The rhetoric and reality of long-term condition self-management in New Zealand

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Abstract

Introduction
A long-term condition impacts an individual in a number of ways, and it is the individual who learns to incorporate and balance the imposition of a long-term condition with other aspects of their lives through the action of self-management. The idea of self-management has been incorporated into health service models with the aim of reducing utilisation of health services and improving quality of life for people living with long-term conditions. However, the literature suggests these goals are not necessarily being achieved. Additionally, there appears to be tension between the perspectives of the individual and the health professional regarding self-management. The focus of this thesis was to explore the individual, nurse and policy perspectives within New Zealand about self-management and how these may impact on an individual’s long-term condition self-management ability.

Method
The design of this study was a qualitatively driven, convergent mixed method research study, incorporating a sequential quantitative component. Data collection involved a critical discourse analysis of three key documents; nine interviews with individuals living with long-term conditions, interviews with fourteen nurses; and a New Zealand wide e-survey with 251 respondents.

Results
The critical discourse analysis revealed two underlying discourses, those of New Public Health and Kaupapa Maori. Findings from this study evidenced nurses held a very strong underlying belief of responsibility for the individuals they worked with. Findings from individual interviews suggested individuals held a supervisory role in self-management, and the e-survey evidenced a theme of regulation. The theme of loss was evident within the individual interviews and the e-survey. The e-survey revealed one-third of respondents reported very good...
to excellent health. High health distress and social and role activity limitations negatively impacted self-efficacy to manage symptoms, and continue with activities of daily life. High self-efficacy resulted in a belief that daily living with a long-term condition was possible. Approximately one-quarter of respondents reported ability to communicate effectively with their doctor, yet only two-thirds believed they were able to. Two-thirds of the respondents reported they were not confident about getting the help they required from others.

**Discussion**
The reality of self-management was shown to be an active and constantly changing, daily process rather than a static, linear or achievable goal. Individuals balanced the loss of their health and altered health status with the necessity for ongoing engagement with everyday life. This process often changed previous priorities and requirements. Additionally, the reality of self-management resulted in a disconnection from others. Expectations embedded within the discourse of policy (the rhetoric of self-management) created obligations for individuals that were not always helpful or achievable. Individuals were shown to make self-management decisions based on the context of their lives. However, this experiential knowledge was not privileged by either policy or healthcare professionals. The rhetoric of self-management affected professional’s practice through medicalisation of self-management and introduction of legislation regulating and monitoring practice. Thus, the healthcare professional became mediator and manager of resources and patient expectations as determined by policy rhetoric, while at the same time having their practice constrained.
Acknowledgements

I would like to acknowledge the people who have contributed to this research without whom, this project would not have been possible. The study participants and respondents who generously gave their time through interviews and filling out the e-survey – thank you for sharing your perspectives on long-term condition self-management.

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<td>Alleviating the Burden of Chronic Conditions in New Zealand</td>
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<td>CCM</td>
<td>Chronic care management</td>
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<td>CDA</td>
<td>Critical Discourse Analysis</td>
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<td>CHERRIES</td>
<td>Checklist for reporting results of internet e-surveys</td>
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<tr>
<td>CHF</td>
<td>Congestive heart failure</td>
</tr>
<tr>
<td>CNS</td>
<td>Clinical Nurse Specialist</td>
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<tr>
<td>CONSORT</td>
<td>Consolidated Standards of Reporting Trials</td>
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<td>COPD</td>
<td>Chronic obstructive pulmonary disease</td>
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<td>CVD</td>
<td>Cardiovascular disease</td>
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<td>DASRA</td>
<td>Daily Activities – Social/Role Activities Limitations</td>
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<td>DALY</td>
<td>Disability adjusted life year</td>
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<td>DHB</td>
<td>District Health Board</td>
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<td>EPP</td>
<td>Expert patient programme</td>
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<td>E-survey</td>
<td>Electronic survey</td>
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<td>GDP</td>
<td>Gross domestic product</td>
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<td>GP</td>
<td>General practitioner</td>
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<td>MCPHY</td>
<td>Medical Care – Communication with Physicians</td>
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<td>MMR</td>
<td>Mixed method research</td>
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<td>MOH</td>
<td>Ministry of Health</td>
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<td>NCD</td>
<td>Non-communicable disease</td>
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<td>NGO</td>
<td>Non-government organisation</td>
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<td>NHC</td>
<td>National Health Committee</td>
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<td>NPH</td>
<td>New Public Health</td>
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<td>NZPHD</td>
<td>New Zealand Public Health and Disability Act, 2000</td>
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<td>PHO</td>
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<td>QUORUM</td>
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<td>SRH</td>
<td>General Health – Self-rated Health</td>
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<td>SOI</td>
<td>Statement of Intent</td>
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<td>SPSS</td>
<td>Statistical Package for the Social Sciences now IBM SPSS</td>
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<td>UK</td>
<td>United Kingdom</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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Chapter 1:

Introduction and background

Having a chronic illness is like being on a "mystery getaway”
where you don’t know exactly where you’re going,
or when you will arrive, or whether the places you stay along the
way will be pleasant or awful
(E-survey, 387).

Introduction
Living with a long-term condition may impact an individual physically,
emotionally, spiritually, economically and socially and it is the individual who
learns to incorporate and balance the imposition of a long-term condition with
other aspects of their lives. This process is understood as self-management.
The idea of self-management has been incorporated into health service models
with the aim that self-managing individuals, along with other service delivery
initiatives, will reduce healthcare service utilisation and improve quality of life
for people living with long-term conditions. Yet the literature suggests these
two goals are not necessarily being achieved. Additionally, tension results from
the differing perspectives of the individual living with a long-term condition and
the health professional regarding their role in self-management. The idea of
differing perspectives regarding self-management has only recently begun to be
investigated and only by a small number of international researchers. Very little
appears to be known about how these different perspectives impact on an
individual’s ability to self-manage a long-term condition within the New
Zealand context. Accordingly, this thesis examines how the perspectives of New
Zealand policy, the individual and the nurse impact on an individual’s ability to
self-manage their long-term condition within New Zealand.
The remainder of this chapter provides the background to the history, prevalence and impact of long-term conditions and discussion around self-care, self-management and self-management support. The chapter concludes with an outline of the thesis.

**History, prevalence and impact of long-term conditions**
The terms “chronic” and “disease” are first reported to appear in the British database, *Index Medicus* (1927) as “Diseases, chronic,” with the term “chronic illness” not making an appearance in the database until 1947 (Armstrong, 1990). These terms did not emerge in the United States until 1949 in the National Commission on Chronic Illness (Galvin, 2002; Sidell, 1997), and then with the first publication of the *Journal of Chronic Diseases*¹ in 1955 (Armstrong, 1990). There are a number of reasons for the ascendency of the new term, chronic illness, and the first reason, a conventional medical explanation, contends that the decline of acute illnesses during the late 19th and early 20th centuries saw the increased incidence of chronic illnesses contributing to overall morbidity (Armstrong, 1990). The second, Armstrong argues, has more to do with the commencement of collection of statistical data during the period between the World Wars through national household type surveys (Armstrong, 1990; Galvin, 2002). The data collected on “long-standing illness, disability and infirmity” allowed for measurement of illness across a population, and as Galvin asserts, chronic illness became a “political entity” derived from surveillance and justifying surveillance over time because of the newly realised magnitude of the issue (Galvin, 2002).

The term “chronic disease” is associated with a medical view of the “pathophysiological alterations to a person’s condition” and use of the term “chronic illness” is more appropriate in that it “refers to the perceived human experience of living with and responding to disease by those with the disease” (Wellard, 2010, p. 2). Different terminology is used depending on sectors and

¹ Known as *Journal of Chronic Diseases* until 1988 when it was renamed *Journal of Clinical Epidemiology*. 
stakeholders involved: for example, the term “non-communicable disease” is often used internationally and particularly by the World Health Organisation (WHO), United Nations and the World Bank (Wellard, 2010). Chronic illness may also be referred to as long-term or chronic conditions and this thesis will utilise the term long-term conditions.

A long-term condition is an illness that progresses slowly (World Health Organisation, 2011b), limits activities of daily living, requires some form of ongoing medical attention (G. Anderson & Horvath, 2004), lasts longer than a year (World Health Organisation, 2011b) and is rarely cured (Dowrick, Dixon-Woods, Holman, & Weinman, 2005). A long-term condition may have an infectious cause (e.g. HIV/AIDS and cancer causing viruses like human papillomavirus, hepatitis B virus and Helicobacter pylori) (Haplan, Morales-Suarez-Varela, & Martin-Moreno, 2010) or be referred to as non-communicable because of its non-infectious cause (Dowrick, et al., 2005; Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004; Haplan, et al., 2010). Non-communicable long-term conditions are:

1. cardiovascular diseases (CVDs) - coronary heart disease, cerebrovascular disease, peripheral artery disease, rheumatic heart disease and congenital heart disease;

2. chronic respiratory diseases – chronic obstructive pulmonary disease (COPD) and asthma;

3. cancer - lung, stomach, colorectal, liver and breast; and

4. diabetes

Examples of other conditions considered to be chronic and/or non-communicable are arthritis, autoimmune diseases (ulcerative colitis, lupus, Crohn’s and coeliac disease), chronic fatigue, chronic hepatitis, chronic pain, chronic renal failure, epilepsy and mental health disorders (Dowrick, et al., 2005; World Health Organisation, 2008a).
Prevalence of long-term conditions
Long-term conditions have been referred to as the health care challenge of this century, and a silent and increasing epidemic (World Health Organisation, 2005). The increased prevalence is attributed to underlying socioeconomic, political and environmental factors of globalisation, rapid urbanisation and aging populations. Additionally, prevalence is linked with modifiable risk factors (smoking, poor nutrition, lack of physical activity and alcohol and drug use); non-modifiable risk factors (age and genetics); infectious agents, and new medical procedures and medications that save and lengthen an individual’s life (G. Anderson & Horvath, 2004; Holroyd & Creer, 1986; Strong, Mathers, Leeder, & Beaglehole, 2005; World Health Organisation, 2011e, 2011f). Yet, the assumption that long-term conditions are a silent and increasing epidemic, particularly in first world countries, should “be treated with a degree of caution” because although the population is ageing, “it is possible that new cohorts entering later life are bringing with them “healthier” past profiles” thus “compressing morbidity” and postponing “illness to the last years of life” (Bury, Newbould, & Taylor, 2005, p. 3).

Figures from a recent WHO report show more than thirty six million people died from long-term conditions in 2008 (World Health Organisation, 2011g). The major long-term conditions contributing to these death rates were CVDs, diabetes and chronic respiratory diseases with arthritis contributing to high disability levels for the individual.

Cardiovascular disease
CVDs were the number one cause of death equally for men and women in the world with an estimated 17.3 million deaths (30% of all deaths). 7.3 million deaths were from coronary heart disease and 6.2 million from stroke with more than 80% of the total CVD deaths occurring in low and middle income countries (World Health Organisation, 2011a). In New Zealand, CVD was the leading cause of death and hospitalisation (2000-2002) (Hay, 2004; Ministry of Health,
2006) with Maori male and female mortality rates 3 and 4.2 times higher than for non-Maori (Bramley et al., 2004).

**Diabetes**

It is estimated 346 million people currently live with diabetes, and in 2004 approximately 3.4 million people died from the side effects of high blood sugar (World Health Organisation, 2011d). Accurate prevalence rates for diabetes specific to New Zealand are unavailable (Berkeley & Lunt, 2006; Joshy & Simmons, 2006). The President of Diabetes New Zealand, Mike Smith, recently highlighted the need for a national prevalence study in order to gain an accurate representation of the number of individuals with diabetes within each area of New Zealand (Diabetes New Zealand, 2010). Estimated diabetes prevalence rates for 2011 were 237,156 people (Diabetes Care Workforce Service Review Team, 2011), and it is estimated that there has been a 35% increase in diabetes rates since 2001 with 80,000 undiagnosed diabetics and another 400,000 at risk of developing diabetes (Diabetes New Zealand, 2010). Ethnic disparities exist for Maori, with Type 2 diabetes being three times more common in Maori than non-Maori, and mortality rates from diabetes seven times higher than for non-Maori (Robson & Harris, 2007).

**Chronic respiratory diseases – COPD and asthma**

Chronic respiratory diseases are considered under diagnosed and account for an estimated 4 million deaths per year (World Health Organisation, 2009b). COPD is the fourth leading cause of death world-wide (World Health Organisation, 2011c). Statistics for COPD in New Zealand (in 1999) show COPD was the fourth leading cause of death after cancer, heart disease and stroke, and was estimated to affect 15% of the population over the age of forty-five years (R. Jackson & Broad, 2003; Martin, Glasgow, & Patterson, 2005). Hospital admission rates suggest COPD prevalence for Maori is more than twice non-Maori rates (R. Jackson & Broad, 2003; Loring, 2009).
The World Health Organisation estimate there are 235 million people with asthma, and note that asthma has a low fatality rate but does impact on an individual’s quality of life (World Health Organisation, 2012). Statistics for asthma in New Zealand reveal asthma is not a major contributor to death rates but is the highest ranked disease for Years Lost to Disability\(^2\) for males, and the third highest for females (Asthma and Respiratory Foundation of New Zealand, 2007).

