for the Māori /non-Māori groups indicating that Māori use healthcare services more than non-Māori.

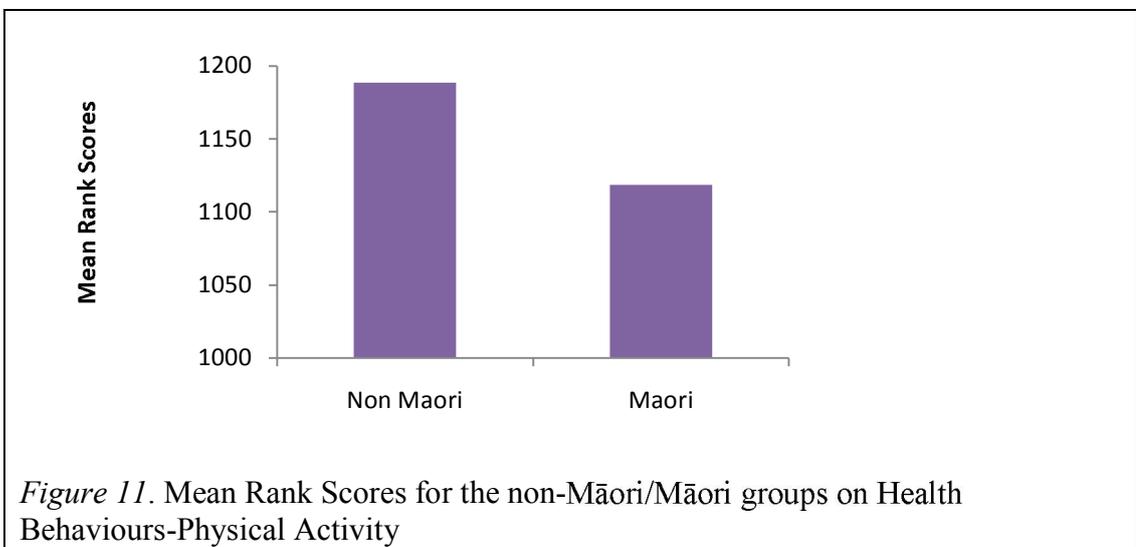


4.5.2 Healthcare Behaviours – Physical Activity

The results showed the differences for the cancer/no cancer group on Physical Activity were not significant $z = -1.90, p = .057$. Cancer survivors had an average rank of 1087.73, while the no-cancer group had an average rank of 1171.63 suggesting that cancer survivors report lower levels of physical activity than those without cancer. While Figure 11 does show a difference in the distributions of the scores on the Healthcare Utilisation measure for cancer/no-cancer groups, this difference was not statistically significant.



The results for the differences in the Māori/non-Māori groups on Physical Activity were significant $z = -2.51, p = .012$. Non-Māori had an average rank of 1188.53 and Māori had an average rank of 1118.71 indicating that non-Māori reported higher levels of Physical Activity compared to Māori. Figure 12 shows the distributions of the scores on the Healthcare Utilisation measure for the Māori /non-Māori groups.



4.6 Multiple Regression Analysis

Two standard multiple regression analyses were performed, one with Physical QOL as the dependent variable and the other with Mental QOL as the dependent variable. In both analyses the independent variables were Social Support, Locus of Control, Socioeconomic Status, Comorbidities and Ethnicity. These analyses were conducted on cancer survivors only. Prior to the analysis the variables used in the regression were screened to ensure they met the assumptions for this analysis. Analysis was performed using SPSS REGRESSION and SPSS FREQUENCIES in accordance with directions from Tabachnik and Fidell (2001). While the scatter-plot did appear to show some outliers the Cooks Distance was 0.07 suggesting they did not cause any statistical problems. All other assumptions were satisfied.

The results of the first multiple regressions using Physical QOL as the dependent variable are contained in Table 5. This includes the Pearson's correlations between the dependent variable Physical QOL and the independent variables, the means and standard deviations, the un-standardised regression coefficients (B), the intercept, the standardised regression coefficients (β), the semi-partial correlations (sr^2) and R^2 . The results in Table 5 indicate that the correlations between Physical QOL and Locus of Control, ELSIsf and Comorbidities are statistically significant. The independent variables explain 23.8% of the variance in the dependent variable. The model reached statistical significance in this test $p < 0.00$. Only two of the five independent variables, contributed significantly to prediction of Physical QOL as logarithmically transformed, ELSIsf ($sr^2 = 0.03$) and Comorbidities ($sr^2 = 0.14$). The five independent variables in combination contributed another 52.02 in shared

variability in levels of Physical QOL. Although the correlation between Physical QOL and Locus of Control was 0.18, Locus of Control did not contribute significantly to regression.

The results of the second multiple regressions USING Mental QOL as the dependent variable are contained in Table 6. This includes the Pearson's correlations between the dependent variable Mental QOL and the independent variables, the means and standard deviations, the un-standardised regression coefficients (B), the intercept, the standardised regression coefficients (β), the semi-partial correlations (sr^2) and R^2 . The results in Table 6 indicate that the correlations between Mental QOL and Locus of Control, ELSIsf, Comorbidities and Ethnicity are statistically significant. The independent variables explain 22.7% of the variance in the dependent variable. The model reached statistical significance in this test $p < 0.00$. Three of the independent variables contributed significantly to prediction of Mental QOL as logarithmically transformed; Locus of Control ($sr^2 = 0.02$), ELSIsf ($sr^2 = 0.04$) and Comorbidities ($sr^2 = 0.02$). The three independent variables in combination contributed another 21.13 in shared variability.

Table 5.

Standard Multiple Regression of Social Support, Locus of Control, Socioeconomic Status, Comorbidities and Ethnicity

| Variables | Physical QOL - DV | Social Support | Locus of Control | Socioeconomic Status | Comorbidities | Ethnicity | B | β | sr^2 |
|-------------------------|-------------------------|----------------------|---------------------|-------------------------|---------------|-----------|-----------|---------|--------|
| Physical QOL | 1 | | | | | | | | |
| Social Support | .063 | 1 | | | | | -.110 | -.097 | |
| Locus of Control | .184** | .160* | 1 | | | | .117 | .058 | |
| Socioeconomic Status | .283** | .385** | .296** | 1 | | | 1.251 | .198 | 0.03 |
| Comorbidities | -.446** | -.189** | -.211** | -.273** | 1 | | -1.559 | -.403 | 0.14 |
| Ethnicity | .116 | .080 | .080 | .238** | -.234** | 1 | -.418 | -.020 | |
| Means | 46.45 | 78.73 | 28.38 | 4.94 | 3.67 | 1.63 | Intercept | 52.02 | |
| Standard Deviations | 10.18 | 8.93 | 5.02 | 1.61 | 2.63 | .485 | | | |
| R ² | .24 ^a | | | | | | | | |
| Adjusted R ² | .22 | | | | | | | | |
| R | | | | | | | | | |
| Unique variability = | 17; | shared variability = | 0.07 | | | | | | |

** Correlation is significant at the 0.01 level (two-tailed)

* Correlation is significant at the 0.05 level (two-tailed)

Table 6 .

Standard Multiple Regression of Social Support, Locus of Control, Socioeconomic Status, Comorbidities and Ethnicity

| Variables | Mental QOL - DV | Social Support | Locus of Control | Socio economic Status | Comorbidities | Ethnicity | B | β | sr^2 |
|-------------------------|-----------------------------------|----------------|------------------|-----------------------|---------------|-----------|-----------|---------|--------|
| Mental QOL | 1 | | | | | | | | |
| Social Support | .273** | 1 | | | | | .127 | .113 | |
| Locus of Control | .289** | .160* | 1 | | | | .315 | .157 | 0.02 |
| Socioeconomic Status | .400** | .385** | .296** | 1 | | | 1.513 | .242 | 0.04 |
| Comorbidities | -.306** | -.189** | -.211** | .273** | 1 | | -.619 | -.162 | 0.02 |
| Ethnicity | .219** | .108 | .080 | -.238** | -.234** | 1 | 2.047 | .099 | |
| Means | 48.62 | 78.73 | 28.38 | 4.94 | 3.67 | 1.63 | Intercept | 21.13 | |
| Standard Deviations | 10.05 | 8.93 | 5.02 | 1.61 | 2.63 | .485 | | | |
| R | .494 ^a | | | | | | | | |
| R ² | .244 | | | | | | | | |
| Adjusted R ² | .227 | | | | | | | | |
| Unique variability | = 0.08; shared variability = 0.16 | | | | | | | | |

** Correlation is significant at the 0.01 level (two-tailed)

* Correlation is significant at the 0.05 level (two-tailed)

CHAPTER FIVE: DISCUSSION

5. Introduction

This study sought to investigate cancer survivorship amongst older New Zealanders and to identify some of the issues that individuals diagnosed with cancer face. The study explored the differences between cancer survivors and those without cancer and whether these differences existed between Māori and non-Māori. In comparing differences between cancer survivors and those without cancer a number of variables were explored; Physical QOL, Mental QOL, Locus of Control, Health Behaviours, Social Support, Socioeconomic Status, Employment, Age, Healthcare Utilisation and Ethnicity. Finally, the effect of these variables on cancer survivors' Physical QOL and Mental QOL and whether ethnicity moderated this effect was investigated. These differences will be discussed, followed by a discussion of the same variables between Māori and Non-Māori groups.

5.1 The Effect of Cancer - Variable Differences between Cancer and Non-Cancer

As previously discussed in Chapter Two, QOL, particularly for older adults with cancer, can depend upon more than just the type of cancer, symptomology, and treatments they receive. Other factors such as comorbidities, social support, health utilisation, levels of physical activity and age related issues such as deterioration in cognitive functioning can negatively impact on a cancer survivors' physical and mental QOL.

Cancer survivors reported lower levels of Physical QOL than those without cancer. This was not unexpected given the disruptive and debilitating symptomology and experiences of cancer. Such experiences include the physical impact of the various surgeries, side effects, acute and long-term effects of treatments, and the ensuing physical challenges such as chronic pain and fatigue. Previous research has highlighted that physical QOL is significantly lowered by physical disability (Burns & Mahalik, 2006), unresolved symptoms, side effects (Vachon, 2001), and the late effects of treatments (Alfano & Rowland, 2006; Harpham, 1999). Many of these factors are features of the experience of cancer and therefore this result is not unexpected.

Comorbidities can further reduce an individual's Physical QOL, independent of a cancer diagnosis. All participants in this sample were over the age of 57 years and therefore have an increased likelihood of having comorbid conditions in addition to cancer (Extermann, 2006). The increased likelihood of comorbidities in all participants in this study may have impacted on the size of the differences between the groups. Had the individual's in the study have been younger, and comorbidities therefore were less frequent, the differences in Physical QOL may have been larger between the two groups. Similarly, international research has shown that older cancer survivors experience lower levels of physical QOL than younger cancer patients. Had this study compared older and younger cancer patients, the difference may also have been larger than what was found in this study.

As mentioned in Chapter Two, research has indicated that the combination of age and cancer is a high predictor of comorbidity in older adults (Balducci & Extermann, 2000; Extermann, 2007). Commonly occurring chronic conditions,

comorbidities and physical deterioration as a result of aging may increase the impact of cancer on QOL (Avis & Deimling, 2008). Cancer survivors reported more comorbidities than those without cancer and, although the difference was small, it was significant. As the sample in the present study consisted of older adults that were similar on a number of demographics, the results suggest that the differences in the rate of comorbidities can be explained by cancer. Research has shown that older cancer survivors have a lower tolerance to cancer therapies and it is likely that this increases their susceptibility to developing new or additional comorbid disorders (Balducci & Extermann, 2000; Ershler, 2003) and this is consistent with study findings. It is also possible that other factors such as lower levels of physical exercise and increased healthcare utilisation leading to increased probability of detection of comorbidities may explain why participants with cancer had more comorbidity.

Cancer survivors reported lower levels of physical exercise than those without cancer. This is understandable when considering the physiological and functional effect of cancer on a person and the likelihood of reduced physical activity, particularly throughout the early stages of treatment. For many cancer survivors chronic fatigue limits levels of physical exercise (Cramp, 2008; Harpham, 1999) and affects Physical QOL. It is also likely that pain levels and functional disability reduce the ability of a cancer survivor to exercise. Given that increased exercise is positively correlated with better health outcomes (National Cancer Institute, 2009) these results suggest that perhaps more emphasis could be put on promoting the benefits of physical activity particularly for cancer survivors through graded exercise programs.

When looking at the numbers of visits to medical services, cancer survivors reported more visits than those without a cancer diagnosis. Again this result is understandable given the medical needs of those with cancer and the number of comorbid disorders that come with having cancer. Cancer survivors require constant monitoring of medication and side-effects as well as for the development of metastasis and recurrences. In New Zealand, cancer treatment occurs largely in the six main centres around the country and may not be immediately accessible to portions of the population. Therefore many cancer survivors depend upon their GP or local health providers to monitor any health issues that may arise and may see a GP more frequently because of this.

Cancer survivors reported marginally lower levels of Mental QOL than those without cancer. This may indicate that people with cancer experienced higher levels of emotional stress and distress or a reduced ability to cope with the demands of everyday life than those without cancer. Given that cancer is potentially a life threatening disease it is not surprising that people with a diagnosis of cancer have increased levels of emotional distress which may be exacerbated by the effects of cancer therapy. These findings are consistent with international research that emphasises the negative psychological effects of cancer on an individual (Yasko & Greene, 2009; Zebrak, 2000; Zebrak & Zeltzer, 2003).

As previously mentioned, older cancer survivors tend to report higher levels of mental quality of life than younger cancer survivors (Zebrak et al., 2008) and tend to face cancer with a more positive attitude than younger adults with cancer. The current study's sample of participants fell within the 57 – 72 years or older age bracket, which could explain why there was only a marginal (although significant)

difference in Mental QOL between cancer survivors and those without cancer. A larger difference would likely to be found if comparing older and younger age groups.

It has been found in international and New Zealand research that disparities in QOL are associated with socioeconomic status (Blakely et al., 2005; Cormack et al., 2005; Jack et al., 2006; Robson et al., 2006; Singh et al., 2006) and poverty (American Cancer Society, 2007). The results in this study supported these findings. The initial analyses on socioeconomic status showed that there were no differences in socioeconomic status between cancer survivors and those without cancer. However, the regression analyses showed that socioeconomic status was the greatest predictor of poor Physical and Mental QOL for cancer survivors over and above the other variables measured. Given this, enhancing the support available for cancer survivors in low SES areas may be crucial for enhancing QOL following a diagnosis.

In the initial analyses there were no significant differences between cancer survivors and those without cancer on levels of Social Support. The regression analyses also showed that Social Support was not related to Physical QOL or Mental QOL. These results are worth mentioning because they are contrary to international research which imparts the importance of Social Support on quality of life (Bowman et al., 2005; Chen et al., 2001; Jefford et al., 2007; Schroevers et al., 2009; Wasserman & Danforth, 1988). Given that cancer has such a profound effect on cancer survivors, their families and friends, and Social Support is highly associated with reducing stress and negative affect for a cancer survivor (Chen et al., 2001) it was expected that Social Support would feature in the regressions. When considering what could have influenced these results factors such as the timing of the assessment

may have had an impact upon the results. This analysis included people at all stages of cancer survivorship therefore the results may not reflect the needs of a survivor going through treatment compared to a survivor who is years into survivorship and not receiving treatment thus potentially creating a greater intra-group variance. Another thought is that perhaps for this particular sample of cancer survivors, the cancer itself and other health issues have become the focus of their attention rather than how much support they are getting from other people. A further point to consider is the measure that was used to test this variable. Although the Social Provisions Scale measure has high internal consistency in trials with older adults it may not be suitable for measuring differences in Social Support when ethnicity is included. This is due to a lack of items relating to cultural support. While other measures could produce different, more health-specific or culturally specific results, they were not available for this particular study.

There were no significant differences between cancer survivors and those without cancer, (nor between Māori and non-Māori) on levels of locus of control. However the multiple regression results showed that locus of control did have a significant effect on cancer survivors Mental QOL. This indicates that locus of control is associated with Mental QOL. When considering that people with a higher internal locus of control tend to report higher levels of quality of life, the results from this study suggest that this sample of older adults could be more evenly spread across the three dimensions of internal, external and powerful others thus giving a less positive result.

There were no reported differences between cancer survivors and those without cancer for job satisfaction. This result could be explained by international

research which indicates that cancer survivors consider returning to work or staying in employment as imperative for regaining and/or maintaining a sense of normality in life (Kennedy et al., 2007; Spelten et al., 2002; Steiner et al., 2009). Previous research indicates that cancer survivors internationally, particularly in USA, confront certain levels of discrimination when attempting to return to the workforce (Rasmussen & Elverdam, 2008; Steiner, Nowels, & Main, 2009) which could reduce the levels of work satisfaction that people without cancer may experience. However the results from this study suggest that there may not be the same levels of discrimination against cancer survivors in New Zealand as evidenced by a lack of difference in job satisfaction between the groups.

5.2 Ethnicity - Variable Differences between Māori and Non-Māori

It has been hypothesised in international research that quality of life is associated with ethnicity (Jeffreys et al., 2005; Singh et al., 2003; Shavers & Brown, 2002) and that ethnicity can impact on quality of life (Blakely et al., 2002; Byers et al., 2008; Crampton et al., Durie, 2005; Jeffrey's et al., 2005; Pearce et al., 2004; Robson et al., 2006). Given this, it was expected that ethnicity would play an important role in the QOL outcomes of cancer survivorship in this study.

When looking at the differences between the groups, Māori reported lower levels of physical QOL than non-Māori. While small, these results were significant and support international research highlighting the physical and functional challenges that cancer survivors experience, particularly those of indigenous origin. This result could be attributed to many of the variables used in this study. Māori are

disproportionately represented in cancer statistics and more likely to experience late stage diagnosis which results in more serious and debilitating treatments, poorer outcomes and decreased quality of life (Cormack et al., 2005). Māori are highly represented in lower socioeconomic areas, have a poorer physical health status than non-Māori (Durie, 2005). They are medically underserved and do not utilise healthcare services in proportion to the need (Jeffreys et al., 2005) all of which affect health in physical terms as well as mentally.

Māori also reported lower levels of Mental QOL than non-Māori. Again, this result could be anticipated given that Māori are a colonised indigenous population and that colonised indigenous populations are reported to have poorer mental health status (Durie, 2005), regardless of the level of education, income or occupation (Pearce et al., 2004). This is supported by other international and national research stating that people of indigenous cultures, particularly those that have been colonised, suffer poorer quality of life than those of the dominant culture (Aishing-Giwa, 2004; Boffa, 2008; Byers et al., 2008; Cancer Control Taskforce, 2005; Coory et al., 2008; Durie, 2005; Gill & Martin, 2002; Pearce et al., 2004). One of the reasons for poorer mental QOL in Māori may be due to changes in societal structures. The accepted ideology of indigenous cultures is that they are inherently *collective societies* whereas the *western society* is more *individualistic*, therefore impacting on the social support available. Given that international research highlights the importance of social support in all its forms as a factor that is imperative for providing more positive outcomes and higher quality of life for cancer survivors (Bowman et al., 2005; Chen et al., 2001; Jefford et al., 2007; Schroevers et

al., 2009; Wasserman & Danforth, 1988) suggest that this is an area that requires further investigation.

Thus it was interesting to note that Māori reported significantly lower levels of social support than non-Māori. When considering why this might occur, and given the nature of cancer and the impact it has upon an individual's health physically and mentally, the following explanations were hypothesised. While chronic illness initially results in increased support for a person, there are occasions when chronic health problems create burnout for those who care for the patient and may cause friends to turn away and be non-supportive by their absence. Chronic illness also creates difficulties for the cancer survivor to attend social functions and mix with people who might otherwise be supportive creating the sense of being unsupported. Furthermore, while the demands for support may increase for the cancer survivor particularly throughout treatment, the support itself could remain the same thus creating the perception that it is lower when the level of support has effectively remained unchanged. Another and more controversial hypothesis is the shift from a collectivist to individualistic society as experienced in colonisation. This has resulted in Māori communities being more dispersed, away from hapu and iwi groups. It is thought that this may negatively impact on the availability of social support.

There were also differences between Māori and non-Māori with Māori reporting a higher utilisation of health services than non-Māori. This is also contrary to current research which states that Māori have a lower health utilisation rate than other New Zealanders (Jeffrey's et al., 2005; Pearce et al., 2004) thus resulting in later-stage diagnoses for cancer and other diseases as well as poorer survival rates

and lower levels of quality of life (Robson et al., 2004). This raises many questions but the most important is why do Māori have poorer health outcomes and more late diagnoses than non-Māori if they go to the doctors more often? Perhaps some of the answers lie in the fact that research indicates Māori are more likely to be diagnosed later than non-Māori (Pearce et al., 2004) and this could result in more visits to healthcare due to being more unwell. Perhaps there is a measure of stereotyping and bias amongst some of the medical professionals which leads to later testing, hence later diagnoses and poorer outcomes for Māori (Pearce et al., 2004). Māori also report higher levels of comorbidity suggesting then that lifestyle choices and health behaviours (Durie, 2005) may lead to increased medical utilisation.

In terms of physical activity, Māori reported lower levels of physical activity than non-Māori. The reported differences in levels of exercise could offer a partial explanation for the differences in comorbidities and health outcomes for Māori. This may be because a lack of exercise is associated with increased comorbidity. This is in turn supported by research that points to lower health status, higher levels of comorbidities and more harmful lifestyles for Māori (Durie, 2005; Jeffreys et al., 2009).

Māori also reported lower levels of job satisfaction than non-Māori. According to statistics Māori are over-represented in unskilled and manual labour types of employment (Department of Labour, 2009). Due to the physical effort that is required in manual labour, job satisfaction could be substantially reduced for Māori who have experienced cancer and are still feeling the effects of treatments. Although physical activity can boost mood, physical labour may be less rewarding when an individual feels unwell. White collar type employment tends to have

structures in place to support employees in the case of illness, whereas unskilled labour employers tend to employ people as casual labourers. Casual employees lack the protective legislation and if unable to work, they can be quickly replaced.

Research suggests other factors such as stereotyping, bias, discrimination and a lack of cultural safety (Pearce et al., 2004) can also influence the effects of the cancer experience for Māori thus affecting QOL physically and mentally. The effects of ethnicity were certainly apparent when looking at the differences between Māori and non-Māori on all variables. However in the regression analyses ethnicity did not have an effect on Physical QOL however, it did have a significant predictive effect on Mental QOL. Again this is to be expected given the association of ethnicity and mental health particularly in New Zealand (Durie, 2005; Jeffreys et al., 2009) Whilst this study corroborates previous research (Byers et al., 2008; Jeffreys et al., 2005) regarding the effect that ethnicity has upon Physical and Mental QOL, it does not provide sufficient insights to conclude why this might be.