**Arthritis**

Arthritis is argued to affect approximately 1% of the world’s total population and is more prevalent among females and in developed countries (Woolf & Pfleger, 2003). Statistics for arthritis in New Zealand suggest that in 2010 over 530,000 New Zealanders aged 15 or over were living with at least one type of arthritis (Access Economics, 2010) (there are over 140 types) (Arthritis New Zealand, n.d). Prevalence rates for Maori are lower than non-Maori but only because the Maori population are younger. However, amongst younger Maori, arthritis is more common (Access Economics, 2010).

**Impact of long-term conditions**

Living with a long-term condition impacts an individual personally. The personal cost to an individual and their family are often intangible (i.e. physical and emotional toll of the long-term condition), but also incorporate detrimental health outcomes and social inequality arising from living with a long-term condition (Ministry of Health, 2009a). Long-term conditions also impact the individual and their household economically (microeconomics) (Busse, Blumel, Scheller-Kreinsen, & Zenter, 2010; Jan, Essue, & Leeder, 2012). A long-term condition affects, among other things, an individual’s ability to save, their discretionary spending, educational attainment, ability to work (participation rates, hours worked, job turnover, early retirement) and productivity (wages/salary earned and position reached) (Busse, et al., 2010). High out-of-

\(^2\) Years Lost to Disability – time when an individual is too unwell to enjoy life as they ideally would (Asthma and Respiratory Foundation of New Zealand, 2007a; World Health Organisation, 2008).
pocket costs are the most direct way a long-term condition will affect an individual’s economic circumstances (Cunningham, 2009; Essue, Kelly, Roberts, Leeder, & Jan, 2011; Jan, et al., 2012; Paez, Zhao, & Hwang, 2009).

Long-term conditions also effect a country’s economic growth (gross domestic product (GDP) or macroeconomics (Busse, et al., 2010; Jan, et al., 2012). The macroeconomic effect of long-term conditions relates to the overall health of a country’s inhabitants (life expectancy, ageing population, population size) and government budgets (health spending on services and cost of providing these services) related to economic growth for that country (Busse, et al., 2010; Ryall, 2007). New Zealand’s estimated cost per capita for health spending in 2010 was $2683 or 9.9% of GDP ($2158 public spending, $154 private spending, $372 out-of-pocket spending) (Squires, 2011). In America, it is estimated out-of-pocket costs only increase for individuals with multiple comorbidities, leading to choices being made about how income is spent (Piette, Heisler, & Wagner, 2004). Current data specific to New Zealand on the impact of out-of-pocket costs to individuals with long-term conditions appears to be lacking. Although the Ministry of Health (2009a) suggest in their report into cost-of-illness studies on long-term conditions that “long-term conditions consume a vast amount of resources in New Zealand”, and that as an estimate out-of-pocket costs sat between one-third and two-thirds of the total cost (which were estimated to be around $100million per condition) (Ministry of Health, 2009a).

The impact of long-term conditions on the health of populations is an important determinant of public policy and therefore public spending. Because of this, the 1990s saw a period of intense social and economic reform in many countries with international financial institutions becoming more involved in individual countries economic policies (De Vos et al., 2009; Gauld, 2009b; Giddens, 1998). During this time the World Bank replaced the WHO as the major international institution for formulation of health policy and imposed neoliberal strategies of privatisation and liberalisation to these policies (De Vos, et al., 2009). In 1991,
the World Bank commissioned the Global Burden of Disease Study, which provided the first comprehensive economic assessment estimates for the burden of disease, injury and common risk factors in eight major regions of the world for the year of 1990 (Lopez, Mathers, Ezzati, Jamison, & Murray, 2006; Lopez & Murray, 1996). A new measure – disability adjusted life year (DALY) – was also introduced, enabling measurement of years of life lost from premature death, and years of life lived in less than full health (World Health Organisation, 2008b). It is argued these figures provide important information for assisting countries in health decision making and planning (World Health Organisation, 2008b). It is suggested policy makers need to be aware of the prevalence of different long-term conditions, the number of deaths caused and prevented in a year, and years of life lost or gained by the population, in order to better direct limited health spending to areas of most need in their countries (Lopez, et al., 2006). Furler, Harris and Rogers (2011) suggest the relatively recent “discovery of self-management” by policy makers and researchers is as a result of the “recognition of the burden of chronic illness” and the attached societal costs (p. 3). They contend defining and supporting patient self-management is now seen as an important task of health services. Thus, self-management has emerged as a ‘policy relevant’ construct, clearly within the remit of the health system and becoming one of the daily tasks of patients and health professionals in their encounters (Furler, et al., 2011, p. 3).

Self-care, self-management and self-management support
Management of a long-term condition is dependent on the concepts of self-care, self-management and self-management support. The terms self-care and self-management are used, sometimes interchangeably, in research and policy literature but continue to lack consensus around their meaning and use (Jones, MacGillivray, Kroll, Zohoor, & Connaghan, 2011; Rijken, Jones, Heijmans, & Dixon, 2008; Wilkinson & Whitehead, 2009). The more recent addition of the term “self-management support” within the literature, since around the beginning of 2000, also muddies the water somewhat. Additionally, Richard and
Shea (2011) suggest nursing and related literature often refer to self-care, self-management, self-monitoring, symptom management and self-efficacy for self-care synonymously, adding to the confusion. The key characteristics of self-care, self-management and self-management support have been delineated by Rijken et al. (2008), according to who is involved, goals or targets and what is involved, in order to clarify definitions for these terms. It is argued researchers need to use these terms “with greater precision” to enable easier comparison of the effectiveness of future self-management or self-management support programmes (Jones, et al., 2011, p. 183).

**Self-care**

There are numerous definitions of self-care within the literature describing self-care as daily lifestyle choices performed by all human beings through to undertaking activities to maintain health, and manage symptoms, treatments and side effects of a short-term illness or a long-term condition for oneself or one’s family (Chambers, 2006; Gantz, 1990; Hoy, Wagner, & Hall, 2007; Jones, et al., 2011; Northrup, 1993; Orem, 1991; Rijken, et al., 2008; Wilkinson & Whitehead, 2009). Some definitions include or exclude the involvement of healthcare professionals and have shown self-care involves choice about which activity to undertake but may include doing nothing (Chambers, 2006; Clark, 2003; Jones, et al., 2011; Rijken, et al., 2008). The WHO (1983) defined self-care as

> the activities individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals (p. 2).

Self-care is noted to be “the basic health behaviour in all societies past and present” (K. Dean, 1981, in Segall & Goldstein, 1989, p. 154) undertaken by people in order to maintain physical, mental and where desired, spiritual health (Wilkinson & Whitehead, 2009). The idea of caring for oneself and or family for
maintenance of health or for treating illness is evident throughout history and since at least 1671 in the United Kingdom (UK), as evidenced by various self-help books and pamphlets offering advice on medical and health matters to lay readers (e.g. Thomas Archer’s, *Every Man His Own Doctor*, (1671); *Domestic Medicine*, by William Buchan (1769); and James Parkinson’s, *The Way to Health*, (1802), read aloud to the labouring poor) (Hurwitz, 2006; Neuhauser, 2003). According to Jones et al. (2011, p. 178) self-care is about a “broad network” (the individual alone or with the involvement of family, community and or healthcare professionals), involving choices that are “unavoidable but with preventative options”, with an outcome of maintenance of health or prevention of illness. Ziguras (2004) further splits self-care into reactive self-care (the variety of individual responses to the symptoms of sickness) and proactive self-care (everyday activities aimed at maintaining or improving health), but notes there is no clear-cut distinction between the two. Yet, Richard and Shae (2011) suggest self-care refers to the individual’s ability and performance of activities for health maintenance and promotion. Self-care then appears to be about the individual, personal responsibility and control of care but may include the individual’s family, community or associated healthcare professionals.

**Self-management**

Again there are numerous definitions, creating confusion. Kendall, Ehrlich, Sunderland, Muenchberger and Ruston et al. (2011, p. 89) assert the term self-management has become a heuristic, shorthand for a complex set of beliefs and ideas about health, the role of people in maintaining their own health, and the responses that should be made by the health system. This shorthand is not uniformly understood or shared across the sectors, but also changes over time.

Literature reviewed appears to suggest self-management involves more collaborative partnerships with healthcare professionals whilst acknowledging that the bulk of the management of a long-term condition is undertaken by the individual at home or away from the direct guidance of a healthcare professional. 
Reference to self-management principles in the literature appear as early as 1925 with *The Diabetic Life*, written by Dr R. Lawrence (a diabetes consultant diagnosed with insulin dependent diabetes). This book was apparently the first medical textbook in the UK espousing the expertise of both doctor and patient and the professional-patient partnership required for self-management of diabetes (Hurwitz, 2006). Direct reference to the word “self-management” appeared around the 1960s in asthma literature, and implied active participation in treatment (Lorig & Holman, 2003).

The WHO suggest self-management is the process an individual engages with when looking after a long-term condition (World Health Organisation, 2002). Lorig and Holman (2003) contend an individual living with a long-term condition “cannot not manage” and that a decision “not to engage in a healthful behaviour or not to be active in managing a disease … reflects a management style” unless, of course, the individual is unaware of healthful behaviours (p. 1).

It has been argued that self-management is an “inevitable activity” that requires a more “focused network” in order to allow the individual to focus on “coping or controlling” the impact of a long-term condition (Jones, et al., 2011, pp. 177, 179, 181). Richard and Shae (2011) suggest self-management specifically relates to an individual’s “ability and performance of activities related to chronic and acute health conditions” (p. 260). Additionally, they suggest self-monitoring and symptom management, when performed by the individual, are facets of self-management.

Lorig and Holman (2003) propose there are six core self-management skills (problem solving, decision making, resource utilisation, formation of partnership with the healthcare provider, taking action and self-tailoring) necessary for an individual to master in order to undertake successful long-term condition management. Mastery of these skills is said to provide the individual with “confidence to deal with medical management, role management, and emotional
management of their condition” (K. Adams, Greiner, & Corrigan, 2004, p. 57). Attainment of the six core self-management skills is important for four broad reasons (Wilson & Mayor, 2006):

1. The majority of self-management of a long-term condition is undertaken independently by the individual with minimal contact with a healthcare provider over the course of a year;
2. “There is some evidence to suggest self-care may improve health outcomes for the individual” (p. 6);
3. Self-management can be seen as empowering for some individuals;
4. Effective self-management by an individual is purported to reduce demand on healthcare services.

It could be suggested that self-management is a facet of self-care undertaken by an individual. Self-management relates specifically to daily management of the functional, psychosocial, cultural and spiritual ramifications of living with a long-term condition by the individual.

**Self-management support**

Overall the literature seems to suggest that self-management support is how the healthcare practitioner collaborates with an individual and their family to facilitate an individual’s self-management endeavour, and enhance the individual’s well-being through improving their ability to make decisions and take action to care for their own health (K. Adams, et al., 2004; Bodenheimer, Lorig, Holman, & Grumbach, 2002; Bycroft & Tracey, 2006; Coleman & Newton, 2005; Glasgow, Davis, Funnell, & Beck, 2003; Jones, et al., 2011; McGowan, 2005; Osborne, Batterham, & Livingston, 2011; Rothman & Wagner, 2003). Sometimes this definition extends to include the wider healthcare system. Self-management support is usually packaged in a programme and can be delivered through one-on-one interventions in a primary care setting, or broadly through population-wide approaches like the internet, telephone and other social marketing approaches (Jordan & Osborne, 2007; Osborne, et al., 2011; Pearson, Mattke, Shaw, Ridgely, & Wiseman, 2007). These programmes generally have two overarching aims: firstly, reduction in
use of healthcare services (emergency and hospital with linked reduction of cost to the healthcare system), and secondly, improvement of health outcomes for people living with long-term conditions (Pearson, et al., 2007). The content of such programmes may vary, but usually aim to influence and change behaviour in a positive way and may also include patient education, coaching, goal setting, skill development, planning, the medical, role, and emotional and problem solving strategy development (K. Adams, et al., 2004; McGowan, 2005; Osborne, et al., 2011; Pearson, et al., 2007; Rijken, et al., 2008).