The variable with the largest predictive effect on Mental and Physical QOL was socioeconomic status. Given that research shows Māori experience lower socioeconomic status than non-Māori in New Zealand (Barnett & Kearns, 1996; Cancer Control Taskforce, 2005; Durie, 2005; Jeffreys et al., 2005; Robson et al., 2006), suggests that socioeconomic status is one of the reasons why Mental QOL is so affected amongst Māori. This is also in keeping with international research which suggests that low socioeconomic status is the primary cause of health disparities for ethnic minorities and has a profound affect on levels of quality of life (Byers et al., 2008; Singh et al., 2003). Socioeconomic status not only affects the quality of life of

Māori but other New Zealanders as well therefore it is a factor that needs more attention when addressing cancer prevention and survivorship in New Zealand.

5.3 Strengths and Limitations of the study

The strength of the study was in the size and representativeness of the sample. The study consisted of 2,495 participants with 1,418 from the general population and 1,069 from the Māori population thus providing a large representative sample of older New Zealanders. This allowed comparisons to be made between cancer survivors and those without cancer and between Māori and non-Māori. The use of standardised measures for Physical QOL, Mental QOL, Locus of Control, Social Support, Health Utilisation and Job Satisfaction also added strength to the results.

There are a number of limitations in this study that should be taken into account when considering the findings. The comorbidities variable used in this study asks the participant to identify specific disorders they have been diagnosed with. A key problem with this is that a belief that one may have a specific diagnosis is not as accurate as information taken from medical records. Furthermore, the HWR survey provides a specific list of conditions that are common in older aged people but does not include some of the late and long-term effects specifically related to cancer such as Osteoporosis, Hypothyroidism and Lymphedema. A more in-depth study identifying types of comorbidities along with more details of the current cancer status may cover some of these issues.

Access to a more representative sample was limited as the HWR study excluded individuals who were currently incarcerated, residents of nursing homes or those under dependent care. These exclusions were likely to include some of the more seriously affected and disabled cancer survivors such as those receiving palliative care creating a further limitation in the results of this study.

The stages, type of cancer and treatment status are all important factors to consider when looking at cancer survivorship, however because they were not controlled for in this study they may have confounded the results. Some of the cancer survivors surveyed were in the early stages of treatment, some were longer term survivors and some are in remission. Those with recent diagnoses are more likely to report lower levels of Physical and Mental QOL compared to longer term survivors who are no longer receiving treatment and this could be reflected in the results. These issues warrant further investigation.

5.4 Future Research

A longitudinal study of the same sample would be very interesting taking into account the interviews that are being collected for the HWR study. Being able to compare results over the years 2006 – 2008 and 2010 would allow a comparison over time that could give a more definitive idea of the impact cancer has on older adults, particularly as health and attitudes can change over time, along with outcomes of cancer.

As this study did not investigate racism, and research suggests that there are problems for Māori in this respect, further research in this area may explain some of

the disparities in health (Cormack et al., 2005; Barnett & Kearns, 1996; Jeffreys et al., 2005; Pearce et al., 2004), and could be beneficial to identifying areas that need attention and in turn reduce the impact that cancer has on Māori.

Social support provided very interesting results for Māori in that they reported lower levels of perceived social support than non-Māori. When looking through the available literature relating to ethnicity and perceived social support for cancer survivors, there were some overseas studies available on specific forms of cancer, but there was very little relating to Māori available from New Zealand making this an important issue for further research.

5.5 Conclusion

Cancer survivorship is a complex and multi faceted experience that one study cannot hope but simply touch upon the challenges that cancer survivor's experience. There are other issues that have not been discussed in this study such as the existential and spiritual aspects that a person must experience when faced with a life threatening illness such as cancer. The differences found in each of the variables above suggest that cancer survivors' needs are not always met in New Zealand, and that Māori are worse off than non-Māori generally. However, the regression analyses indicated that the disparity is a more complex issue than one single factor such as ethnicity. Therefore one is left wondering, is the fact that Māori are reported to be more likely to have late stage diagnoses (Jeffrey's et al., 2005) and a higher mortality rate (Robson et al., 2006) because they come from lower socioeconomic

areas or is it because of other reasons such as, poor access to medical services, cultural safety or institutionalised racism.

This study indicated that socioeconomic status far outweighs the other variables when considering quality of life of cancer survivors and particularly when combined with the number of comorbidities an individual has. This suggests that the more vulnerable a group of people are socioeconomically, the poorer the outcomes health-wise. This would be important to consider in terms of future legislation and resourcing for healthcare.

APPENDIX I: MEASURES USED IN HWR STUDY

Including

PAGE NUMBERS andQUESTION NUMBERS

| PAGE | QUESTION | DESCRIPTION |
|-------|----------|--|
| 1 – 4 | 1 -11 | SF-36 v1 |
| 4 | 12 | Vision questions x 2 (HWR) |
| 4 | 13-14 | Body Mass Index (HWR) |
| 5 | 15-16 | Diagnosed illnesses and cancer treatment (HWR) |
| 6 | 17-18 | Cigarette and alcohol use. Bush, K., Kivlahan, D. R., McDonell, M. B., Fihn, S. D., & Bradley, K. A. (1998). The AUDIT Alcohol Consumption Questions (AUDIT-C): An Effective Brief Screening Test for Problem Drinking. <i>Archives of Internal Medicine</i> , 15,1789-1795. |
| 7 | 19-24 | Healthcare utilisation |
| 8 | 25 | Prescription drug use (HWR) |
| 8-9 | 26-28 | Quality of life World Health Organisation Quality Of Life - Brief Version |
| 9 | 29 | Locus of control Sapp, S. G. & Harrod, W. J. (1993). Reliability and validity of a brief version of Levenson's locus of control scale. <i>Psychological Reports</i> , 72, 539-550. |
| 10 | 30-31 | Physical activity SPARC. (2004). <i>The New Zealand physical activity questionnaires: Report on the validation and use of the NZPAQ-LF and NZPAQ-SF self-report physical activity survey instruments</i> . Wellington: SPARC. |
| 11 | 32-33 | Driving anxiety Joanne Taylor, School of Psychology, Massey University |
| 11-12 | 34-35 | Happiness HAPPI - Ms Annette Hendricks, School of Psychology, MU |
| 13 | 36 | Volunteer activities Dr Patrick Dulin |
| 13-14 | 37-39 | Wenger Wenger, G.C. (1994). Support networks of older people: A guide for practitioners. Bangor: Centre for Social Policy Research and Development, University of Wales. |
| 14 | 40-42 | Trust, isolation, and attending meetings |
| 14-16 | 43-46 | Caregiving Comes from the Women's Health Australia – caring from your health pilot study |
| 17 | 47 | Social provisions Cutrona, C. E. and Russell, D. (1987). The provisions of social relationships and adaptation to stress. In W. H. Jones & D. Perlman (Eds.) <i>Advances in personal</i> (Vol. 1, pp. 37-67). Greenwich, CT: JAI Press.relationships |
| 18 | 48 | Employment status of self and partner (HWR) |
| 18-19 | 49 | Work history (HWR) |
| 19 | 50 | Shift work and Number of work hours |
| 19 | 51 | Work/family conflict Kopelman, R. E., Greenhaus, J. H., & Connolly, T. F. (1983). A model of work, Family, and interrole conflict: A construct validation study. <i>Organizational Behavior and Human Performance</i> , 32, 198-215. |

| | | |
|----------|---------------------|--|
| 20 | 52 | Job satisfaction Brayfield, A. G. & Rothe, H. F. (1951). An index of job satisfaction. <i>Journal of Applied Psychology</i> , 35 (5), 307 - 311 |
| 21 | 53 | Job demands/decision latitude Bernin, 2002 P. Bernin, Managers' working conditions -stress and health, Department of Public Health Sciences Division of Psychosocial Factors and Health, Karolinska Institutet, Repro Print AB, Stockholm (2002). Cited in Sundin et al., (in press). A scale for measuring specific job demands within the health care sector: Development and psychometric assessment. <i>International Journal of Nursing Studies</i> . |
| 21 23 | 54(a-b) 58 (d-f) | Anticipated retirement finances Adams, G. A., & Beehr, T. A. (1998). Turnover and retirement: A comparison of their similarities and differences. <i>Personnel Psychology</i> , 51, 643-665. |
| 21 | 55 | Age at which R expects self and spouse to retire |
| 22 | 56 | Retirement planning Mr Jack Noone, School of Psychology, Massey University |
| 23 | 57 | Expectations about full-time, part-time-or no work in retirement Health and Retirement Study (USA) |
| 23 | 58 (a-c) | Retirement context factors |
| 23 21 | 58 (g-i) 54 (c) | Anticipated retirement adjustment Taylor, M. A., & Shore, L. M. (1995). Predictors of planned retirement age: An application of Beehr's model. <i>Psychology and Aging</i> , 10, 76-83. |
| 23 | 59 | Work involvement Kanungo, R. N. (1982). Measurement of job and work involvement. <i>Journal of Applied Psychology</i> , 67, 341-349. |
| 24 | 60-61 | Positive and negative aspects of retirement Health and Retirement Study (USA) |
| 25 | 62-63 | Reason for stopping work (HWR), satisfaction with previous work (HRS) |
| 26 | 64-68 | DOB, marital status, Ethnicity, tertiary qualifications |
| 27 | 69 | Job title |
| 27 | 70 | Migration questions (HWR) |
| 27 | 71 | Household composition |
| 28 | 72 | Location of residence |
| 28-29 | 73-76 | Economic Living Standards Index (not incl. Q76i) The New Zealand Ministry of Social Development. http://unpan1.un.org/intradoc/groups/public/documents/APCITY/UNPAN028781.pdf |
| 30 | 77-79 | Ways of receiving income, personal and household income New Zealand Treasury – Grant Scobie |
| 31 | 80-81 | Assets and liability ownership New Zealand Treasury – Grant Scobie |
| 31-32 | 82 | Superannuation (HWR) |
| 32 | 83-87 | Financial questions New Zealand Treasury – Grant Scobie |
| 33-34 | 88-94 | Cultural identity Te Hoe Nuku Roa study, Massey University. (Dr Mason Durrie) |

APPENDIX II: 2008 HWR STUDY QUESTIONNAIRE

**HEALTH WORK
AND RETIREMENT**



**E tū te huru mā,
haramai e noho**

LONGITUDINAL STUDY



Massey University

**Health, Work and
Retirement
Survey**

May 2008

A research collaboration between:

The School of
Psychology
Massey University

The Health
Research Council
of New Zealand

The New Zealand
Institute for
Research on Ageing

The Centre for Maori Health
Research and Development
School of Maori Studies
Te Putahi-a-Toi
Massey University

How to complete this survey

Instructions:

- Use a blue/black pen or pencil to complete this survey
- Try to mark your response clearly with a tick
- When asked to write a response, please print clearly.
- If you make a mistake, please put a cross over the incorrect response and place a tick in the box that best reflects your answer

Example:

| | |
|---|-------------------------------------|
| At this time do you consider yourself partly retired, completely retired, or not retired at all (Please tick <u>one</u> box) | |
| Completely retired | <input type="checkbox"/> 1 |
| Partly retired | <input checked="" type="checkbox"/> |
| Not retired at all | <input type="checkbox"/> 3 |
| <i>Not applicable (e.g., have not or do not work for pay)</i> | <input type="checkbox"/> 4 |

Example:

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives etc.) (Please tick one box)

| | | | | |
|----------------------------|-------------------------------------|----------------------------|----------------------------|----------------------------|
| All of the time | Most of the time | Some of the time | A little of the time | None of the time |
| <input type="checkbox"/> 1 | <input checked="" type="checkbox"/> | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Please read the following carefully:

- All the information you give us is in confidence and will be used only for the purposes of this study.
- There are no right or wrong answers; we want the response that is best for you.
- It is important that you give your own answers to the questions. Please do not discuss your answers with others.
- Do not linger too long over each question; usually your first response is best.
- Completion and return of this survey implies consent to take part in the study
- We are sorry that some questions appear repetitive, but please answer all questions that apply to you.

Thank you for taking the time to complete this survey

If you need help to answer any questions please contact us either by toll-free phone or via email at:

Phone: 0800 100 134

Email: hwr@massey.ac.nz

Firstly, we would like to ask you some questions about your health and things related to your health. This information will help us keep track of how you feel and how well you are able to do your usual activities. For each of the following questions, please tick the box that best describes your answer.

Q 1 In general, would you say your health is:
(Please tick one box)

| | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Excellent | Very good | Good | Fair | Poor |
| ▼ | ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 2 Compared to one year ago, how would you rate your health in general now?
(Please tick one box)

| | | | | |
|-------------------------------------|---|--------------------------------------|--|------------------------------------|
| Much better than one year ago | Somewhat better than one year ago | About the same as one year ago | Somewhat worse than one year ago | Much worse than one year ago |
| ▼ | ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 3 The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
(Please tick one box on each line)

| <u>Activities</u> | Yes, limited a lot | Yes, limited a little | Not limited at all |
|---|----------------------------|-----------------------------|----------------------------|
| | ▼ | ▼ | ▼ |
| (a) <i>Vigorous activities</i> , such as running, lifting heavy objects, participating in strenuous sports | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| (b) <i>Moderate activities</i> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| (c) Lifting or carrying groceries | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| (d) Climbing <i>several</i> flights of stairs | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| (e) Climbing <i>one</i> flight of stairs | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| (f) Bending, kneeling, or stooping | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| (g) Walking <i>more than one</i> kilometre | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| (h) Walking <i>several blocks</i> | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| (i) Walking <i>one block</i> | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| (j) Bathing or dressing yourself | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |

Q 4 During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? (Please tick one box)

| | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Not at all | Slightly | Moderately | Quite a bit | Extremely |
| ▼ | ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 5 During the past 4 weeks, how much of the time have you had any of the following problems with your work OR other regular daily activities as a result of your physical health?

(Please tick one box on each line)

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| (a) Cut down on the <i>amount of time</i> you spent on work or other activities | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (b) Accomplished less than you would like | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (c) Were <i>limited</i> in the <i>kind</i> of work or other activities | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (d) Had <i>difficulty</i> performing the work or other activities (for example, it took <i>extra</i> effort) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 6 How much bodily pain have you had during the past 4 weeks?

(Please tick one box)

| None | Very mild | Mild | Moderate | Severe | Very severe |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |

Q 7 During the past 4 weeks, how much of the time have you had any of the following problems with your work OR other regular daily activities as a result of any emotional problems (e.g. feeling depressed or anxious)?

(Please tick one box on each line)

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| (a) Cut down on the <i>amount of time</i> you spent on work or other activities | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (b) Accomplished less than you would like | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (c) Didn't do work or other activities as <i>carefully</i> as usual | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 8 During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (Please tick one box)

| Not at all | Slightly | Moderately | Quite a bit | Extremely |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 9 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives etc.) (Please tick one box)

| All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 10 These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that is closest to the way you have been feeling. How much of the time during the past 4 weeks...

(Please tick one box on each line)

| | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| (a) Did you feel full of life? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| (b) Have you been very nervous? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| (c) Have you felt so down in the dumps that nothing could cheer you up? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| (d) Have you felt calm and peaceful? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| (e) Did you have a lot of energy? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| (f) Have you felt downhearted and blue? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| (g) Did you feel worn out? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| (h) Have you been happy? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| (i) Did you feel tired? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |

Q 11 How **TRUE** or **FALSE** is each of the following statements for you?

(Please tick one box on each line)

| | Definitely true | Mostly true | Don't know | Mostly false | Definitely false |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| (a) I seem to get sick a little easier than other people | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (b) I am as healthy as anybody I know | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (c) I expect my health to get worse | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (d) My health is excellent | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 12 Can you see ordinary newsprint, with glasses or contact lenses if you usually wear them; easily, with difficulty or not at all? (Please tick one box)

| | Easily | With difficulty | Not at all |
|-----|----------------------------|----------------------------|----------------------------|
| (a) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 2 |

Are you a registered member of the Royal New Zealand Foundation of the Blind?

(Please tick one box)

| | | | | |
|-----|-----|----------------------------|----|----------------------------|
| (b) | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
|-----|-----|----------------------------|----|----------------------------|

Q 13 What is your height?

| Feet | Inches | OR | Centimetres |
|----------------------|----------------------|----|----------------------|
| <input type="text"/> | <input type="text"/> | | <input type="text"/> |

Q 14 What is your weight?

| Stones | Ounces | OR | Kilograms |
|----------------------|----------------------|----|----------------------|
| <input type="text"/> | <input type="text"/> | | <input type="text"/> |

Q 15

The following questions focus on health problems you may have. Please tick the box(s) marked 'Yes' to indicate if a doctor, nurse or other health care worker has told you that you have any of the following health problems. Please also indicate the year in which each health problem (if applicable) was diagnosed

| | | (Tick all that apply) | Year Diagnosed | | | |
|-----|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | | <input type="checkbox"/> |
| (a) | Diabetes? | <input type="checkbox"/> | | | | |
| (b) | Epilepsy? | <input type="checkbox"/> | | | | |
| (c) | High blood pressure or hypertension? | <input type="checkbox"/> | | | | |
| (d) | Heart trouble (e.g., angina or myocardial infarction)? | <input type="checkbox"/> | | | | |
| (e) | Asthma? | <input type="checkbox"/> | | | | |
| (f) | Other respiratory conditions (e.g., bronchitis)? | <input type="checkbox"/> | | | | |
| (g) | Stomach ulcer or duodenal ulcer? | <input type="checkbox"/> | | | | |
| (h) | Chronic liver trouble (e.g., cirrhosis)? | <input type="checkbox"/> | | | | |
| (i) | Bowel disorders (e.g., colitis or polyps)? | <input type="checkbox"/> | | | | |
| (j) | Hernia or rupture? | <input type="checkbox"/> | | | | |
| (k) | Chronic kidney or urinary tract conditions? | <input type="checkbox"/> | | | | |
| (l) | Chronic skin conditions (e.g., dermatitis or psoriasis)? | <input type="checkbox"/> | | | | |
| (m) | Arthritis or rheumatism? | <input type="checkbox"/> | | | | |
| (n) | Hepatitis? | <input type="checkbox"/> | | | | |
| (o) | Sight impairment (that cannot be corrected by glasses)? | <input type="checkbox"/> | | | | |
| (p) | Hearing impairment? | <input type="checkbox"/> | | | | |
| (q) | Stroke? | <input type="checkbox"/> | | | | |
| (r) | Depression? | <input type="checkbox"/> | | | | |
| (s) | Leg ulcers? | <input type="checkbox"/> | | | | |
| (t) | Anaemia (low iron)? | <input type="checkbox"/> | | | | |
| (u) | HIV/AIDS? | <input type="checkbox"/> | | | | |
| (v) | Chronic fatigue syndrome? | <input type="checkbox"/> | | | | |
| (w) | Fibromyalgia? | <input type="checkbox"/> | | | | |
| (x) | Sleep disorder? | <input type="checkbox"/> | | | | |
| (y) | Cancer? | <input type="checkbox"/> | | | | |
| | Please specify type (e.g. lung, leukaemia, melanoma): | <input type="checkbox"/> | | | | |
| (z) | Secondary cancer? | <input type="checkbox"/> | | | | |
| | Please specify type: | | | | | |

Q 16 If you have been diagnosed with cancer, what is your current treatment status? (Excluding long term hormone therapy)

| | | | | | | | | |
|-------------------------|--------------------------|--------------------------|---|-------------------------|--|--|--|--|
| | <input type="checkbox"/> | <input type="checkbox"/> | → | Year treatment finished | | | | |
| Currently being treated | | Finished treatment | | | | | | |

The following questions concern alcohol and cigarette use. For each question, please tick the answer that is correct for you.

Q 17

(a) How often do you have a drink containing alcohol?

(Please tick one box)

| | | | | |
|----------------------------|----------------------------|-----------------------------|-----------------------------|----------------------------|
| Never | Monthly or less | Two to four times per month | Two to three times per week | Four or more times a week |
| ▼ | ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

If you answered "Never" please answer Q 17 (b) below. All others skip to Q 17 (c) below.

(b) Have you ever drunk alcohol in the past?

| | |
|---------------------------|----------------------------|
| Yes (Tick and go to Q 18) | <input type="checkbox"/> 1 |
| No (Tick and go to Q 18) | <input type="checkbox"/> 2 |

(c) How many drinks containing alcohol do you have on a typical day when drinking?

(Please tick one box)

| | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 1 or 2 | 3 or 4 | 5 or 6 | 7 to 9 | 10 or more |
| ▼ | ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

(d) How often do you have six or more drinks on one occasion?

(Please tick one box)

| | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Never | Less than monthly | Monthly | Weekly | Daily or almost daily |
| ▼ | ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 18 Would you currently consider yourself a *regular* tobacco smoker?

(Please tick one box)

| | |
|-----------------------------|----------------------------|
| Yes (Tick and go to Q 18 b) | <input type="checkbox"/> 1 |
| No (Tick and go to Q 18 c) | <input type="checkbox"/> 2 |

IF YOU CONSIDER YOURSELF A *REGULAR* SMOKER: How many do you think you would smoke on an average day?

(Please tick one box)

| | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|
| 1 to 10 a day | 11 to 20 a day | 21 to 30 a day | 31 or more a day |
| ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |

IF YOU DO NOT CONSIDER YOURSELF A *REGULAR* SMOKER: Have you, at any stage of your life, ever been a *regular* smoker?

(Please tick one box)

| | |
|-----|----------------------------|
| Yes | <input type="checkbox"/> 1 |
| No | <input type="checkbox"/> 2 |

The following questions concern your use of health services (such as doctors or hospitals) and prescription drugs. For each question please tick the answer that is correct for you.

Q 19 In the last 12 months, have you seen a doctor or been visited by a doctor about your own health? By 'doctor' we mean any GP or family doctor, but not a specialist.

(Please tick one box)

| | | |
|---------------------------------------|--------------------------|---|
| Yes | <input type="checkbox"/> | 1 |
| No (Tick and go down to Q 21) | <input type="checkbox"/> | 2 |
| Don't know (Tick and go down to Q 21) | <input type="checkbox"/> | 3 |

Q 20 How many times?

(Please tick one box)

| | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1 time | 2 Times | 3 to 5 times | 6 to 11 times | 12 times or more |
| ▼ | ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> |
| 1 | 2 | 3 | 4 | 5 |

Q 21 In the last 12 months, have you yourself used a service at, or been admitted to, a hospital (either public or private)?

(Please tick one box)

| | | |
|---------------------------------------|--------------------------|---|
| Yes | <input type="checkbox"/> | 1 |
| No (Tick and go down to Q 23) | <input type="checkbox"/> | 2 |
| Don't know (Tick and go down to Q 23) | <input type="checkbox"/> | 3 |

Q 22 In the last 12 months, how many times were you admitted for one night or longer?