The concept of self-management support has gained traction over the last decade, but evidence supporting effectiveness of components of these programmes is “diverse and sparse” (Elzen, Slaets, Snijders, & Steverink, 2007; Jones, et al., 2011; Kennedy et al., 2007; Newbould, Taylor, & Bury, 2006; Pearson, et al., 2007, p. 9; Taylor & Bury, 2007). A recent systematic review of randomised controlled trials of lay-led self-management education programmes for people with chronic conditions suggests “modest, short-term improvements in patients’ confidence to manage their condition and perceptions of their own health” may occur; however, the programmes did not decrease time spent in hospital, visits to the doctor or improve quality of life (Foster, Taylor, Eldridge, Ramsay, & Griffiths, 2007, p. 2). Whatever the content, Wagner, Austin and Von Korff (1996) maintain the individual with a long-term condition and their needs must be central to any self-management support provided.

Self-management by individuals living with long-term conditions is not a new concept. What appears relatively new is the increased involvement of health professionals in facilitating, managing and directing the self-management endeavours of these individuals (Furler, et al., 2011), in order to improve their quality of life and reduce use of healthcare services (Pearson, et al., 2007). It is this possible tension arising from the differing perspectives of the individual living with a long-term condition and the health professional regarding their roles in “self-management” that has given rise to this research.
The structure of the thesis
The thesis is comprised of a further seven chapters as outlined below:

Chapter 2: Literature review
This chapter provides an overview of the literature around long-term condition management, and education available to nurses and patients, both internationally and within New Zealand, about self-management of a long-term condition. A summary of relevant literature surrounding clinician and individual perspectives on their role in long-term condition self-management is presented, and the rationale for undertaking this study is outlined.

Chapter 3: Methodology and methods
The third chapter sets out the underlying theoretical position for the study that of a dialectic stance set within a postmodern context, the research methodology and design, and rationale of this mixed methods research (MMR). The methods, for this qualitatively driven, convergent MMR study with sequential quantitative component, are presented. The study includes three sections;

- critical discourse analysis of three key New Zealand policy and postgraduate nurse education documents pertaining to self-management
- qualitative individual interviews, nurse interviews and focus group; and,
- an electronic survey comprising demographics, Likert scales and open-ended questions.

Chapter 4: Results - Critical discourse analysis
This chapter provides a critical discourse analysis of three key documents The National Health Committee: Meeting the needs of people with chronic conditions, The Flinders Chronic Condition Management Program™, and Whanau Ora: Report of the Taskforce on whanau-centred initiatives using Fairclough’s critical discourse analysis approach.
Chapter 5: Results – Individual interviews with participants living with long-term conditions

This chapter presents findings from thematic analysis of individual interviews with participants living with long-term conditions, exploring views, beliefs, interpretation and experience regarding self-management.

Chapter 6: Results - E-survey undertaken with participants living with long-term conditions

Results from descriptive statistics and correlations from Sections 1 and 2 of the e-survey and findings from thematic analysis of Section 3: Open-ended questions undertaken with New Zealand respondents with one or more long-term conditions are presented in this chapter.

Chapter 7: Results - Nurse focus group and interviews

This chapter presents findings from thematic analysis of nurse focus group and interviews exploring views, beliefs, interpretation and experience regarding long-term condition self-management.

Chapter 8: Discussion and conclusion

This chapter commences with a summary of key findings. Findings and results are then presented within the context of the rhetoric and reality of self-management. Suggestions follow, drawn from the literature, on how nurses might successfully facilitate the middle ground between the rhetoric and reality of self-management. The strengths and limitations of the research are outlined, followed by suggestions for future research and an overall conclusion is provided.
Chapter 2 :

Literature Review

Self-management is ... looking under the hood every day and doing what is needed to keep things running smoothly (E-survey, 434).

Introduction

Long-term conditions are argued to be the “healthcare challenge of this century” because of the rapid increase in knowledge of incidence, and cost to the individual, their family, the healthcare system and society in general. Literature suggests management of a long-term condition is dependent on the concept of self-management; the daily tasks carried out by the individual in order to live well, but undertaken away from the direct guidance of healthcare professionals (Jones, et al., 2011; McDonald, et al., 2008; Rijken, et al., 2008; Wilkinson & Whitehead, 2009). However, self-management is also argued to rely on the idea of self-management support. That is, support from the healthcare provider that facilitates an individual’s self-management endeavour, and enhances the individual’s well-being through improving their ability to make decisions and take action to care for their own health (Bodenheimer, et al., 2002; Glasgow, et al., 2003; Jones, et al., 2011; McGowan, 2005; Osborne, et al., 2011).

Because the concept of self-management is believed to be central to effective long-term condition management, it is important to gain an understanding of the perspectives of the individual, practitioners and policy with regard to the concept of self-management. In order to do this, an investigation of the current international and New Zealand perspective on long-term condition management must be undertaken. This review also outlines the current international and New Zealand situation on long-term condition management, and nurse and individual
education available about self-management of long-term conditions. Investigation of the literature to ascertain which educational programmes are available is important because it has been suggested that educational programmes reflect the underlying beliefs of the current or dominant paradigms and the “beliefs learned during professional education exert a “deep hold” on the student’s mind” (R. Anderson & Funnell, 2005, p. 153). Additionally, the chapter presents an overview and synthesis of relevant literature around clinician and individual perspectives on their role in long-term condition management. The chapter is comprised of three sections: international and New Zealand strategy on long-term condition management; current international and New Zealand nurse and patient education on this topic, and the clinician and patient perspectives about self-management of a long-term condition.

**International and New Zealand strategy on long-term condition management**

A search of the internet and databases was undertaken to gain an understanding of the international and New Zealand position on long-term condition management with regard to models and frameworks used and their effectiveness. A further search was undertaken of the internet to ascertain current international (America, Australia, Canada and UK) and New Zealand policy for long-term condition management, and where each of these countries is in regard to development and implementation of a long-term condition management framework.

**Long-term condition management – International strategy**

*Background*

A number of publications were located, dating from 2002-2008. These review documents were developed specifically to provide up-to-date background information on internationally used models and frameworks of care and the efficacy of these for government departments in the UK and Wales (National Public Health Service for Wales, 2005; Singh, 2005; Singh & Ham, 2006), as a
stocktake of factors that purchasers and developers of self-management support programmes need to consider (Pearson, et al., 2007) or as research filling an identified gap within existing published literature regarding effective interventions in long-term condition management programmes (Weingarten et al., 2002). One study is a meta-analysis (Weingarten, et al., 2002) and the other four are reviews but do not claim to be systematic as they intended only to provide an overview of available literature. All the reviews source experimental and quasi experimental research and or draw on opinion from experts from a range of governments and health organisations in America, Australia, Canada, France, Germany, Italy, New Zealand, Singapore, Turkey, UK and the WHO. One study also utilised survey as a means of data gathering (Singh & Ham, 2006). Pearson et al. sourced only published research conducted in America and interviewed experts from that country. The Welsh review updated Weingarten et al.’s (2002) search for the period 2002-2005 and used Singh’s (2005) review as an overview and framework for reporting results (National Public Health Service for Wales, 2005). Articles reviewed and synthesised in these publications cover the years 1987-2006.

The Chronic Care Model (McColl Institute (E. Wagner et al., 2001; E. Wagner, et al., 1996)) and the WHO Innovative Care for Chronic Conditions Model (World Health Organisation, 2002) were the two most frequently used frameworks internationally (Singh & Ham, 2006). These models are aimed at reorganising primary care, improving outcomes in long-term conditions and creating a more supportive and integrative environment for individual’s living with long-term conditions. Care is based on best practice and includes practice redesign, provider education and support, information, reminders, feedback and patient education which incorporates self-management (E. Wagner, et al., 1996). However, there was “limited high quality evidence about the impact of any model” (Singh & Ham, 2006, p. 31), whether the Chronic Care Model was more effective than others; and whether all components of the models or
frameworks were necessary or effective (Singh & Ham, 2006; Weingarten, et al., 2002).

Many interventions for management of a long-term condition exist, and the most commonly used interventions were patient education aimed at improving self-management followed by healthcare provider education (Singh, 2005; Weingarten, et al., 2002). Little is known about which of the many interventions used result in greatest improvement in care (Weingarten, et al., 2002), but one of the reviews suggested interventions (such as involving people in decision making, providing accessible structured information and self-management education) did improve care and enhance satisfaction of care, quality of life and to some extent, use of health services (Singh, 2005). However, these reviews argue further research is required to measure effectiveness of interventions for improving clinical outcomes and reducing healthcare utilisation (National Public Health Service for Wales, 2005; Singh, 2005).

Two of the reviews showed a more consistent approach to design, development, implementation and evaluation of long-term condition management programmes is required; the research evidence base for the design, development and evaluation was very limited; and further robust and extensive research was recommended (Pearson, et al., 2007; Weingarten, et al., 2002). Service delivery in most western countries appears to be based on the Kaiser Pyramid of Care Service, and delivery models appear to have some impact on quality of care and healthcare utilisation, but evidence was mostly available from only the US context (Singh & Ham, 2006).

**Current situation**
A search of the internet for “long-term condition (chronic disease or condition) strategies” for America, Australia, Canada and the United Kingdom revealed these countries are at various stages for development of and implementation of national long-term condition management strategy. The idea of long-term condition management in America seems to have a lengthier history than most
of the other countries investigated, and there are a number of different agencies (public and private) involved in long-term condition management (United States Department of Health and Human Services, 2010). The focus of government strategy seems to have shifted to address multiple or concurrent long-term conditions and coordination of the “considerable work already directed toward this need” rather than single conditions (United States Department of Health and Human Services, 2010, p. 5). Many of the long-term condition management programmes used internationally have their genesis in programmes developed in America (that is, the Chronic Care Model (McColl Institute) (E. Wagner, et al., 2001; E. Wagner, et al., 1996) and the Stanford Self-management Programs (Stanford School of Medicine, 2011a)) and incorporate some element of education aimed at improving an individual’s self-management of their long-term condition.

Australia implemented a national chronic disease strategy around 2005-2006. The framework provides nationally agreed policy and direction for improving chronic disease prevention and care across the country (with frameworks for asthma, cancer, diabetes, heart, stroke and vascular disease, osteo and rheumatoid arthritis, and osteoporosis) (National Health Priority Action Council (NHPAC), 2006). It is based on seven principles and four action and implementation areas, and includes self-management (apparently based on Flinders Program™ principles (Flinders Human Behaviour & Health Research Unit, 2011)). Canada appears to have a more fragmented long-term condition management strategy (probably because of the constitutional set up of the country) but has overarching federal government strategies in place for heart, lung, diabetes and mental health. Each of the ten provinces within Canada may have some form of long-term condition strategy (e.g., NewFoundland and Labrador’s, Improving health together: A policy framework for chronic disease prevention and management in Newfoundland and Labrador (Department of Health and Community Services, 2011). The provincial government strategies
appear to be based on the McColl Institute Chronic Care Model (E. Wagner, et al., 1996).

Within the UK, the overarching strategy for long-term condition management seems to have been devolved to each country’s government, with the UK Department of Health currently developing its own cross government strategy for long-term condition management for England only (due out at the end of 2012) (Department of Health, n.d.). Scotland’s Self-management Strategy, *Gaun Yersel*³, was developed by the Health and Social Care Alliance, Scotland, not the Scottish government and is driven by the people rather than policy makers (The Alliance and Scottish Government, 2008). Wales also has its own policy which is a population approach to long-term condition management (Llywodraeth Cynulliad Cymru - Welsh Assembly Government, 2007). Most of these strategies have been implemented since around 2000 and encompass strategies to improve self-management and better manage the health status of individuals with long-term conditions, but particularly target utilisation, resourcing and cost implications associated with management of these conditions.

The World Health Organisation also monitors and reports global epidemiology related to long-term conditions, and provides evidenced based guidance on effective, feasible interventions and their implementation (World Health Organisation, 2005). A recent report on the long-term condition management status for 193 countries summarised prevalence statistics on mortality and risk factor, trends from 2008, and the country’s capacity to address and respond to long-term conditions⁴. Of particular note, under “capacity to address and respond to NCDs” is the question “has a unit/branch/dept in MOH with responsibility for NCDs” (sic) (World Health Organisation, 2011g). New

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³ “The phrase ‘Gaun Yersel!’ is used to cheer a person on as they embark on a challenge. It is a vote of confidence and a message that the person has your support” (The Alliance and Scottish Government, 2008).

⁴ These figures were sourced from country responses to the World Health Organisation non-communicable disease (NCD) country capacity survey undertaken in 2009-2010 (World Health Organisation, 2011).
Zealand was the only country reported without a specific unit in the Ministry of Health with responsibility for long-term conditions when compared with America, Australia, Canada and the United Kingdom (World Health Organisation, 2011g).

**Long-term condition management – New Zealand strategy**

**Background**

Long-term condition management within New Zealand is viewed as a system used to enhance primary care through reminders, decision support and case management, and is linked with integrated care (Rea et al., 2007). Integrated care encompasses preventative and social care along with home based support and care, and suggests long-term condition management will be more effective when situated in an integrated healthcare system (Rea, et al., 2007). New Zealand has a number of overarching health strategies broadly related to long-term condition management, and these are:

- The New Zealand Health Strategy 2001 (Ministry of Health, 2001b)
- The Primary Healthcare Strategy 2001 (Ministry of Health, 2001c)
- The New Zealand Disability Strategy: Making a world of difference - Whakanui Oranga 2001 (Ministry of Health, 2001a)

The New Zealand Disability Strategy\(^5\) and the New Zealand Positive Ageing Strategy\(^6\) both link with aspects of long-term condition management but are not directly relevant to the focus of this thesis.