(Please tick one box)

| | | | |
|---------------------------|--------------------------|--------------------------|--------------------------|
| Never admitted over-night | 1 or 2 times | 3 or 4 times | 5 or more times |
| ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 1 | 2 | 3 | 4 |

Q 23 In the last 12 months, how many times did you go to a hospital *emergency* department as a patient?

(Please tick one box)

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Never | 1 or 2 times | 3 or 4 times | 5 or more times |
| ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 1 | 2 | 3 | 4 |

Q 24

- (a) Is there a doctor or place that is most responsible for your health care? Yes 1 No 2
- (b) How long have you been going there? Years: Months:
- (c) When you go to the doctor, are you taken care of by the *same* person each time? Yes 1 No 2
- (d) Do you have personal health insurance? Yes 1 No 2

Q 25 Please indicate how many prescription drugs you are currently taking:

(a) Number of prescription drugs:

Please list the names of the prescription drugs you are currently taking:

(b)

| | | |
|-----|-----|-----|
| 1. | 2. | 3. |
| 4. | 5. | 6. |
| 7. | 8. | 9. |
| 10. | 11. | 12. |
| 13. | 14. | 15. |

The following questions ask about different aspects of your quality of life.

Q 26 For each of the following statements and/or questions, please tick the box that you feel is most appropriate in describing you. (Please tick one box on each line)

Not a very happy person ←————→ A very happy person

(a) In general I consider myself: 1 2 3 4 5 6 7

Less happy ←————→ More happy

(b) Compared to most of my peers, I consider myself: 1 2 3 4 5 6 7

Q 27

Very poor Poor Neither poor nor good Good Very good

(a) How would you rate your quality of life? 1 2 3 4 5

Very poorly Poorly Neither poorly nor well Well Very well

(b) How well are you able to get around? 1 2 3 4 5

(c) **To what extent do you feel your life to be meaningful?**

Not at all A little A moderate amount Very much An extreme amount

1 2 3 4 5

(d) **How important is religious faith to you?**

Not important at all Slightly important Moderately important Very important Extremely important

1 2 3 4 5

Q 28

| | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very satisfied |
|--|----------------------------|----------------------------|------------------------------------|----------------------------|----------------------------|
| (a) How satisfied are you with your sleep? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (b) How satisfied are you with your ability to perform your daily living activities? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (c) How satisfied are you with your capacity to work? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (d) How satisfied are you with yourself? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (e) How satisfied are you with your personal relationships? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (f) How satisfied are you with your sex life? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (g) How satisfied are you with the support you get from friends? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (h) How satisfied are you with the conditions of your living space? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (i) How satisfied are you with your access to health services? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (j) How satisfied are you with your transport? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (k) How satisfied are you with your health? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (k) How satisfied are you with your life at present? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 29

| | Strongly agree | Somewhat agree | Neither agree nor disagree | Somewhat disagree | Strongly disagree |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| (a) My life is determined by my own actions. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (b) To a great extent, my life is controlled by accidental happenings. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (c) My life is chiefly controlled by powerful others. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (d) I am usually able to protect my personal interests. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (e) I feel like what happens in my life is mostly determined by powerful people. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (f) When I get what I want, it's usually because I'm lucky. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (g) I can pretty much determine what will happen in my life. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (h) Often there is no chance of protecting my personal interest from bad luck. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (i) People like myself have very little chance of protecting our personal interests where they conflict with those of strong pressure groups. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Activities

The following questions concern the kinds of physical activities that people do as part of their everyday lives. Please answer each question even if you do not consider yourself to be an active person.

Q 30 If you add up all the times you spent on each of the following activities in the **LAST 7 DAYS**, how much time did you spend **ALTOGETHER** doing each activity? Please think about the activities you do at work, as part of your house and garden work, to get from place to place or in your spare time for recreation, exercise or sport.

(If you **did not** do an activity, please write '0' in the box)

(a) *Briskly walking* (at a pace where you are breathing harder than normal, but only a little harder; e.g., for recreation or exercise, or to get from place to place) Hours

(b) *Moderate physical activity* (which makes you breath harder than normal, but only moderately harder; e.g., carrying light loads, gardening, bicycling at a regular pace, recreational swimming) Hours

(c) *Vigorous physical activity* (that makes you breathe a lot harder than normal or huff and puff; e.g., heavy lifting, fast bicycling, aerobics, running) Hours

Q 31 Thinking about all your physical activities (brisk walking, moderate or vigorous) on how many of the **LAST 7 DAYS** were you active?

('Active' means doing 15 minutes or more of vigorous activity, OR 30 minutes or more of moderate activity or brisk walking).

(Please tick one box)

| | | | | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |
| 0 days | 1 day | 2 days | 3 days | 4 days | 5 days | 6 days | 7 days |

Q 32 What is your current driving status?

Current driver

Past driver

Never been a driver

(a) 1 2 3

How often do you currently drive?

Daily

Weekly

Monthly

Less than
monthly

Never

(b) 1 2 3 4 5

How anxious are you about driving?

(Anxiety is an unpleasant feeling of nervousness or distress that may have no explanation)

Not at all
anxious

Extremely
anxious

(c) 0 1 2 3 4 5 6 7 8 9 10

If you answered "Not at all anxious", please skip to Question 33 on the next page

Because of driving anxiety, do you use any of the following forms of transport? (Tick as many as apply)

| | | | | | |
|------------------------------------|----------------------------|---------|----------------------------|-------------------------------|----------------------------|
| (d) Transport by family or friends | <input type="checkbox"/> 1 | Taxi | <input type="checkbox"/> 2 | Public transport (bus, train) | <input type="checkbox"/> 3 |
| Walking | <input type="checkbox"/> 4 | Cycling | <input type="checkbox"/> 5 | Community services (e.g. RSA) | <input type="checkbox"/> 6 |

How long have you been anxious about driving?

(e) _____ Years:

In the past month, for how many days were your usual activities or work affected because of driving anxiety?

(f) _____ Days:

How fearful are you about driving?

Q 33 (Fear is a stronger anxiety feeling related to a specific event, object, or situation)

Not at all fearful ←————→ Extremely fearful

0 1 2 3 4 5 6 7 8 9 10

Q 34 Here is a list of activities people often engage in to enhance their happiness. Please indicate how important you find each activity for increasing or maintaining your level of happiness, and how often you engage in each activity. (Please tick two boxes for each activity: one regarding importance and the other regarding frequency)

| Activity | Importance | | | | | Frequency | | | | |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|------------------------------|----------------------------|
| | Extremely important | Very important | Moderately important | Slightly important | Not important at all | Daily or more often | Several times a week | Several times a month | Several times a year or less | Never/not applicable |
| (a) Spending time on hobbies or interests (e.g., gardening, reading, following sports) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (b) Exercising or doing some other form of physical activity (e.g., walking, cycling) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (c) Spending quality time with your partner | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (d) Speaking to or doing something with family (e.g., children, grandchildren) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (e) Speaking to or doing something with good friends | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (f) Spending time with a pet animal/animals | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (g) Meeting with others who share something in common (e.g., interest groups, support groups, faith-related) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

| Activity | Importance | | | | | Frequency | | | | |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|------------------------------|----------------------------|
| | Extremely important | Very important | Moderately important | Slightly important | Not important at all | Daily or more often | Several times a week | Several times a month | Several times a year or less | Never/not applicable |
| (h) Going on outings (e.g., going out for a meal or function, time out in nature) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (i) Going on trips (e.g., visiting family or friends, day trips, holidays away) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (j) Spending time helping others (e.g., providing expertise, money, time, effort) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (k) Spending quality time alone doing your own thing (e.g., relaxing, watching something, treating yourself) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (l) Spiritual activities (e.g., praying, meditating, worshipping) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (m) Working in a role that you enjoy (either paid or unpaid) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (n) Doing something you find mentally challenging | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (o) Counting your blessings | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (p) Framing things in a more positive light | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (q) Doing something you find amusing (e.g., winding someone up, watching a comedy) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (r) Doing something that uses your particular strengths and skills | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (s) Working on something you get a sense of achievement from | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (t) Devoting time to an important personal goal (e.g., a relationship, health, holiday) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (u) Working towards achieving a property goal (e.g., grounds, new house, vehicle) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (v) Devoting effort to a work goal (e.g., cutting back workload, reaching a target) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 35 Overall, thinking about the above activities, please indicate how satisfied or dissatisfied you are with the amount of time you spend on the activities you consider important for your happiness. Answer by ticking the box that best reflects how you feel. (Please tick one box)

Amount of time spent on activities:

| | | | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Extremely satisfied | Very satisfied | Moderately satisfied | I'm not sure | Moderately unsatisfied | Very unsatisfied | Extremely unsatisfied |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |

Q 39 Please answer the following questions about your contact with family and friends.
(Please tick one box on each line)

| | Yes | No |
|--|----------------------------|----------------------------|
| (a) Do you feel you have regular contact with your family? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| (b) Do you feel you have regular contact with your friends? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| (c) Do you regularly participate in family (whanau) activities? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| (d) Do you have family or friends over for a meal at least once a month? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |

Q 40 Which of the following statements, about people in general, do you agree with the most?

(Please tick one box)

| People can almost always be trusted | People can usually be trusted | You usually can't be too careful | You almost always can't be too careful |
|-------------------------------------|-------------------------------|----------------------------------|--|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |

Q 41 Some people tell us that they feel lonely or isolated while others say that they don't. In the last 12 months how often have you felt lonely or isolated?
(Please tick one box)

| Always | Most of the time | Sometimes | Rarely | Never |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |

Q 42 Do you attend any of the following:
(Please tick one box on each line)

| | Yes, regularly | Yes, on occasion | No |
|---|----------------------------|----------------------------|----------------------------|
| (a) Religious meetings | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| (b) Meetings of any community/neighbourhood or social groups, such as clubs, lectures or anything like that | <input type="checkbox"/> 2 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |

Q 43 Which of the following statements best applies to you?
(Please tick one box)

| | |
|--|----------------------------|
| (a) I <u>currently</u> care for someone with a long-term illness, disability, or frailty | <input type="checkbox"/> 1 |
| (b) I <u>have been</u> caring for someone with a long-term illness, disability or frailty who has passed away or moved into a nursing home or hospital in the last 12 months | <input type="checkbox"/> 2 |
| (c) I <u>used</u> to care for someone with a long-term illness, disability, or frailty more than 12 months ago but do not actively care for them now. | <input type="checkbox"/> 3 |
| (d) I have not cared for someone with a long-term illness, disability, or frailty. | <input type="checkbox"/> 4 |
| (e) I currently care for someone as part of my paid work | <input type="checkbox"/> 5 |

Please go to question 44 on the next page

Please skip to question 46 on page 16

Q 44 Do you regularly provide care or assistance (e.g., personal care, transport) to any of the following people because of their long-term illness, disability or frailty?
(Please tick one box on each line)

| | | Yes ▼ | No ▼ |
|-----|--|----------------------------|----------------------------|
| (a) | Someone who lives with you | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| (b) | Someone who lives privately elsewhere | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| (b) | Someone who is now in a nursing home or hospital | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |

(c) How many people with a long-term illness, disability or frailty do you regularly provide care for?
(Please tick one box)

One person 1 Two people 2 More than two people 3

Please select the person you have cared for the longest and complete the following questions about that person.

Is the person you care for your:

| | | | | | | | |
|-----------------------|----------------------------|---------------------------------|----------------------------|--------------------|----------------------------|--------------------|----------------------------|
| (d) Mother or father? | <input type="checkbox"/> 1 | Mother-in-law or father-in-law? | <input type="checkbox"/> 2 | Spouse or partner? | <input type="checkbox"/> 3 | Brother or sister? | <input type="checkbox"/> 4 |
| Son or daughter? | <input type="checkbox"/> 5 | Other relative? | <input type="checkbox"/> 6 | Friend? | <input type="checkbox"/> 7 | Other? (specify) | <input type="checkbox"/> 8 |

Does the person you care for:

| | | | | | |
|--------------------------|----------------------------|--|----------------------------|-------------------------|----------------------------|
| (e) Live with you? | <input type="checkbox"/> 1 | Live alone? | <input type="checkbox"/> 2 | Live with their family? | <input type="checkbox"/> 3 |
| Live with their friends? | <input type="checkbox"/> 4 | Live in a nursing home or care facility? | <input type="checkbox"/> 5 | Other (please specify) | <input type="checkbox"/> 6 |

(f) How old is the person you care for? Years old.

(g) How long have you been caring for that person? Years Months

How often in total do you provide this care or assistance?
(Please tick one box)

| | Every day | Several times per week | Once a week | Once every few weeks | Less often |
|-----|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| (h) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

How much time do you usually spend providing such care or assistance on each occasion?
(Please tick one box)

| | All day and night | All day | All night | Several hours | About an hour |
|-----|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| (i) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 45 Does the person you care for have any of the following major medical conditions

or disabilities? (please tick all that apply)

- | | | |
|-----|---|--------------------------|
| (a) | Alzheimer's disease / dementia | <input type="checkbox"/> |
| (b) | Autism spectrum disorder | <input type="checkbox"/> |
| (c) | Autoimmune disorder | <input type="checkbox"/> |
| (d) | Cancer | <input type="checkbox"/> |
| (e) | Cerebral palsy | <input type="checkbox"/> |
| (f) | Down's syndrome | <input type="checkbox"/> |
| (g) | Frailty in old age | <input type="checkbox"/> |
| (h) | Head injury | <input type="checkbox"/> |
| (i) | Infectious disease | <input type="checkbox"/> |
| (j) | Mental health problem (e.g. depression, anxiety) | <input type="checkbox"/> |
| (k) | Musculoskeletal condition (e.g. break / fracture) | <input type="checkbox"/> |
| (l) | Severe arthritis / rheumatism | <input type="checkbox"/> |
| (m) | Visual impairment | <input type="checkbox"/> |
| (n) | Paralysis | <input type="checkbox"/> |
| (o) | Respiratory condition (e.g. asthma, emphysema) | <input type="checkbox"/> |
| (p) | Spinal cord injury | <input type="checkbox"/> |
| (q) | Stroke | <input type="checkbox"/> |
| (r) | Substance abuse / addiction | <input type="checkbox"/> |
| (s) | Other neurological disorder (eg multiple sclerosis, motor neuron disease) | <input type="checkbox"/> |
| (t) | Other (please specify) | <input type="checkbox"/> |
-

Q 46 Do you provide unpaid care for your grandchildren?

(Please tick one box)

- | | | | | | |
|-----|--------------------------|--------------------------|--------------------------|--------------------------|------------------------------|
| | Yes, daily | Yes, weekly | Yes, occasionally | No, never | No, don't have grandchildren |
| (a) | <input type="checkbox"/> |

Do you provide unpaid care for other people's children?

(Please tick one box)

- | | | | | |
|-----|--------------------------|--------------------------|--------------------------|--------------------------|
| | Yes, daily | Yes, weekly | Yes, occasionally | No, never |
| (b) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Q 47 To what extent do you agree that each statement describes your current relationships with other people?

(Please tick one box on each line)

| | Strongly disagree | Disagree | Agree | Strongly agree |
|---|----------------------------|----------------------------|----------------------------|----------------------------|
| (a) There are people I can depend on to help me if I really need it. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (b) I feel that I <u>do not</u> have close personal relationships with other people. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (c) There is no one I can turn to for guidance in times of stress. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (d) There are people who depend on me for help. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (e) There are people who enjoy the same social activities I do. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (f) Other people do not view me as competent. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (g) I feel personally responsible for the well-being of another person. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (h) I feel part of a group of people who share my attitudes and beliefs. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (i) I do not think other people respect my skills and abilities. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (j) If something went wrong, no one would come to my assistance. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (k) I have close relationships that provide me with a sense of emotional security and well-being. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (l) There is someone I could talk to about important decisions in my life. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (m) I have relationships where my competence and skills are recognized. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (n) There is no one who shares my interests and concerns. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (o) There is no one who really relies on me for their well-being. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (p) There is a trustworthy person I could turn to for advice if I were having problems. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (q) I feel a strong emotional bond with another person. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (r) There is no one I can depend on for aid if I really need it. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (s) There is no one I feel comfortable talking about problems with. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (t) There are people who admire my talents and abilities. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (u) I lack a feeling of intimacy with another person. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (v) There is no one who likes to do the things I do. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (w) There are people I can count on in an emergency. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (x) No one needs me to care for them. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |

The following questions are for all participants. Where questions are not applicable to you, you will be asked to skip forward in the survey.

Q 48 In the following table:

- ▶ Please tick in column 1 next to the best description of your current situation.
- ▶ Please tick in column 2 next to the best description of your preferred situation.
- ▶ Please tick in column 3 next to the best description of your spouse or partner's current situation (if applicable).

| Employment Status | ① Your <i>current</i> situation | ② Your <i>preferred</i> situation | ③ Your <i>spouse's</i> situation (If applicable) |
|--|---------------------------------------|--|---|
| Full-time paid employment, including self employment (35 or more hours per week) | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |
| Part-time paid work, including self employment (less than 35 hours per week) | <input type="checkbox"/> 2 | <input type="checkbox"/> 2 | <input type="checkbox"/> 2 |
| Retired, no paid work | <input type="checkbox"/> 3 | <input type="checkbox"/> 3 | <input type="checkbox"/> 3 |
| Full-time homemaker | <input type="checkbox"/> 4 | <input type="checkbox"/> 4 | <input type="checkbox"/> 4 |
| Full-time student | <input type="checkbox"/> 5 | <input type="checkbox"/> 5 | <input type="checkbox"/> 5 |
| Unable to work due to health or disability issue | <input type="checkbox"/> 6 | <input type="checkbox"/> 6 | <input type="checkbox"/> 6 |
| Unemployed and seeking work | <input type="checkbox"/> 7 | <input type="checkbox"/> 7 | <input type="checkbox"/> 7 |
| Other (please specify) | <input type="checkbox"/> 8 _____ | <input type="checkbox"/> 8 | <input type="checkbox"/> 8 _____ |

Q 49

(a) Approximately, how many part-time and full-time (paid) jobs have you held since age 18?

| | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| None | 1 to 10 | 11 to 20 | 21 to 30 | 30 or more |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

(b) Approximately, how many years have you spent in the paid workforce (part-time and full time) since age 18?

| | |
|----------------------|----------------------|
| <input type="text"/> | <input type="text"/> |
|----------------------|----------------------|

Not
applicable

(c) Approximately, what is the greatest number of years you have spent in one (paid) job?

| | |
|----------------------|----------------------|
| <input type="text"/> | <input type="text"/> |
|----------------------|----------------------|

▼
 0

(d) If you have spent more than 1 year out of the paid workforce since age 18, please indicate the main reason(s) why and the approximate number of years for each reason.

| | | | |
|---|---|--|--------------------------------|
| Homemaker or child rearing <input type="checkbox"/> | Retirement <input type="checkbox"/> | Caregiving for a relative or friend <input type="checkbox"/> | Study <input type="checkbox"/> |
| Years: <input type="text"/> | Years: <input type="text"/> | Years: <input type="text"/> | Years: <input type="text"/> |
| Poor health or disability <input type="checkbox"/> | Made redundant <input type="checkbox"/> | Other: Please specify _____ <input type="checkbox"/> | |
| Years: <input type="text"/> | Years: <input type="text"/> | Years: <input type="text"/> | |

If you are currently working for pay either full-time or part-time, please continue to Q 50

If you are completely retired or otherwise not working for pay, please skip to Q 58 on page 23.

Q 50 How many hours do you work in paid employment per week?

(a) Hours per week

Do you regularly perform shift work?

(b) Yes No

Q 51 Please indicate how much you agree or disagree with the following statements. Answer by ticking the box that best reflects how you feel.

(Please tick one box on each line)

| | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|---|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|
| (a) My work schedule often conflicts with my family life. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (b) After work, I come home too tired to do some of the things I'd like to do. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (c) On the job I have so much work to do that it takes away from my personal interests. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (d) My family dislikes how often I am preoccupied with my work while I am home. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (e) Because my work is demanding, at times I am irritable at home. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (f) The demands of my job make it difficult to be relaxed all the time at home. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (g) My work takes up time that I'd like to spend with my family. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (h) My job makes it difficult to be the kind of spouse or parent I'd like to be. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Q 52 Please indicate how much you agree or disagree with the following statements.
Answer by ticking the box that best reflects how you feel.
 (Please tick one box on each line)

| | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|--|----------------------------|----------------------------|----------------------------------|----------------------------|----------------------------|
| | ▼ | ▼ | ▼ | ▼ | ▼ |
| (a) There are some conditions regarding my job that could be improved | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (b) My job is like a hobby to me | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (c) My job is usually interesting enough to stop me getting bored | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (d) It seems that my friends are more interested in their jobs | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (e) I consider my job rather unpleasant | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (f) I enjoy my work more than my leisure time | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (g) I am often bored with my job | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (h) I feel fairly well satisfied with my present job | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (i) Most of the time I have to force myself to go to work | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (j) I am satisfied with my job for the time being | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (k) I feel that my job is just as interesting as any others I could get | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (l) I definitely dislike my work | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (m) I feel like I am happier in my work than most people. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (n) Most days I am enthusiastic about work | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (o) Each day of work feels like it will never end | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (p) I like my job better than the average worker does | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (q) My job is pretty uninteresting | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (r) I find real enjoyment in my work | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (s) I am disappointed that I ever took this job | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 53

| | Never | Rarely | Sometimes | Often |
|--|----------------------------|----------------------------|----------------------------|----------------------------|
| (a) Do you have a choice in deciding how you do your work? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (b) Do you have a choice in deciding what you do at work? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (c) Do you have to work very fast? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (d) Do you have to work very intensively? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (e) Does your work demand too much effort? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (f) Do you have enough time to do everything? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| (g) Does your work often involve conflicting demands? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |

Q 54

| | Strongly disagree | Somewhat disagree | Neither agree nor disagree | Moderately agree | Somewhat agree | Strongly agree |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| (a) I can financially afford to retire now | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| (b) One reason I continue to work is because I cannot afford to retire | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| (c) When I imagine what retirement will be like, I feel depressed | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |

Q 55

IF YOU ARE WORKING FULL-TIME (35 or more hours per week) : **At what age do you think you will retire completely?**

(a) I think I will retire at age:

IF YOU ARE WORKING PART-TIME (less than 35 hours per week) : **At what age do you think you will retire completely?**

(b) I think I will retire at age:

If you are working part-time, at what age did you stop working full-time?