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\(^5\) The New Zealand Disability Strategy aims to guide government action in promotion of a more inclusive society and to influence attitudes and behaviour of New Zealand society about and toward people with physical, sensory, neurological, psychiatric, intellectual or other impairments.

\(^6\) The New Zealand Positive Ageing Strategy promotes the value and participation of older people in communities as they are considered to provide New Zealand with a valuable resource and one of the goals regarding health encompasses equitable, timely, affordable and accessible health services.
The New Zealand Health Strategy provides the platform for government action on health, outlining principles and providing a framework by which the New Zealand health system (District Health Boards (DHB) and other organisations) must address and reduce the impact of health disparities from diseases such as cardiovascular, diabetes, mental illness and other long-term conditions. The Primary Healthcare Strategy provides further focus for provision of long-term condition care through strengthened primary health organisations. One of the declared aims of the Primary Healthcare Strategy is access by all New Zealanders to low cost primary health care, and the strategy emphasises approaches to long-term condition management based on the McColl Chronic Care Model (ABCC NZ Study, 2011; Hefford, Crampton, & Foley, 2005; Ministry of Health, 2001c). These two strategies and associated funding have given rise to programmes such as Chronic Care Management in Counties Manukau, and Care Plus, a national programme aiming to improve chronic care management and providing extra funding and time for primary health nurses and general practitioners (GPs) to support more in-depth interactions with people living with long-term condition/s (Ministry of Health, 2004, 2011b; Rea, et al., 2007). He Korowai Oranga is particularly aimed at “whanau ora: Maori families supported to achieve their maximum health and wellbeing”, but also addresses reducing health inequalities affecting Maori (Ministry of Health, 2002, p. 1).

Singh and Ham (2006) in their review noted New Zealand had trialled a number of service delivery models and in 2005 the government approach was based on a “Life Course” model7 and an “Outcomes Intervention” model8 which balanced aetiology, interventions and outputs.

A further strategy, being worked on prior to the change of government in 2008, was a specific long-term condition management strategy which built on the

7 The Life Course Model is based on the Centre for Disease Control’s diabetes systems modelling project.
8 The documents the review references are unpublished draft reports or unpublished discussion documents and were not able to be located or obtained by this researcher.
National Health Committee document, *Meeting the needs of people with chronic conditions* (National Health Committee, 2007). However, the strategy was never publically released as the Long-term Condition Unit within the Ministry of Health was disbanded during the reorganisation of the Ministry of Health, post-election of the Key led National government of 2008, and the strategy was replaced with Ryall’s “Better, Sooner, More Convenient” initiatives (J. O’Hallahan, personal communication, September 30, 2009; N. Valentino, personal communication, May 17, 2011).

The introduction of *Better, Sooner, More Convenient Primary Health Care* (Ministry of Health, 2012a) and *Better, Sooner More Convenient Health Care in the Community* (Ministry of Health, 2011a) has led to a change in focus for health service providers in New Zealand whilst still working within the frameworks provided by the New Zealand Health and Primary Healthcare strategies. These initiatives aim to reduce acute pressure on hospitals through improved management of long-term conditions in the community, and specifically by encouraging health professionals to work collaboratively and cooperatively across primary, secondary and tertiary services to provide a more personalised and closer to home primary healthcare service (Ministry of Health, 2011a, 2012a). The overall aim of the Better, Sooner, More Convenient initiatives is to remove barriers and create a seamless health service for the patient, and reduce waiting time for treatment through provision of more services in the community, at times and places that suit the individual seeking help (Ministry of Health, 2011a).

**Current situation**

New Zealand currently appears to have a decentralised approach to long-term condition management. The Alleviating the Burden of Chronic Conditions in New Zealand (ABCC NZ Study) notes “many DHBs are already developing chronic conditions strategies and some are developing chronic conditions management programmes”, but fails to provide references or elaborate on which DHBs are doing so (ABCC NZ Study, 2011, p. 17). A search of DHB websites
revealed each DHB appears to develop their own policy based on population requirements, funding constraints, and the previously mentioned overarching national strategies and Ministry of Health targets, and instigates their own long-term condition management programmes (which incorporate self-management). Of the 20 DHBs in New Zealand, two have available on their website a framework for long-term condition management and these date from 2008-2009 (Capital and Coast DHB and South Canterbury DHB). The remaining DHBs appear to prioritise long-term condition or chronic disease management in their Statement of Intent (SOI) or focus on strategies in the SOI for individual diseases (e.g., cardiovascular, diabetes and cancer), initiatives aimed at reducing incidence (e.g., Smoke free) or through primary and community services (ABCC NZ Study, 2011). The two frameworks found were based on the McColl Institute Chronic Care Model (E. Wagner, et al., 1996), though one added whanau ora to their model (Capital and Coast DHB).

The concept of health targets have been applied to long-term conditions, particularly diabetes and cardiovascular disease, for example heart and diabetes checks. These check-ups aim to have 90% of the eligible population undertake a cardiovascular risk assessment within the last five years, satisfactory or better diabetes management, and an increased number of people with diabetes attending free annual checks (Ministry of Health, 2012b, 2012c). District Health Boards through Primary Health Organisations (GPs and practice nurses) and non-government organisations such as the National Heart Foundation are working together to meet these targets set by the Ministry of Health, to lower people’s level of risk to these long-term conditions and assist New Zealanders to “live longer, healthier, more independent lives” (Ministry of Health, 2011c; 2012c, p. 18).
However, a recent review argued effective management of chronic conditions needs to extend beyond better services or treatment (ABCC NZ Study, 2011). This New Zealand study⁹ investigated priority areas of chronic care. The study:

1. reviewed New Zealand and international literature for effective interventions to improve outcomes and reduce inequalities, particularly for Maori and Pacific peoples. This review informed the stocktake questionnaire;
2. identified local initiatives, and critical components of these, that achieve successful outcomes for people with long-term conditions through a questionnaire and interviews with experts in long-term condition management, and;
3. produced a workbook to guide DHBs in providing key interventions for improving health care for people with long-term conditions (specifically respiratory and cardiovascular diseases, stroke, diabetes and other long-term conditions) based on information from the literature review, interviews and the stocktake questionnaire (ABCC NZ Study, 2009; District Health Board Research Fund, 2007-2012).

The stocktake questionnaire, comprised of generic questionnaires capturing overall practice (chronic care management, a primary care questionnaire and a health inequality questionnaire), and specific disease questionnaires (on COPD, CVD, CHF and Stroke), was piloted with two DHBs and then sent to the remaining DHBs, primary health organisations and Maori/Iwi providers. The study authors note report completion of the questionnaires was patchy (59-88%), four DHBs declined to participate, and fifteen returned partially or fully completed questionnaires (ABCC NZ Study, 2009). The chronic care portion of the generic questionnaire focused on nine chronic care management (CCM) dimensions arising from the literature review, pilot study and workshops. The dimensions encompass leadership, community linkages, inequalities in health

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⁹ Alleviating the Burden of Chronic Conditions in New Zealand (The ABCC NZ Study) funded by District Health Board Research Fund (DHBRF) (via Health Research Council of NZ) now completed
care, organisation of health care delivery system, collaboration, systems for knowledge transfer, self-management support, decision support and programme delivery system design.

Of particular interest are the findings relating to self-management support as the report notes self-management support “may be the most important component of any CCM approach” because “responsibility for management techniques for chronic illnesses typically falls to the patient and/or whanau” (ABCC NZ Study, 2009, p. 27). Results for the self-management support dimension suggested participating DHBs were only performing

1. “‘averagely’ in most of the variables of self-management support;”
2. had a perception that “self-management is not strongly encouraged or developed within DHBs”, and;
3. strategies placing the individual and/or whanau at the centre of the system are “underdeveloped relatively to measures that place the health provider at the centre of the system” (ABCC NZ Study, 2009, pp. 27, 32).

Yet a very recent paper prepared for Treasury (New Zealand) suggests a number of specific foci “that need to be pursued over a concerted period of time to manage upward pressure on resources”; one of which is “encouraging self-care and the ‘expert patient’” (Mays, 2013, pp. 3-4).

The purpose of The ABCC NZ Study Workbook is facilitation of implementation of New Zealand research into practice. It suggests ten action areas for long-term condition management along with practical ideas. The ten action areas include conceptual understanding, effective leadership, implementation of clinical guidelines, collaboration, sustainable community links, self-management support for patients and as relevant their

10 Dimensions of self-management support - assessment and documentation of self-management needs and activities, self-management support, addressing concerns of patients and families, effective behaviour change interventions and peer support and patient engagement with the chronic care management programme.
families/whanau/support people, reducing health inequalities, delivery system
design, decision support and knowledge transfer (Connolly et al., 2010). The
key points regarding self-management and collaborative care encompass the
pivotal role of general practice and disease specific secondary care, a
“reorientation of services to patient centeredness and empowerment” and an
interdisciplinary team approach (Connolly, et al., 2010, p. 30). Action
recommendations include expansion of primary care teams, recognising the role
of community peer leaders, ensuring staff are skilled in core self-management
skills (problem solving, goal setting, reflective listening, motivational
interviewing, opportunistic intervention and supporting readiness for change)
and investment in change management (Connolly, et al., 2010). Arguably some
time may elapse before evidence of the required translation of research into
practice, as outlined in the ABCC NZ Study workbook, becomes apparent,
consistent across and embedded within DHB frameworks and programmes
centred on long-term condition management, and change becomes evident for
the individual living with the long-term condition.

This section of the review has revealed that the health system in New Zealand is
not currently supportive of WHO recommended guidelines regarding a
dedicated unit overseeing national strategy for long-term condition management.
This is in contrast with other countries such as America, Australia, Canada and
the UK. As a consequence, New Zealand appears to have a decentralised or
fragmented approach to long-term condition management as evidenced by the
dearth of DHB strategies regarding long-term condition management and a
perception that self-management is not strongly encouraged or developed within
DHBs. However, as DHB strategy is directed by government policy, it could be
argued that this lack of direction regarding long-term condition management is
as a direct result of recent political decisions around direction of the New
Zealand health system. In fact, it would appear that a business model has been
applied, leading to targets, and a goal of long-term condition management
devolved to primary health, under the guise of removing barriers and creating
seamless health services for individuals, available at times and places that suit the individual seeking help (Ministry of Health, 2011a). This devolved and fragmented approach to long-term condition management in New Zealand, impacts on an individual’s ability to self-manage a long-term condition through difficulty accessing appropriate, timely and affordable long-term condition management support, the geographic variability of service delivery; and additionally, the individual and their family are not the central focus of the health system (ABCC NZ Study, 2009). The next section reviews the literature available on education for nurses and patients about self-management of a long-term condition.

**International and New Zealand nurse and patient education regarding self-management of a long-term condition**

To gain an overall picture of education available for nurses working with individuals living with long-term conditions, and long-term condition management education provided for individuals, a search of the internet and databases was undertaken. Exploration of nursing education was restricted to postgraduate education about long-term condition management, in order to limit the size of the overall study and this review. Two variations of self-management programmes seem to exist: those that provide training for the healthcare provider to assist them in facilitating individuals’ self-management endeavours, and those that focus on increasing an individual’s ability to cope and improve self-efficacy (can be lay (peer) or professionally led); some programmes bridge both.

**International**

*Nurse education*

Internationally, postgraduate nurse education for long-term condition management appears to be embedded in university programmes. It is impossible to tell from university websites what the programme entails with regard to self-management and which long-term condition management model/s the courses
cover (e.g., Flinders Program™ in New Zealand). However, in America, Pearson et al. (2007) note that training is also available through independent or government funded sources (e.g., facilitator training for the Chronic Disease Self-Management Program). In fact, Pearson et al.’s report seems to suggest nurse education regarding long-term condition management is fragmented, content varied considerably, and the expertise of the nurse varied. They suggest these issues need addressing if self-management programmes are to be more successful in assisting individuals to manage and live with a long-term condition. In the UK, the Community Interest Company\textsuperscript{11} provides training for healthcare professionals, service design and operation assistance to support and enhance self-management by individuals with a long-term condition(s). (Expert Patients Programme Community Interest Company, 2011; Newbould, et al., 2006; Rogers et al., 2008).

**Patient education**

A number of programmes exist as vehicles for delivery of patient education for long-term condition management; some are generic programmes and others are disease specific. Most appear to be based on the Stanford self-management programmes (e.g., the Chronic Pain Self-Management Program (Canada) and the UK’s Expert Patient Programme). A fairly new addition is the Flinders Program™ from Australia.

**Stanford Self-management Programs**

Over the last thirty years, the Stanford Patient Education Research Centre in America has developed, tested and evaluated eleven different self-management programmes. These programmes aim to reduce healthcare costs and improve the physical and emotional health of participants through assisting people with long-term conditions to gain self-confidence in self-managing their symptoms and health problems (Stanford School of Medicine, 2011a, 2011c). Courses are offered in English and Spanish, as workshops or online, and are facilitated by

\textsuperscript{11} The company set up by the UK Government to deliver the EPP
trained peer leaders who are not health professionals and have a long-term condition themselves.

The Arthritis Self-management Program was the first patient education programme developed at Stanford University and all other Stanford self-management programmes are modelled on it. The underlying premise of the Stanford courses is that people with long-term conditions have similar self-management difficulties and illness related tasks, can learn the day to day management of their condition/s, and as a result of undertaking the course, will have decreased use of health resources and improved health status (Lorig, Hurwicz, Sobel, Hobbs, & Ritter, 2005; Lorig et al., 1999). The courses are predicated on Bandura’s Self-efficacy Theory and aim to increase participants’ coping ability when self-managing their long-term condition(s) (Bandura, 1977). The Self-efficacy Theory suggests that an individual will evaluate their capacity for success at any given task based on “their perceptions of the knowledge, skills and strategies they have at their command” (Bandura, 1986). These skills, knowledge and strategies are generated from sources of personal accomplishment, vicarious experience, verbal persuasion and the emotional state of the individual (Bandura, 1977). Additionally, the more dependable the source, the more likely an individual will use the source, succeed at the task and experience increased self-efficacy (Bandura, 1977).

A wide range of topics are covered such as pain and fatigue management, exercise, medication use, communication, diet, sleep and problem solving. The Chronic Disease, Diabetes, HIV/AIDS, Pain, and Arthritis self-management programmes have and continue to be widely licensed and utilised by health researchers around the world (S. Chan, Siu, Poon, & Chan, 2005; W. Chan et al., 2011; Dongbo et al., 2003; Elzen, et al., 2007; Gitlin et al., 2008; Griffiths et al., 2005; M. Rose et al., 2008; Siu, Chan, Poon, Chui, & Chan, 2007; Stanford School of Medicine, 2011c; Swerissen et al., 2006; Tomioka, Braun, Compton, & Tanoue, 2012).
**Expert Patient Programme**

The UK Expert Patient Programme (EPP) was introduced in 2001 by the Department of Health and is a central policy for long-term condition management that has slowly been integrated into the UK national health system. The EPP is an amalgamation of the Stanford Chronic Disease Self-management programme and self-management programmes developed within the UK (Department of Health, 2001; Newbould, et al., 2006; Taylor & Bury, 2007). The EPP is predicated on the belief that individuals affected with long-term conditions have developed self-management expertise in relation to their illness, and this expertise is an “untapped resource” (Department of Health, 2001, p. 33; Tattersall, 2002; Wilson, Kendall, & Brooks, 2007). EPP is about self-management support and increasing an individual’s confidence and motivation to self-manage a long-term condition, thereby enhancing the individual’s quality of life (Rogers, et al., 2008; Taylor & Bury, 2007). The EPP is now delivered through a national provider (set up by the UK Government), the Community Interest Company, and provides a diversified variety of free lay-led online or community self-management courses to assist individuals to improve daily management of their long-term condition(s) (Expert Patients Programme Community Interest Company, 2011; Newbould, et al., 2006; Rogers, et al., 2008).

**The Flinders Program of Chronic Condition Self-Management**

The *Flinders Program™* arose from the South Australia HealthPlus trials of 1997-1999, and a mid-trial finding that showed health benefits from coordinated care depended more on the “patient’s self-management capacity, not just the severity of his or her disease; that is, self-management capacity may provide a method of determining who requires coordinated care” (Battersby et al., 2007, p. 58). The *Flinders Program™* was designed in the Flinders Human Behaviour and Health Research Unit, Flinders University, Adelaide, Australia (Flinders Human Behaviour & Health Research Unit, 2011). The program is based on cognitive behaviour therapy, motivational interviewing and problem solving and uses tools to facilitate collaborative assessment of self-management skills,
behaviours, barriers, psychosocial issues and client preferences. The assessment phase is followed by the individual identifying their problems and collaborative goal setting leading to the creation of an individualised care plan. The Flinders Program™, as a pilot study, has been run in an aboriginal community (Battersby et al., 2008) and for people living with mental illness (Lawn et al., 2007); a randomised controlled trial study has been run in South Australia (but has not been reported as yet) (Battersby et al., 2010).

**New Zealand**

*Nurse education*

There appears to be limited information and research about nurse education around long-term condition management. The Flinders Program™ has been used in New Zealand since around 2005 for training healthcare providers (mostly nurses) (Horsburgh et al., 2010; Roy, Mahony, Horsburgh, & Bycroft, 2011). For nurses, the Flinders Certificate is embedded into three New Zealand university postgraduate primary healthcare and long-term condition management nursing programmes (Horsburgh, et al., 2010). Nursing Council New Zealand require all providers of undergraduate and postgraduate nursing education to meet standards as outlined in *Education programme standards for registered nurse scope of practice* and must be approved by the Nursing Council (Nursing Council of New Zealand, 2008b). Undergraduate curriculum is based on national health priorities, contemporary health care and practice trends, contemporary nursing practice, and includes chronic disease state management (Nursing Council of New Zealand, 2010). DHB’s are responsible for identifying and prioritising postgraduate nurse training requirements and funding for their areas, and are bulk funded by Health Workforce New Zealand (Health Workforce New Zealand, 2012). Over the last four to five years, the New Zealand government has funded places for nurses to undertake postgraduate long-term condition management education; however, anecdotal information suggests uptake by nurses for these places did not reach the maximum places in any given year.
The ABCC NZ Study Generic Stocktake report (ABCC NZ Study, 2009) suggests DHBs are underperforming and “only basic level support for provider education for chronic illness care” is available (p. 29). However, the report also suggests that “continuing education for doctors, nurses and other primary providers appears to be somewhat better implemented in primary care than CCM variables around service provision” (ABCC NZ Study, 2009, p. 50). Ashworth and Thomson (2011) found nurses had difficulty accessing professional development and education but that opportunities were increasing and relevance of the education, had improved. Overall, it would appear there is a need for increased research in this area and a more coordinated approach to nurse education in this area is required.

**Patient education**

Again, there appears to be limited research and information about patient education for long-term condition management in the New Zealand context. Horsburgh et al (2010) assert anecdotal evidence suggests “there has been limited uptake of self-management programmes in New Zealand” (p. 290). The Generic Stocktake Report undertaken by the ABCC NZ Study suggests disease specific programmes for people with CHF, CVD COPD and stroke are very limited and for DHBs who responded, there is a belief that there is an “absence of patient education and of outreach and only limited provision of culturally specific programmes” (ABCC NZ Study, 2009, p. 54). Health Navigator New Zealand, a website started by health professionals and consumers, lists some long-term condition management courses available, both generic and disease specific (Health Navigator NZ, 2012).

Most courses appear to be based on Stanford’s models and are provided through DHBs and primary health organisations or non-government organisations such as the Heart Foundation, Arthritis Society and Diabetes New Zealand. Unfortunately, as the ABCC NZ Study (2009) highlight, education and support for a long-term condition appears to be “postcode dependent”. However, the Roy et al. (2011) study findings suggest nurses trained in the use of the *Flinders*
Program™ principles were able to better support and assist individuals improve their self-management of a long-term condition (Horsburgh, et al., 2010; Roy, et al., 2011). Participants found they benefitted from the relationship dynamic between themselves and nurses changing to one of partnership, which allowed for enhancement of their personal self-management capacity, increased motivation and confidence in goal setting, and ability to achieve set goals (Roy, et al., 2011).

This section of the review has shown that internationally there appear to be a number of well-developed self-management programmes for individuals living with long-term conditions. However, there is disagreement in the literature as to whether or not these programmes actually meet their intended goals of improved clinical outcomes and reduced healthcare utilisation. Information regarding nurse education in long-term condition management in other countries appears scarce. One article from America seemed to suggest nurse education regarding long-term condition management was fragmented and needed addressing if nurses were expected to provide effective long-term condition self-management education to their patients.

There appears to be scant information and research about both patient and nurse education for long-term condition management in the New Zealand context. The Flinders Program™ was only introduced seven years ago, but there appears to have been limited uptake by individuals for this programme and other disease specific programmes are limited. Funding for New Zealand nurses to undertake postgraduate education in long-term condition management has been available via DHBs. But, anecdotal evidence suggests uptake has been low for these courses. Ashworth and Thompson (2011) found that although educational opportunities were increasing, nurses had difficulty accessing professional development and education. It might be postulated that these issues are directly related to the fragmented and devolved approach to long-term condition management in New Zealand. The limited research that has investigated
effectiveness of the *Flinders Program™* training suggests both nurses and individuals found the course beneficial.

**Long-term condition management: Clinician and patient perspectives**

Long-term condition management is management of a condition that cannot be cured; therefore the condition requires controlling over time by the individual via self-management, often through medication and lifestyle choices. Self-management is argued to be undertaken in partnership and supported by healthcare providers and the health system (E. Wagner, et al., 2001). However, the multifaceted nature of this relationship creates “tension between patient autonomy, professional responsibility for the delivery of evidence-based practice”, and the funding constraints, goals or set up of the health system (Blakeman, Bower, Reeves, & Chew-Graham, 2010, p. 137). This section of the review draws on research to present self-management of a long-term condition from the clinician and patient perspectives.

**Self-management of a long-term condition - Clinician role and perspective**

There appears to be limited literature offering the perspective of the clinician (general practitioners and nurses) on long-term condition management. Recent published literature was from America (Hunt & Arar, 2001; Hunt, Arar, & Larme, 1998), Australia (Oldroyd et al., 2003), Canada (Johnston, Liddy, & Ives, 2011), New Zealand (Ashworth & Thompson, 2011; Horsburgh, et al., 2010; Roy, et al., 2011), and the UK (Blakeman, et al., 2010; Blakeman, Macdonald, Bower, Gately, & Chew-Graham, 2006; Macdonald, Rogers, Blakeman, & Bower, 2008; McDonald, et al., 2008; Pill, Rees, Stott, & Rollnick, 1999; Pooley, Gerrard, Hollis, Morton, & Astbury, 2001; Rogers, Kennedy, Nelson, & Robinson, 2005; Wilson, Kendall, & Brooks, 2006). Two of the New Zealand articles investigated long-term condition management
perspectives of nurses specifically around use of the Flinders Program™ (Horsburgh et al.; Roy et al.). Four UK studies reported findings drawn from nurse data (Macdonald et al.; McDonald et al.; Pill et al.; Wilson et al.). Eight of the fifteen studies were undertaken in the UK.

These studies used a combination of semi structured interview, open ended survey questions and focus group to collect data. Most studies interviewed a mix of doctor, nurse, physician assistant, management, and healthcare consultant, other health professionals (podiatrists, physiotherapists, assistant health practitioners) and people living with long-term conditions. Four studies specifically recruited only nurses (Horsburgh, et al.; Macdonald, et al.; McDonald, et al.; Pill, et al.), and two studies recruited only general practitioners (Blakeman, et al., 2006; Oldroyd, et al., 2003). A summary of these articles by the author, year, aim, setting, country, participant numbers and method of data analysis is provided in Appendix 1. As limited information appeared to be available and most studies used the generalised term “healthcare provider” or “general practitioner”, the following sections synthesise the studies’ findings for doctors and where possible highlight nurse perspective and beliefs.

**Doctors’ role**

It has been suggested long-term condition management from a clinical perspective, particularly medical, focuses on purely the clinical aspects of care and in particular “metabolic processes, clinical indicators, and prescribed behaviors” (Hunt & Arar, 2001, p. 361; Hunt, et al., 1998). Johnston et al. (2011) found that among Canadian general practitioners there may be a lack of understanding around what long-term condition management actually entails, and health system integration failure which leads to the isolation of doctors and professional territory protection. Key issues identified by Ashworth and Thompson’s (2011) New Zealand study revealed that management issues (who delivers long-term condition management, limited funding streams, time constraints and general practice structures) and disconnected information and technology systems across primary and secondary care resulted in poor
communication. Additionally, a lack of clinical leadership and professional development were sources of frustration for healthcare providers in relation to delivery of long-term condition management (Ashworth & Thompson, 2011). In the UK, time constraints, communication and coordination across sectors and continuity of care were issues highlighted by Pooley et al. (2001).