(c) Age: Not applicable 0

Do you expect your spouse/partner to retire at about the same time as you?
(Please tick one box)

(d) Yes 1 No 2 Spouse not working 3 Not applicable (no spouse/partner) 4

Q 56 The following are statements that some people make about their planning for life in retirement. Please indicate how true these statements are for you.

| | Not true for me at all | ←————→ | | | Definitely true for me |
|--|------------------------------|----------------------------|----------------------------|----------------------------|------------------------------|
| | ▼ | | | | ▼ |
| I often speak to retired people about their experiences of retirement | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| I am separating myself from my work | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| I plan to undertake some other kind of job before I retire | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| I am reducing or will soon reduce my work hours | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| I am actively developing ways to spend my time when or if I retire | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| There are many things I could do with my time if I was forced to retire today | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| I have recently taken up new interests, activities, or hobbies | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| I only eat foods that will benefit my long-term health | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| I never get medical screening for diseases such as cancer, diabetes, and heart disease | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| I never have general medical check-ups | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| I try to keep physically active. (e.g. by taking regular walks, playing sport, or doing yoga etc) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| I undertake many healthy behaviours such as regular exercise and keeping a healthy diet | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| I avoid unhealthy behaviours such as excessive drinking and cigarette smoking | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| By the time I retire I will have sufficient income, investments, and/or superannuation to ensure the standard of living I want in retirement | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| By the time I retire I will own a house without a mortgage | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| There are <u>other</u> things I am doing to prepare for retirement | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

If there are other things you are doing to prepare for retirement, please list them here:

Q 57 Some people want to stop paid work entirely when they retire, while others would like to continue doing some paid work – what about you?

(Please tick one box)

| | | |
|-----|-------------------------|--------------------------|
| (a) | Stop paid work entirely | <input type="checkbox"/> |
| | Continue some paid work | <input type="checkbox"/> |
| | Don't know | <input type="checkbox"/> |

| | A lot | Some | A little | Hardly at all | Not applicable |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| (b) How much have you thought about retirement? | <input type="checkbox"/> |
| (c) How much have you discussed retirement with your spouse or partner? | <input type="checkbox"/> |
| (d) How much have you discussed retirement with your friends or co-workers? | <input type="checkbox"/> |

Q 58

| | Strongly disagree | Somewhat disagree | Neither agree nor disagree | Somewhat agree | Strongly agree |
|--|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|
| (a) I feel uncertain about how economic trends will affect my life in retirement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (b) I feel secure that the government will financially support me in retirement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (c) I feel/felt pressure to retire | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (d) I worry about the standard of living I will have in retirement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (e) I worry about having enough income in retirement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (f) I am satisfied with what my family income will be in retirement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (g) I am confident that I will easily adjust to retirement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (h) I don't think I will have any trouble handling retirement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (i) I expect to enjoy retirement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Q 59

| | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| (a) The most important things that happen in life involve work | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (b) Work is something people should get involved in most of the time | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (c) Work should be only a small part of one's life | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (d) Work should be considered central to life | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (e) In my view, an individual's personal life goals should be work-oriented | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| (f) Life is worth living only when people get absorbed in work | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Q 60 Below is a list of things that some people like about retirement. Please indicate how important you think they are or will be during your retirement. We would like you to respond even if you are not currently retired.

(Please tick one box on each line)

| | Very important | Moderately important | Somewhat important | Not important at all | Not applicable |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| (a) Being your own boss | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (b) Lack of pressure | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (c) Being able to take it easy | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (d) Having more time with husband/wife/partner | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (e) Spending more time with grand/children | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (f) Spending more time on hobbies or sports | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (g) Having more time for volunteer work (church, civic organisation etc) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (h) Having the chance to travel | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |

Q 61 Below is a list of things that some people don't like about retirement. Please indicate how bothersome you think they will be during your retirement. We would like you to respond even if you are not currently retired.

(Please tick one box on each line)

| | Bothered a lot | Bothered somewhat | Bothered a little | Not at all bothered | Not applicable |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| (a) Being bored, having too much time on your hands | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (b) Not doing anything productive or useful | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (c) Missing people you work(ed) with | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (d) Illness or disability | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (e) Not having enough income to get by | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| (f) Inflation and the cost of living | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |

If you are completely retired or partly retired, please go onto Q 62 on the next page

All others please skip to Q 64 on page 26

Q 62 What was your reason(s) for stopping or reducing work? (Tick all that apply)

| | | | |
|---|--|---|---|
| Forced due to poor health <input type="checkbox"/> | Forced due to disablement or injury <input type="checkbox"/> | Employer forced Retirement <input type="checkbox"/> | Lacked skills to continue <input type="checkbox"/> |
| Became eligible for New Zealand Superannuation <input type="checkbox"/> | Wanted to do other things <input type="checkbox"/> | Don't need to work <input type="checkbox"/> | Felt it was time to retire <input type="checkbox"/> |
| Caregiving responsibilities <input type="checkbox"/> | Unhappy at work <input type="checkbox"/> | Other: Please specify <input type="checkbox"/> | |

Q 63

If you consider yourself completely retired, how long have you been retired?

(a) Years Months Not completely retired yet

If you consider yourself completely retired, how satisfying did you find your previous work? (Please tick one box).

(b) Extremely unsatisfying Unsatisfying Somewhat unsatisfying Neither satisfying nor unsatisfying Somewhat satisfying Satisfying Extremely satisfying

How long did it take you to get used to retirement?

(c) Less than one month Six months Nine months One year Two years I'm not used to retirement yet

How difficult has it been for you to adjust to retirement?

(d) Very difficult Not difficult at all

“It took quite some time for me to adjust to retirement”

(e) Completely agree Agree Neither agree nor disagree Disagree Completely disagree

All in all, would you say that your retirement has turned out to be:

(f) Very satisfying Somewhat satisfying Not at all satisfying

Background Information

We would like to ask you for some general background information. **Please place a tick** next to the answer that you believe gives an accurate indication of your **CURRENT** situation, or write details in the spaces provided.

Q 64 When were you born?

| | | | | | | | | | |
|--|-----|---|--|-------|---|--|------|---|---|
| | D | D | | M | M | | 19 | Y | Y |
| | Day | | | Month | | | Year | | |

Q 65 Which one of these statements is true about your legal marital status?

(If you have been married more than once, answer for your most recent marriage)

| | | |
|--|--------------------------|---|
| I am legally married | <input type="checkbox"/> | 1 |
| I am in a civil union/de facto/partnered relationship | <input type="checkbox"/> | 2 |
| I am permanently separated from my legal husband or wife | <input type="checkbox"/> | 3 |
| I am divorced or my marriage has been dissolved | <input type="checkbox"/> | 4 |
| I am a widow or widower | <input type="checkbox"/> | 5 |
| I have never been legally married | <input type="checkbox"/> | 6 |

Q 66 Which ethnic group do you belong to?

(Please tick all the boxes that apply to you)

| | | | | | | | | |
|--|--------------------------|---|--------|--------------------------|---|--------|--------------------------|----------------------|
| Pakeha / New Zealander of European descent | <input type="checkbox"/> | 1 | Māori | <input type="checkbox"/> | 1 | Samoan | <input type="checkbox"/> | 1 |
| Cook Island Māori | <input type="checkbox"/> | 1 | Tongan | <input type="checkbox"/> | 1 | Niuean | <input type="checkbox"/> | 1 |
| Chinese | <input type="checkbox"/> | 1 | Indian | <input type="checkbox"/> | 1 | Other | <input type="checkbox"/> | 1 |
| | | | | | | | Please specify: | <input type="text"/> |

Q 67 Do you have a post-secondary or tertiary qualification? (Please tick one box)

| | | |
|--------------------------------|--------------------------|---|
| Yes (Tick and go down to Q 68) | <input type="checkbox"/> | 1 |
| No (Tick and go to Q 69) | <input type="checkbox"/> | 2 |

Q 68 If yes, please specify your highest tertiary qualification below
(Please tick one box only)

| | | | |
|--|---|--|--|
| Level 1, 2, 3 or 4 post-secondary certificate (E.g. City and Guilds –Catering/Baking/Cooking, City and Guilds – Steel making, Registered Surveyor, Enrolled nurse) | | Level 5 and 6 diploma (E.g. Advanced Trade Cert, Engineer First Class, City & Guilds - Advanced Trained Teacher, Nursing Diploma.) | |
| <input type="checkbox"/> | | <input type="checkbox"/> | |
| Bachelor degree (E.g. BBS, BSc, BA.) | Post-graduate or honours degree (E.g. LLB Hons, BA Hons.) | Masters degree (E.g. MSc, MBA, Physician, surgeon.) | Doctoral degree (E.g. PhD, DPhil.) |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other post-secondary or tertiary qualification (please specify): <input type="text"/> | | | |

Q 69 If in paid employment, what is your occupation in your main job?
 (Try to be as specific as you can. For example: Primary School Teacher, Clothing Machinist, Motel Manager, Word Processor Operator).

Q 70 In what year did you move to your current location of residence?

(a) Year:

(b) What was your main reason for moving to your current home? (Please tick one box)

| | | | | |
|--|---|--|--|--|
| To be near or with children <input type="checkbox"/> ₁ | Larger home <input type="checkbox"/> ₂ | Smaller home <input type="checkbox"/> ₃ | Climate or weather <input type="checkbox"/> ₄ | Leisure activities <input type="checkbox"/> ₅ |
| Health problems or to be closer to health services <input type="checkbox"/> ₆ | To be near or with other relatives or friends <input type="checkbox"/> ₇ | Work or retirement related <input type="checkbox"/> ₈ | Easier maintenance of house and/or gardens <input type="checkbox"/> ₉ | Returning to family lands <input type="checkbox"/> ₁₀ |
| Change in marital status <input type="checkbox"/> ₁₁ | To free up equity <input type="checkbox"/> ₁₂ | Other: <input type="checkbox"/> ₀ (Please specify) | | |

Q 71 Excluding yourself, please give the total number of people that live in the same household as you.

(a) Total number of people

How many people, excluding yourself, are dependent on you for their financial support?

(b) Total number of people

Tick as many boxes as you need to show all the people who live in the same household as you.

| | |
|---|---|
| (c) My legal husband or wife <input type="checkbox"/> ₁ | My partner or de facto, boyfriend or girlfriend <input type="checkbox"/> ₁ |
| My son(s) and/or daughter(s) <input type="checkbox"/> ₁ | My sister(s) and/or brother(s) <input type="checkbox"/> ₁ |
| My mother and/or father <input type="checkbox"/> ₁ | My flatmate(s) <input type="checkbox"/> ₁ |
| Other (Please state: e.g. my grandmother, my mother-in-law, caregiver etc). <input type="checkbox"/> ₁ | None of the above – I live alone <input type="checkbox"/> ₁ |

If you indicated above that you live with some of your children, please indicate below how many children live in the same household as you and their ages:

Number of children

(d) Ages:

Q 72 Which of the following best describes the area where you live?

(Please tick one box)

| | | | | |
|-----------------------------|---|--|---|--------------------------|
| Main Urban Area | ⇒ | A city with population of 30,000 or more | ⇒ | <input type="checkbox"/> |
| Secondary Urban Area | ⇒ | A town / city with a population of between 10,000 & 29,999 | ⇒ | <input type="checkbox"/> |
| Minor Urban Area | ⇒ | A town with a population of between 1,000 & 10,000 | ⇒ | <input type="checkbox"/> |
| Rural Centre | ⇒ | A town with a population of between 300 & 1,000 | ⇒ | <input type="checkbox"/> |
| Rural Area | ⇒ | Outside a town / city boundaries | ⇒ | <input type="checkbox"/> |

Q 73 For the following questions, please indicate whether or not you have (or have access to) the item by ticking one of the boxes.