Specifically, long-term condition management was “viewed as one of the most difficult aspects of practice” (Blakeman, et al., 2010, p. 146). Evidence suggests that some general practitioners compared long-term condition care with acute care and considered long-term condition care more complicated, time consuming, chaotic, burdensome, emotionally draining, costly and threatening, in that it exposed their inadequacies (Blakeman, et al., 2006; Oldroyd, et al., 2003; Pooley, et al., 2001). Two studies indicated doctors found goals for long-term condition care were hard to define and therefore were less satisfying than acute care goals (Blakeman, et al., 2006; Oldroyd, et al., 2003). These studies also indicated long-term condition care created conflict, as Oldroyd et al. (2003, p. 31) suggest, between “long-term clinical goals and the patient’s shorter-term quality of life goals, between a systematic evidence-based approach and a patient-centred approach, and between patient satisfaction as an outcome versus achieving high quality care” (Blakeman, et al., 2006; Pooley, et al., 2001). Multiple co-morbidities added to the challenge of long-term condition management (Johnston, et al., 2011). It was suggested that doctors felt threatened because their sense of identity and self-worth was challenged during interactions with aggressive or disengaged patients (Blakeman, et al., 2010). However, long-term condition care was also viewed as rewarding, as doctors were able to build relationship with their patients over time (Oldroyd, et al., 2003).

Beliefs
Only four studies referred to some aspect of doctor’s beliefs about long-term condition management. One study found that doctors viewed themselves as advocates for patients in their care (Oldroyd, et al., 2003), however how they
advocated for their patients was not explained in the study. Two studies reported doctors believed they coordinated, facilitated, educated and partnered with the patient in their self-management (Blakeman, et al., 2006; Oldroyd, et al., 2003). One study suggested self-management was “interpreted narrowly as referring to compliance with medical instructions”, and that these consultants judged which patients were capable of self-management (Rogers, et al., 2005, p. 231). The fourth study highlighted doctors’ reluctance to specifically discuss self-management topics with patients as they did not wish to upset the patient, create an extra burden or increase anxiety through constantly bringing the long-term condition and its implications to the centre of conversations (Blakeman, et al., 2010). However, the responsibility the professional felt “for addressing behaviours or [clinical] parameters” (Blakeman, et al., 2010, p. 144) conflicted with their desire to maintain a happy, relaxed patient. If self-management did not lead to change, these professionals felt “discouraged, mad or annoyed” (Blakeman, et al., 2010, p. 145). This feeling of responsibility meant doctors maintained the need to be in control, follow up and guide patients because they believed patients might lose enthusiasm, use medication inappropriately, not recognise warning signs or base decisions on incorrect information derived from other sources, or not seek help because of over confidence in self-management skills (Blakeman, et al., 2010; Rogers, et al., 2005), leading to marginalisation of individuals’ “experiential self-management strategies” (Rogers, et al., 2005, p. 232).

**Nurse perspective and beliefs**

Studies exploring nurse perspectives regarding long-term condition self-management evidenced a number of key issues that nurses believed impacted on their ability to provide the self-management support required by individuals living with long-term conditions. Issues common to a number of studies were time pressures, resource restraints, continuity of care, complexity of care when multiple co-morbidities were present, and communication (Ashworth & Thompson, 2011; Johnston, et al., 2011; Pooley, et al., 2001). A lack of coordination and planning of services between primary and secondary care in
New Zealand was highlighted as impacting on the self-management support nurses were able to deliver (Ashworth & Thompson, 2011). Nurses, participating in a UK study about long-term condition self-management, felt the “expert patient” was a personal challenge because of their fear of litigation (Wilson, et al., 2006). An earlier study found nurses faced a dilemma when working with individuals with non-insulin dependent diabetes (Pill, et al., 1999). The authors contend that the nurse must decide their “level of responsibility in the face of informed patient choice not to conform with conventional biomedical wisdom” (Pill, et al., 1999, p. 1496). Two further studies showed nurses were not able to trust that the patient would be able to self-manage their long-term condition (McDonald, et al., 2008; Wilson, et al., 2006) and one study suggested that nurses categorised patients, based on their initial impression, according to how well they thought the individual would self-manage their long-term condition (Macdonald, et al., 2008). In Pill et al.’s (1999) study nurses perceived themselves as monitors, educators and motivators of individuals’ self-management of diabetes.

An article by McDonald et al. (2008) revealed some interesting facets of underlying nurse beliefs not drawn out in other studies. The article reveals the introduction of policy (the Expert Patient Programme) espousing empowerment and greater control by individuals over their care, is not congruent with how nurses perceive their role in long-term condition management. The authors suggest nurses believed patients lacked knowledge and understanding and were dependent on nurses for self-managing their long-term condition. As a result of this “‘mothering’ approach … nurses were reluctant to relinquish their nurturing (or controlling, depending on one’s interpretation) role with regard to their ‘children’” (McDonald, et al., 2008, p. 298). In fact, McDonald et al. (2008, p. 299) argued nurses attempted to control patient behaviour because nurses in this study were “dependent on patients to comply with treatment and lifestyle regimes” in order “to achieve target outcomes” as set out in UK government policy. This study suggested that although nurses supported views of patient
empowerment and the idea of patient self-management, the reality was quite the opposite. The authors highlighted only one nurse from their study who “expressed the view that patients were the best judge of their condition” because “they know far more about diabetes than I’ll ever know” (McDonald, et al., 2008, p. 302).

**Self-management of a long-term condition – Individual’s role and perspective**

Current understanding, from the individual’s perspective, about the experience of living with a long-term condition has been influenced by the work of a number of sociological researchers (e.g. Parsons, Glaser, Strauss, Corbin, Charmaz, Kelly, Field and Bury). These researchers have explored issues such as how a long-term condition interrupts an individual’s life through concepts of biographical disruption (Bury, 1982), loss of and adaptation of identity (Charmaz, 1983, 1987, 1995) and narrative reconstruction (G. Williams, 1984). More recently researchers appear to have focused on the post diagnosis transformational process undertaken by the individual and how they reconstruct (Cooper, Collier, James, & Hawkey, 2010), reconcile (Whitehead, 2006), or transforms (Aujoelat, Marcolongo, Bonadiman, & Deccache, 2008) their identify. Because of this illustrious history, there appears to be considerable research investigating the experience of living with a long-term condition or the transformation an individual undertakes; yet research investigating the individual’s understanding of their role in long-term condition management and their perspective on self-management appears limited.

Despite the research suggesting those living with long-term conditions have similar self-management issues, living with a long-term condition is argued to be an individual experience (Pooley, et al., 2001). It has been described as an emotional experience encompassing frustration, fear, anxiety, anger and a sense of loss (Wilson, et al., 2006, 2007). Self-management of a long-term condition requires dealing with the emotional impact along with the symptoms, disability,
medication, lifestyle adjustments while also obtaining helpful medical care (E. Wagner, et al., 2001). Many people with a long-term condition already believe they self-manage (Furler, et al., 2011), know what needs to be done, are quite motivated to undertake self-management (Hunt & Arar, 2001; Wilson, et al., 2007), and work hard on mutual communication with their doctor (Wilson, et al., 2007).

Self-management for individuals living with diabetes has been revealed as an ability to generate “goals, strategies, and evaluations not within the circumscribed world of clinical meanings and measures, but in constant interaction with the unbounded world of everyday life action” (Hunt & Arar, 2001, p. 361). These authors contend a long-term condition cannot be separated from the wider context of an individual’s life and “many factors compete for the time and attention that treatment regimens require” (Hunt & Arar, 2001, p. 361). Experience and observation play an important part in self-management and Hunt and Arar suggest individuals “seek practical ways to apply specific behaviors and to identify the links between actual behaviors and observed outcomes” (p. 361). Self-management then is more than ability to follow a prescribed treatment plan. It is about using personal knowledge and an awareness of how the body responds in order to maintain balance in life (Rogers, et al., 2005).

The idea of having to balance aspects of one’s life is contained within the Shifting Perspectives Model of Chronic Illness (Paterson, 2001; Thorne & Paterson, 1998). This model was derived from a metasynthesis of published qualitative research from 1980-1996 investigating living with a long-term condition (Thorne & Paterson, 1998). This model suggests that living with a long-term condition is “an on-going, continually shifting process in which people experience a complex dialectic between themselves and their “world”” (Paterson, 2001, p. 23). In this model, Paterson (2001) explains the experience of living with a long-term condition as “changing perspectives about the disease that enable people to make sense of their experience” (p. 23). These perspectives
represent the context of the individual’s life such as their values, beliefs, expectations and feelings about their long-term condition experience (Paterson, 2003) and influence the individual’s personal response to the long-term condition, their family and others, and their response to external situations affected by the condition (Paterson, 2001). Because individuals living with a long-term condition live in a world of wellness and illness, they necessarily move between what Paterson has termed “illness in the foreground and wellness in the foreground” in order to learn about the long-term condition, protect themselves, and/or live well despite a changed life (Paterson, 2001). Further insights on this model were generated after Paterson (2003) member checked the model with an individual living with multiple sclerosis. Although this individual thought the model reflected the fluctuating nature of her illness, she suggested that rarely were “illness or wellness totally in the foreground in one’s life at any time” (Paterson, 2003, p. 990). Other authors suggest the theme of “balance” captures the experience of maintaining equilibrium between identity management and symptom control, with symptom control shown to be secondary to maintenance of control over social roles, a sense of normality, value and meaning in life (Bury, 1991; Townsend, Wyke, & Hunt, 2006; S. Williams, 2000). It is argued the major focus of self-management becomes coping with the effect of the condition on personal worth (Blakeman, et al., 2010).

Studies, from the individual’s perspective, propose the following as important aspects of the interface between the healthcare provider and the individual in self-managing a long-term condition:

- communication - time to discuss matters of importance, interpersonal and communication skills of the healthcare provider;
- outside support - referral to appropriate community and consumer organisations, access to other healthcare providers and second opinions;
the whole person - attention to psychological and social effects of long-term condition as well as clinical aspects; recognition of the individual’s expertise and individuality of the experience;

- information - education and explanations at an appropriate level;

- a good “doctor” - continuity of care and regular visits with a familiar doctor (Cheek & Oster, 2002; Infante et al., 2004; Pooley, et al., 2001).

However, Blakeman et al. (2010) found some people, when communicating with their doctor, were reluctant to discuss self-management topics because the process contributed to their perception of disruption of life by the long-term condition, increased anxiety, and decreased their feelings of competence in their ability to live and deal with a long-term condition.

What has become clear from this section of the review is that for the individual living with a long-term condition, self-management is about maintaining balance in life. The literature suggests that the individual maintains control of social roles and a sense of normality to re-establish value and meaning in life often to the detriment of symptom control. However, much of the research focuses on the perspective of an individual living with a single long-term condition (Townsend, et al., 2006) avoiding the issues of living with multiple long-term conditions. From the clinician’s perspective, self-management of a long-term condition appears to be about symptom control as measured by clinical indicators and maintenance of professional responsibility, despite the idea of self-management support being presented as enhancing the individual’s well-being through improving their ability to make decisions and take action to care for their own health. Given these perspectives are widely divergent; it would appear that the clinician and individual are talking past each other, to the detriment of more effective self-management by the individual.

As Blakeman et al. (2010) contend, the relationship between the individual and the healthcare professional is multifaceted and as such conflict may arise when
the ideals of patient autonomy and professional responsibility meet in the healthcare setting. Add to this funding constraint, goals or set up of the health system and the multiplicity of views within the field of self-management, inevitably there is likely to be underlying tension and discord. What appears to be missing from the literature, and particularly New Zealand literature, is how the perspectives of the individual, healthcare provider and health system interact and impact on an individual’s ability to self-manage a long-term condition. Accordingly, this thesis examines how policy, patient, and practitioner perspectives of self-management in New Zealand impact on an individual’s ability to self-manage their long-term condition.
Chapter 3:
Methodology and Methods

Self-management is ... Making the most of each day. Sometimes it might be a 'blob' out day, when the body says to take it easy today (E-survey, 296).

Introduction
In order to adequately explore the research question, three parts to the study were developed, necessitating a strategy of mixed method research (MMR). The chapter commences by setting out the underlying theoretical position for the research, that of a dialectic stance set within a postmodern context and outlining the overarching strategy, the methodology of MMR. MMR typology for this study, rationale, and validity in MMR are elucidated, followed by explanation about the methods employed for each of the three studies.

A dialectic stance
A dialectic stance explicitly seeks synergistic benefit from integrating differing paradigms, in order to produce stronger research (Greene, 2007). The resultant research embodies a fuller understanding of the phenomena of interest through representing a “plurality of interests, voices, and perspectives” (Rocco, Bliss, Gallagher, & Perez-Prado, 2003, p. 21). A dialectic stance to mixed methods research has a commitment to using mixed methods to attain the same efficacy and accurateness of other approaches but with a particular emphasis of purpose on complementarity (Rocco, et al., 2003). Complementarity is achieved through the researcher seeking a “broader, deeper and more comprehensive social understanding by using different methods to tap into different facets or dimensions of the same complex phenomenon” (Greene, 2007, p. 101). Each
paradigm behind those methods is valued because they have importantly
different underlying assumptions. But the paradigms themselves are understood
as “historical and social constructions” and are argued to therefore not be
“inviolate or sacrosanct” (Greene, 2007, p. 67). Greene and Caracelli (1997)
suggest researchers need to move forward from “debating paradigmatic
differences that may well be irreconcilable” (p. 19), and instead focus on
utilising research methods to generate relevant, useful and practical results. As
this MMR was driven by the research question, the question demanded
understanding through dialogue with multiple realities; therefore, the research is
best framed within a dialectic stance in order to facilitate that dialogue with
those multiple realities (Greene, 2007; Rocco, et al., 2003).

The underlying theoretical perspective for this MMR is that of postmodernism,
because the research takes a variety of approaches aimed at revealing underlying
beliefs about self-management. Postmodernism is, Crotty (1998, p. 183)
contends, “the most slippery of terms” in that it covers developments in many
domains of human enterprise (i.e., philosophy, social science, architecture, arts,
literature). Postmodernism is defined and understood by people in a myriad of
ways resulting in vagueness and ambiguity and because of this, is a highly
contested term (Agger, 1991; Cheek, 2000; Crotty, 1998). Postmodernism can
be characterised as a “movement of ‘unmaking’” (Crotty, 1998, p. 192),
fragmentation, instability and incoherence, “ways of thinking about the world
that shape the type of research that is done and the types of analyses that are
utilized” and recognising of multiple voices and views (including those not
suggests postmodernism is a “theory of society, culture, and history” and its
main proponents were Foucault, Barthes, Lyotard and Baudrillard (p. 112). It is
argued a postmodern perspective “allows for analysis of why certain players and
practices … have been relegated to the margins, often designated as “other”
rather than “another”” (Cheek, 2000, p. 35). A postmodern approach needs to be
viewed as a tool rather than “rigid sets of rules” for understanding the world and for bringing to light concealed value positions (Cheek, 2000, p. 2).

**Mixed methods research**
The idea of using different ways of gathering data to explore a topic of interest is not a new phenomenon. Earliest use of MMR was evidenced within research from the 1880’s where studies incorporated “demographic analysis, participant surveys and observations, and social mapping techniques” (Hesse-Biber, 2010b, p. 2). However, reported use of MMR did not apparently occur until relatively recent times when Fry, in 1934, discussed “mixing methods of study” (B. Johnson & Gray, 2010) and Campbell and Fiske utilised multiple quantitative sources within a study in the 1950’s (Creswell & Plano Clark, 2011; Hesse-Biber, 2010a). In fact Fry commented “research work usually requires more than proficiency in one particular technique. Time and again the really creative part of a social inquiry is deciding how different approaches should be combined to yield the most fruitful results” (Fry, 1934, cited in B. Johnson & Gray, 2010, p. 87).

Renewed interest in MMR came together around the 1980’s when writers, from numerous disciplines (sociology, evaluation, management, nursing and education) and countries (America, UK and Canada) began to publish articles and books on this new approach to research, its rationale, methods, methodology, philosophy and the “how to” for mixing, integrating and combining diverse types of data (Bryman, 2006; Creswell & Plano Clark, 2011). Bryman (2006) suggests mixed methods has now, for some writers, become “a distinctive research approach in its own right” (p. 97) resulting in three approaches to research. These approaches are quantitative, qualitative and what has been variously called multi-methods, multi-strategy, mixed methods, mixed methodology (Bryman, 2006), integrative or mixed (R. Johnson, Onwuegbuzie, & Turner, 2007) and multi-dimensional (Manson, 2006). Today the most commonly used name is “mixed methods research” and a number of authors
assert use of this name will “encourage researchers to see this approach as a distinct model of inquiry” (Creswell & Plano Clark, 2011, p. 22).

Definitions for MMR include a variety of components from the research process (design, methods, and philosophy) (Creswell & Plano Clark, 2011). Some definitions refer to MMR purely as a method, that is “a research tool rather than a methodology” (Giddings & Grant, 2006, p. 4); whereby studies merely incorporate “at least one quantitative method (designed to collect numbers) and one qualitative method (designed to collect words)” (Greene, Caracelli, & Graham, 1989, p. 256). More recent definitions have a methodological focus and incorporate “mixing in all phases of the research process” (Creswell & Plano Clark, 2011, p. 2) from theoretical (philosophical) positions through to the results (R. Johnson, et al., 2007; Tashakkori & Teddlie, 1998). Other definitions of MMR focus on methods and philosophy (Creswell & Plano Clark, 2011; Greene, et al., 1989) and purpose or type of research (R. Johnson, et al., 2007).

A number of core characteristics exist for MMR allowing for diverse viewpoints. These core characteristics may be used in a single study or across multiple phases within a programme of research (Creswell & Plano Clark, 2011). One of the core characteristics of contemporary MMR is centrality of the research question which focuses researcher choice, regarding design and methods for the study, on which tools will best answer the research question/s (Creswell & Plano Clark, 2011; Giddings & Grant, 2006; Teddlie & Tashakkori, 2010). A second characteristic, that of paradigmatic pluralism, understands that a “variety of paradigms may serve as the underlying philosophy” for the use of MMR (i.e., critical theory, pragmatism, the dialectic stance, critical realism) (Teddlie & Tashakkori, 2010, p. 9). Other characteristics allow the researcher to decide which form of data has priority (qualitative/quantitative/equal), how collection and analysis of both forms of data is to be undertaken and at which stage of the research “mixing” might take place (Creswell & Plano Clark, 2011).
MMR provides a multiple worldview position that assists in:

- answering multifaceted questions (Creswell & Plano Clark, 2011; R. Johnson & Onwuegbuzie, 2004; Manson, 2006),
- gaining a better understanding of a phenomena (Giddings & Grant, 2006; Greene, 2007; Manson, 2006),
- making room for interdisciplinary collaborations that investigate complex problems (Sosulski & Lawrence, 2008),
- delivering to the researcher a toolbox of varied methods to investigate and understand the world (Creswell & Plano Clark, 2011; Hesse-Biber, 2010b); and
- offsetting weaknesses inherent within qualitative and quantitative methods (Creswell & Plano Clark, 2011; Giddings & Grant, 2006).

Controversies remaining for MMR appear to centre on the evolution of the definition and discourse of mixed methods, terminology, design possibilities, philosophical issues and the value of MMR (Creswell & Plano Clark, 2011; R. Johnson, et al., 2007). Nurse theorists and researchers contributing to the MMR debate on issues of method, methodology and philosophy, particularly from a “qualitative” perspective are Giddings (2006), Giddings and Grant (2006, 2007, 2009), Lipscomb (2008), Morse (2010) and Sandelowski (2000).

**Qualitatively driven, convergent MMR study with sequential quantitative component**

MMR in this thesis has been defined as an approach allowing for multiple ways of seeing, hearing and making sense of the social world (Greene, 2007), that combines different paradigmatic viewpoints, data collection methods, analysis and inference techniques for the purpose of breadth, depth and greater understanding about the topic of interest (R. Johnson, et al., 2007). Additionally, this MMR seeks

understanding that is woven from strands of particularity and

generality, contextual complexity and patterned regularity, inside
and outside perspectives, the whole and its constituent parts … [it] seeks not so much convergence as insight … the generation of important understandings and discernments through the juxtaposition of different lenses, perspectives and stances (Greene, 2005, pp. 208, emphases in original).

Rationale for choosing MMR were related to a desire to develop a “bigger picture” understanding of the topic of interest (complementarity) (Greene, 2007) and a belief that the choice of research method tools should be driven by the research question (Hesse-Biber, 2010b). The research question was designed to enable exploration of a number of different perspectives regarding long-term condition self-management and thus required a study design with three parts:

1. Critical discourse analysis (CDA) of policy/education material relevant to long-term condition self-management in New Zealand. Inclusion of this approach was deemed necessary in order to understand how health policy, along with nursing education at the postgraduate level, portrays and shapes the concept of self-management in the New Zealand context.

2. Interviews with individuals living with long-term conditions and focus group and interviews with nurses working with individuals who live with long-term conditions. The aim of the interviews was to elicit these individual’s perspectives, beliefs and understanding about the concept of long-term condition self-management. Additionally, findings from initial interviews with individuals living with long-term conditions informed development of the open-ended questions within the e-survey.

3. A New Zealand wide electronic survey (e-survey) for individuals living with long-term conditions. The purpose of the e-survey was to gain a snapshot of health status, self-management behaviour and self-efficacy of New Zealanders living with long-term conditions. Additionally, the e-survey aimed to test validity of qualitative findings through extending these findings to a wider population living with long-term conditions (Hesse-Biber, 2010c), and to obtain triangulation or convergence in order increase confidence in conclusions generated at the
end of this project (Greene, 2007; Greene, et al., 1989; Hesse-Biber, 2010c).

As the study does not fit neatly into any of the common typologies for MMR, this researcher considered four key elements of interaction, priority and timing between qualitative and quantitative strands, and where and how to mix these (stage of integration) in order create the design of the study (Creswell & Plano Clark, 2011). For this MMR, greater priority will be placed on the interviews. The e-survey will be utilised in a secondary role leading to sequentiality and interaction between the interviews and e-survey (Creswell & Plano Clark, 2011) (the questions within the open-ended section of the e-survey will be informed by themes generated from interviews with individuals living with long-term conditions). A convergent design will also be employed as the interview and critical discourse analysis phases will be initiated separately allowing this researcher to obtain complementary but different data on the topic of interest. Stage of integration for this project will occur during data collection (interview findings will shape research questions for the open-ended section of the e-survey) and within the final stages of the project (mixing during interpretation) (Creswell & Plano Clark, 2011). Thus the design of this MMR study is a qualitatively driven, convergent MMR study with a sequential quantitative component informed by themes generated from one of the qualitative components (Figure 1).
Figure 1: Qualitatively driven, convergent MMR study with sequential quantitative component
(Refer to Creswell, Plano Clark (2011) for MMR typology)

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<th>QUAL data collection</th>
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<td><strong>Procedures:</strong></td>
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<tr>
<td>Select:</td>
<td>Search NZ government websites for health policy related to self-management</td>
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<td>A. up to 10 individuals living with long-term condition/s</td>
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<td>B. 6-10 primary healthcare and specialist nurses working with individuals living with long-term condition/s</td>
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<td>Semi-structured interviews and nurse focus group</td>
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<td><strong>Products:</strong> Transcripts</td>
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<tr>
<td>Recruit up to 200 individuals living with long-term conditions via e-survey</td>
<td>Search NZ government websites for health policy related to self-management</td>
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<tr>
<td>Demographics, Stanford scales for health status, self-management behaviour and self-efficacy and eight open-ended questions derived from themes from individual interviews</td>
<td>Locate postgraduate nurse education documents related to self-management training</td>
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<tr>
<td><strong>Products:</strong> Numerical item scores and transcripts</td>
<td><strong>Products:</strong> Texts</td>
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<td>A. Individual’s interviews</td>
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<td>B. Focus group</td>
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<td>C. Nurse interviews</td>
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<td>Plus thematic analysis of transcripts from e-survey</td>
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<td><strong>Products:</strong></td>
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<tr>
<td>A. Individual interviews - two major themes</td>
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<td>B. Nurse focus group and interviews - one major theme</td>
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<td>C. E-survey - two major themes</td>
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<tr>
<td><strong>Procedures:</strong> Critical discourse analysis of three key documents</td>
<td></td>
<td><strong>Products:</strong> Narrative – critical discourse analysis</td>
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<th>Interpretation</th>
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<tr>
<td><strong>Procedures:</strong> Synthesis of themes, narrative and means, SD’s, correlations</td>
<td><strong>Product:</strong> Narrative - discussion</td>
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Validity in MMR

The issue of validity within MMR appears to be somewhat bewildering, given the plethora of terminology available to describe how to ensure quality within a project, and the dearth of discussion specific to addressing validity within a MMR study. The term “validity” has been chosen to describe the overall process of ensuring potential threats within this MMR are addressed. Morse et al., (2002) contend that verification strategies for ensuring validity in a project must be built into the process from the outset so that “reliability and validity are actively attained, rather than proclaimed by external reviewers at the end of the project” (Morse, et al., 2002, p. 17). Verification strategies (Morse, et al., 2002) or techniques for demonstrating validity (Whittemore, Chase, & Mandle, 2001) are used to shape and direct the research.

A number of authors have been referred to in order to explain the techniques used to address potential threats to validity within this MMR. From a MMR perspective, I have drawn on Dellinger and Leech’s (2007) framework of construct validation for MMR, and Creswell and Plano Clark’s (2011) recommendations. Dellinger and Leech (2007) recommend the researcher must focus on revealing their bias, experience, personal and theoretical knowledge, and prior understanding of the phenomena and how these impact on a study, along with addressing potential issues arising from MMR data collection, analysis and interpretation stages (Creswell & Plano Clark, 2011). Additionally, Creswell and Plano Clark (2011) recommend the researcher attend to the applicable validity checks for both the qualitative and quantitative components embedded within the project.