1. Tick the first box if you have the item or have access to it
2. Tick the second box if you don't have the item because you don't want it
3. Tick the third box if you don't have the item because of its cost
4. Tick the fourth box if you don't have the item because of some other reason.

| | Yes I have it | No because I don't want it | No because of the cost | No for some other reason |
|--|--------------------------|----------------------------|--------------------------|--------------------------|
| (a) Telephone | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (b) Washing machine | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (c) Heating available in all main rooms | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (d) A good pair of shoes | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (e) A best outfit for special occasions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (f) Personal computer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (g) Home contents insurance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (h) Enough room for family to stay the night | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Q 74 For the following questions, please indicate whether or not you do the activity by ticking one of the boxes.

| | Yes I do it | No because I don't want to | No because of the cost | No for some other reason |
|--|--------------------------|----------------------------|--------------------------|--------------------------|
| (a) Give presents to family or friends on birthdays, Christmas or other special occasions. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (b) Visit the hairdresser at least once every three months | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (c) Have holidays away from home every year | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (d) Have a holiday overseas at least every three years | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (e) Have a night out at least once a month | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (f) Have family or friends over for a meal at least once a month | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Q 75

The following questions are about your material standard of living – the things that money can buy (this does not include your health or capacity to enjoy life). Tick the answer that best applies to you.

(a) Generally, how would you rate your material standard of living?

| | | |
|-------------|--------------------------|---|
| High | <input type="checkbox"/> | 1 |
| Fairly high | <input type="checkbox"/> | 2 |
| Medium | <input type="checkbox"/> | 3 |
| Fairly low | <input type="checkbox"/> | 4 |
| Low | <input type="checkbox"/> | 5 |

(b) Generally, how satisfied are you with your current material standard of living?

| | | |
|------------------------------------|--------------------------|---|
| Very satisfied | <input type="checkbox"/> | 1 |
| Satisfied | <input type="checkbox"/> | 2 |
| Neither satisfied nor dissatisfied | <input type="checkbox"/> | 3 |
| Dissatisfied | <input type="checkbox"/> | 4 |
| Very dissatisfied | <input type="checkbox"/> | 5 |

(c) How well does your total income meet your everyday needs for such things as accommodation, food, clothing and other necessities?

| | | |
|---------------------------------|--------------------------|---|
| My income is not enough | <input type="checkbox"/> | 1 |
| My income is <i>just</i> enough | <input type="checkbox"/> | 2 |
| My income is enough | <input type="checkbox"/> | 3 |
| My income is more than enough | <input type="checkbox"/> | 4 |

Q 76

The following are a list of things some people do to help keep costs down. In the last 12 months, how often have you done any of these things? Tick the box that best applies to you.

| | Not at all | A little | A lot |
|--|--------------------------|--------------------------|--------------------------|
| (a) Gone without fresh fruit and vegetables to keep down costs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (b) Continued wearing clothing that was worn out because you couldn't afford a replacement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (c) Put off buying clothes for as long as possible to help keep down costs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (d) Stayed in bed longer to save on heating costs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (e) Postponed or put off visits to the doctor to help keep down costs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (f) NOT picked up a prescription to help keep down costs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (g) Spent less on hobbies than you would like to keep down costs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (h) Done without or cut back on trips to the shops or other local places to help keep down costs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (i) Done without or cut back on dairy products (e.g. milk and cheese) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Q 77 Tick as many boxes as you need to show all the ways you received income in the 12 months ending today.

NOTE: Please DON'T count loans because they are not income.

- (a) Wages, salary, commissions, bonuses...etc, paid by my employer
- (b) Self-employment, or business I own and work in
- (c) Interest, dividends, rent, other investments
- (d) Regular payments from ACC or a private work accident insurer
- (e) New Zealand Superannuation or Veterans Pension
- (f) Other superannuation, pensions, annuities (other than NZ Superannuation, Veterans Pension or War Pension)
- (g) Unemployment Benefit
- (h) Domestic Purposes Benefit
- (i) Invalids Benefit
- (j) Student Allowance
- (k) Other government benefits, income support payments, or war pensions
- (l) Other sources of income, counting support payments from people who do not live in my household
- (m) No source of income during that time

Q 78 From all the sources of income you marked in question 77, what would the total income be that you yourself received **BEFORE** tax in the last 12 months?

(Please tick one box below)

| | | | | | | |
|----------------------------|----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|----------------------------|
| Loss | Zero income | \$1 - \$5,000 | \$5,001 - \$10,000 | \$10,001 - \$15,000 | \$15,001 - \$20,000 | \$20,001 - \$25,000 |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |
| \$25,001 - \$30,000 | \$35,001 - \$40,000 | \$40,001 - \$50,000 | \$50,001 - \$70,000 | \$70,001 - \$100,000 | \$100,001 or more | |
| <input type="checkbox"/> 8 | <input type="checkbox"/> 9 | <input type="checkbox"/> 10 | <input type="checkbox"/> 11 | <input type="checkbox"/> 12 | <input type="checkbox"/> 13 | |

Q 79 What would be the combined income that every other member of your household received **BEFORE** tax in the last 12 months?

(Please tick one box below.)

| | | | | | | |
|----------------------------|----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|----------------------------|
| Loss | Zero income | \$1 - \$5,000 | \$5,001 - \$10,000 | \$10,001 - \$15,000 | \$15,001 - \$20,000 | \$20,001 - \$25,000 |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |
| \$25,001 - \$30,000 | \$35,001 - \$40,000 | \$40,001 - \$50,000 | \$50,001 - \$70,000 | \$70,001 - \$100,000 | \$100,001 or more | |
| <input type="checkbox"/> 8 | <input type="checkbox"/> 9 | <input type="checkbox"/> 10 | <input type="checkbox"/> 11 | <input type="checkbox"/> 12 | <input type="checkbox"/> 13 | |

Q 80

Do you own any of the following? Please provide the approximate value.

(Please tick all that apply)

| | Yes ▼ | | Value | | | | | | | |
|--|----------------------------|----|-------|--|--|--|--|--|--|--|
| (a) The property where you live? | <input type="checkbox"/> 1 | \$ | | | | | | | | |
| A farm or farms? | <input type="checkbox"/> 1 | \$ | | | | | | | | |
| A business or businesses? | <input type="checkbox"/> 1 | \$ | | | | | | | | |
| A holiday house? | <input type="checkbox"/> 1 | \$ | | | | | | | | |
| A rental property or properties? | <input type="checkbox"/> 1 | \$ | | | | | | | | |
| Any shares? | <input type="checkbox"/> 1 | \$ | | | | | | | | |
| Any managed funds? | <input type="checkbox"/> 1 | \$ | | | | | | | | |
| Any banks deposits or savings? | <input type="checkbox"/> 1 | \$ | | | | | | | | |
| A motor vehicle or vehicles? | <input type="checkbox"/> 1 | \$ | | | | | | | | |
| Other <u>major</u> assets? (Please specify below) | <input type="checkbox"/> 1 | \$ | | | | | | | | |

(b) **Is the property where you live owned by a trust?**

Yes 1 No 2

Q 81

Do you have any of the following? Please provide the approximate value.

(Please tick all that apply).

| | Yes ▼ | | Value | | | | | | | |
|--|----------------------------|----|-------|--|--|--|--|--|--|--|
| A mortgage or mortgages? | <input type="checkbox"/> 1 | \$ | | | | | | | | |
| A loan from a bank, finance company, family member or friend? | <input type="checkbox"/> 1 | \$ | | | | | | | | |
| Unpaid bills which you are not able to pay? | <input type="checkbox"/> 1 | \$ | | | | | | | | |

Q 82

(a) **Aside from New Zealand Super, do you belong to a superannuation or pension programme?**

(Please tick one box)

Yes 1
No 2

(b) **If yes, tick all that apply:**

| | | | |
|----------------------------|---|------------------------------------|---------------------------------|
| Kiwisaver | Other employer sponsored superannuation | Overseas superannuation or pension | Other pension or superannuation |
| ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |

If you have Māori ancestry, please continue to Q 89 below. If you do not have Māori ancestry, please turn to page 35.

Q 89 Do you identify as Māori?
(Please tick one box)

| | | |
|-----|--------------------------|---|
| Yes | <input type="checkbox"/> | 1 |
| No | <input type="checkbox"/> | 2 |

Q 90 How many generations of your Māori ancestry can you name?
(Please tick one box)

| | | |
|------------------------------------|--------------------------|---|
| I generation (parents) | <input type="checkbox"/> | 1 |
| 2 generations (grandparents) | <input type="checkbox"/> | 2 |
| 3 generations (great-grandparents) | <input type="checkbox"/> | 3 |
| More than 3 generations | <input type="checkbox"/> | 4 |

Q 91 Have you ever been to a marae; and if yes – how often over the past 12 months?
(Please tick one box)

| | | |
|------------------------|--------------------------|---|
| Not at all | <input type="checkbox"/> | 1 |
| Once | <input type="checkbox"/> | 2 |
| A few times | <input type="checkbox"/> | 3 |
| Several times | <input type="checkbox"/> | 4 |
| More than once a month | <input type="checkbox"/> | 5 |

Q 92 In terms of your involvement with your whanau, would you say that your whanau plays...
(Please tick one box)

| | | |
|--------------------------------|--------------------------|---|
| A very large part in your life | <input type="checkbox"/> | 1 |
| A large part in your life | <input type="checkbox"/> | 2 |
| A small part in your life | <input type="checkbox"/> | 3 |
| A very small part in your life | <input type="checkbox"/> | 4 |

Q 93 Do you have a financial interest in Māori land (i.e. as an owner, part/potential owner or beneficiary)?
(Please tick one box)

| | | |
|---------------------|--------------------------|---|
| Yes | <input type="checkbox"/> | 1 |
| No | <input type="checkbox"/> | 2 |
| Not sure/don't know | <input type="checkbox"/> | 3 |

Q 94 This question considers your contacts with people. In general, would you say that your contacts are with...

(Please tick one box)

| | | |
|--|--------------|--------------------------|
| | Mainly Māori | <input type="checkbox"/> |
| | Some Māori | <input type="checkbox"/> |
| | Few Māori | <input type="checkbox"/> |
| | No Māori | <input type="checkbox"/> |

Q 95 How would you rate your overall ability with Māori language?

(Please tick one box)

| | | |
|--|-----------------------|--------------------------|
| | Excellent | <input type="checkbox"/> |
| | Very good | <input type="checkbox"/> |
| | Good | <input type="checkbox"/> |
| | Fair | <input type="checkbox"/> |
| | Poor | <input type="checkbox"/> |
| | <i>Not applicable</i> | <input type="checkbox"/> |

Thank you for taking the time to complete this survey



Please go to the next page

Contact Details and Invitation

This is a longitudinal survey and it is important that we are able to get hold of you to complete further surveys. We would like you to nominate three people whom we can contact in the event that we lose track of you. This is very important for the success of this study. Please make sure you inform the people you have nominated.

| Contact Person Number 1 | | |
|--------------------------------|------------|--------|
| Surname | First Name | |
| Address: | | Phone: |
| | | |
| | | Email: |
| Contact Person Number 2 | | |
| Surname | First Name | |
| Address: | | Phone: |
| | | |
| | | Email: |
| Contact Person Number 3 | | |
| Surname | First Name | |
| Address: | | Phone: |
| | | |
| | | Email: |

If you have changed your address recently, or are planning to shift, please call us on 0800 100 134 to provide us with your new address. Alternatively, you may change your address online via our website: <http://hwr.massey.ac.nz/participants.htm>

We are still interested in interviewing a small number of people regarding the topics covered in this survey. If you are interested in being interviewed please tick the box below:

“Yes, I am interested in being interviewed”

(If you tick this box you will receive more information about the interview).

Before you place the completed survey in the addressed, FREEPOST envelope, please check to see that you have NOT skipped any pages and that you have answered all the questions.

Thank you for completing this survey 😊

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