In order to address applicable validity checks for the qualitative components, I have drawn on Morse, Barrett, Mayan Olsen and Spiers’s (2002) verification

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12 The term “validity” has been chosen based on recommendation by Creswell and Plano Clark (2011). They suggest that the term validity is the best term “because of its acceptance by both quantitative and qualitative researchers today and that such use presents a common language understandable to many researchers” (Creswell & Plano Clark, 2011, p. 239).
strategies and Whittemore, Chase and Mandle's (2001) techniques for demonstrating validity. For the e-survey I have referred to Eysenbach’s (2004) checklist for reporting results of internet e-surveys (CHERRIES). The following discussion outlines this researcher’s personal and theoretical knowledge and the possible impact on the study. This is followed by discussion around how potential validity issues related to the specific components (critical discourse analysis, thematic analysis and e-survey methodology and methods) have been addressed in order to “actively attain reliability and validity” throughout the study.

In order to outline my role in this research, I would like to make reference to Grant and Giddings’ diagram of the postmodern researcher/researched relationship (Figure 2), to diagrammatically portray how I am embedded in the “discourses” of this research project (Grant & Giddings, 2002), and to show how my prior experiences and knowledge may impact this research project (Dellinger & Leech, 2007). As the primary researcher, I identify personally with both groups represented within the project; the nurses and individuals living with long-term conditions. I registered as a nurse in 1995 and until taking up full time PhD study, I have worked in within a hospital that has a focus on adults (mostly older) and rehabilitation.

In my early years of practice, I came face to face with the apparent disconnect between what I did to encourage and assist an individual to self-manage, what an individual actually chose to undertake, and the feeling of frustration I experienced when I did not achieve “the best” for that person. In 2004, I began my postgraduate nursing education journey and completed a Master’s thesis in 2009. During the process of completing this thesis, I immersed myself in the literature about self-care and self-management and developed a theoretical understanding of these concepts.
In 2007, I was diagnosed with Coeliac Disease. I recall being utterly dumbfounded, confused and ignorant, but also relieved by the diagnosis as it provided an explanation for the symptoms that I had been experiencing for some years. Thus began my journey of learning to self-manage and negotiate from a personal perspective with the labels of “patient” and “chronic disease/illness/long-term condition”. I initially went through anger and frustration at the changes required (Coeliac Disease is only currently only “managed” through removing gluten – all wheat, barley, rye and oats from the diet), at being exhausted by the mental shift required to negotiate the social nature of food and at having to regain some semblance of normalcy and enjoyment in my life around what I and my family ate. However, in order to regain balance and control of my life, I channelled my developing research skills to gain as much knowledge as I could about history, genetics and pathophysiology of Coeliac Disease and into learning the food science involved with cooking and baking gluten free. Yes, there were failures that even the birds did not eat! As a result, I have gained a personal insight into the daily challenge of self-managing a long-term condition. In 2008, our two girls Georgia (now 13) and Sian (now 9) were also diagnosed with Coeliac Disease. So began their journey into self-management, my new role as facilitator, educator, gate keeper,
It has been reflection on my journey and that of our girls’ journey to more independence with self-management of Coeliac Disease, along with the theoretical understanding gained through postgraduate study that has contributed to this project. I openly acknowledge that these experiences have influenced my perceptions and understanding, and have potentially impacted on development of the research question, chosen methodology and data analysis for this current study. However, Beach, Becker and Kennedy (2006) contend every researcher must address the potential impact of prior experience and knowledge on the study, allowing the reader to judge for themselves how these may have impacted on the interpretation of findings and conclusion. A researcher should consider the new research findings and their prior knowledge like puzzle pieces that need to be fitted together (Beach, et al., 2006). Beach et al., (2006) assert “the problem that researchers face, therefore, is not one of how to put aside prior knowledge but rather one of how to capitalize on prior knowledge and use it to extract as much new knowledge as possible from the findings” (p. 502)

One of the major aims of this project was to gather a number of different perspectives on self-management of a long-term condition and to explore how these perspectives impact on an individual’s ability to self-manage their long-term condition. Development of this study was undertaken with direction from my supervisors (LW and MC) in order to establish coherence between the research question, the methods chosen to collect data, and the methodology (Morse, et al., 2002) and to allow for integration of findings (Bryman, 2007). In order to ensure an appropriate sample (Morse, et al., 2002; Whittemore, et al.,
2001), I used a number of sampling strategies and my knowledge of the population, to seek individuals and nurses who would be able to share their perspective on long-term condition self-management. During the interview, transcription and data analysis processes, many of the participant experiences resonated with me. Because of this, I endeavoured to set aside temporarily (or bracket) my previous knowledge and experiences (Tufford & Newman, 2012) so that I could reflect more fully on what the participants were communicating. However, my experiences have given me insight into the topic and hopefully have enabled me to be more responsive to the data.

Credibility, auditability and fittingness (D. Jackson, Daly, & Chang, 2003) were established through involvement of my supervisors throughout the qualitative data analysis process. When my supervisors and I discussed the potential themes, their naming words and descriptions, and how I had derived the themes, I returned to the raw data rather than my memory and experiences to support or refute the point under discussion. Sometimes, as a result of the discussion, I needed to revisit the data, or a name or description of a theme in order to more clearly represent the emerging interpretation of the participants’ experiences. Credibility of findings from the individual interviews was sought through triangulation of themes with the wider audience recruited for the e-survey. Data saturation certainly became evident when I undertook analysis of the open-ended questions from this survey which is suggestive of sampling adequacy (Morse, et al., 2002). One of my supervisors (MC) who is skilled in critical discourse analysis was involved in guiding me through the critical discourse analysis process. As a result, I have been able to provide a clear explanation around how the texts were chosen and analysed and acknowledge the interpretive and subjective nature of the final analysis.

For the e-survey, Eysenbach’s (2004) checklist for reporting results of internet e-surveys (CHERRIES) was followed to enable the reader to judge bias and validity of the e-survey through reporting of view, participation and completion.
rates (see Chapter 6 for fuller explanation). Cookies were employed to prevent
duplicate entries from the same computer address. However, this did not stop
individuals from completing the survey on a number of different computers. To
counteract this, once the e-survey was deactivated, I screened the downloaded
file by hand for duplicate entries. The e-survey also utilised previously validated
scales from the Stanford Patient Education Research Centre (Lorig et al., 1996;
Stanford School of Medicine, 2007). These tools have been psychometrically
tested in both paper and online formats, thus minimising any potential threat to
validity with the transference of these scales to an online format (Whitehead,
2007). The scales have a Cronbach alpha above 0.7, suggesting that these scales
are homogenous and measure the concepts they were intended to measure
(Elliot, 2003). The scales have also been previously used by other researchers. I
also sought input from a biostatistician and one of my supervisors (LW) to
enhance rigor of data and results obtained from the e-survey.
Method
In order to adequately explore the research question, it was important that this research be undertaken with the appropriate groups of participants and documents. Therefore, individuals living with, and nurses working with individuals living with long-term conditions, were sought; along with government policy and postgraduate nurse education relating to long-term condition self-management. These groups of individuals and documents were required to enable greater understanding on how these different perspectives may impact on an individual’s ability to self-manage a long-term condition in New Zealand. To facilitate the gathering of these different perspectives a qualitatively driven, convergent MMR study with a sequential quantitative component was developed to assist in exploring the research question.

The first part of this study comprised a critical discourse analysis of three key policy and education documents relevant to the New Zealand context. The second phase involved exploration of how expertise in self-management was viewed, interpreted, defined and experienced by nurses working with and individuals living with, long-term conditions. This section also explored beliefs held by individuals that enhance or impede development of the individual’s ability to self-manage their long-term condition. The third part of this study involved an e-survey to determine health status, self-management behaviour and self-efficacy of individuals living with long-term conditions and to triangulate the findings from individual interviews with a wider audience. Qualitative data was gathered via semi-structured interviews, focus group and open-ended questions. Quantitative data was gathered through reporting of demographics and use of pre-existing tools available online from the Stanford Patient Education Research Centre: Chronic Disease Self-management Program (Stanford) measuring health status, self-management behaviour and self-efficacy (Lorig, et al., 1996; Stanford School of Medicine, 2007).
**Research question**

For this study the following research questions and sub-questions were developed:

How do policy, patient and practitioner perspectives of self-management in New Zealand impact on an individual’s ability to self-manage a long-term condition?

- What are the underlying beliefs held by people living with long-term condition/s that enhance or impede the development of an individual’s ability to self-manage?
- What are the health status, self-management behaviour and self-efficacy of New Zealand individuals living with long-term conditions?
- What are the underlying beliefs held by nurses working with people living with long-term condition/s that enhance or impede the development of an individual’s ability to self-care/manage?
- What are the underlying discourses embedded within New Zealand health policy and New Zealand postgraduate nurse education documents regarding self-management and how may these impact/influence an individual’s, their family/whanau and nurses’ understanding of long-term condition self-management?

**Ethical approval**

An initial application to the Health and Disability Multi-region Ethics Committee was made in September 2009. A revised application was returned to the Committee in November 2009 and approval was granted in Feb 2010 (MEC/09/10/117) with the provision that the researcher apply for approval from the committee for the updated version of the e-survey once interviews were completed. Small amendments were granted ethical approval by the Chairperson of the committee under delegated authority in July 2010. In April 2011 final approval for the e-survey was requested from the Chairperson and granted in May 2011. Appendices 2-9 contain ethical approval letters, and consent forms and information sheets provided to participants.
Maori consultation process
In September 2009, the researcher met with Elizabeth Cunningham, Research Manager – Maori to discuss this study and identify potential concerns for Maori. The relevance of the research was discussed in regard to improving Maori health status and it was agreed that ethnicity data would need to be collected. Once the research is completed, a copy of the final report is to be provided to Ms Cunningham so that findings may be disseminated to appropriate Maori organisations, health professionals and researchers.

Setting
The study was conducted within the New Zealand context drawing interview participants from the Christchurch region, focus group participants from Wellington through to Dunedin and e-survey respondents from around the country. Documents were located via the internet and specifically pertain to New Zealand policy on self-management and education for nurses regarding self-management.
Critical discourse analysis – policy and education documents
This section outlines aim of the critical discourse analysis section of the thesis, how relevant documents were located and the data analysis process of critical discourse analysis applied to the documents.

Aim
The aim of this section was to undertake a discourse analysis of New Zealand government policy and New Zealand postgraduate nursing education documents relevant to long-term condition management and particularly those referring to self-management. This was undertaken in order to understand how health policy along with nursing education at postgraduate levels portray and shape the concept of self-care/management in long-term condition management within the New Zealand context. The research question was how does New Zealand policy and postgraduate education for nurses about self-management of a long-term condition influence an individual’s, their family or whanau and nurses’ understanding of self-management of a long-term condition?

Search strategy and data collection
An initial exploration of the topic was undertaken via the internet through the search engine Google in November 2009. Search terms used were self-care, self-management, long-term conditions and reports and policy and Whanau Ora. A scoping exercise was undertaken around government structure, health system and relevant legislation in order to better understand the New Zealand government structure and interrelatedness of different ministries within the government. Further exploratory searches were undertaken of individual websites, i.e., Ministry of Health (MOH) and District Health Boards (New Zealand) (DHB). The search strategy aimed to find all relevant reports, strategic plans, policy, legislation and course outlines relevant to long-term condition management within the New Zealand context and those specifically referring to the concept of self-management.

These searches were followed by an intensive search of the MOH and individual DHB websites. Keywords used on the DHB websites were: long-term strategy,
long-term framework and statement of intent combined with the terms self-care and self-management. The MOH website was searched via links to “more health topics and long term conditions” and from the search page with long-term condition AND chronic conditions (or disease) AND policy AND reports. The New Zealand Government website was also searched by individual portfolio (health) in an attempt to collect any other relevant documents. These searches were undertaken between December 2009 and April 2010.

On completion of these searches, three key documents remained for analysis:

1. *Meeting the needs of people with chronic conditions* (National Health Committee, 2007);

2. *Whanau Ora: Report of the task force on whanau-centred initiatives* (Ministry of Social Development, 2010); and

3. The *Flinders Program™* training used at the postgraduate level to increase New Zealand nurses knowledge around the principles of self-management (Flinders Human Behaviour & Health Research Unit, 2011).

There were a number of other potential documents that could have been analysed, such as District Health Board frameworks for long-term condition management, but these are generated from and reflective of *Meeting the needs of people with chronic conditions*. Plus, the three documents were deemed more than sufficient for critical discourse analysis and contribution to this thesis.

**Data analysis**

The three key documents were analysed using the process of critical discourse analysis (CDA) described by Fairclough (Fairclough, 1992, 2003, 2010). Fairclough’s process of CDA goes beyond language syntax and morphology, and may be used to analyse the spoken word, written text, visual image or sound effect (Fairclough, 2003). This approach to discourse analysis endeavours to explore, interpret and understand how social, cultural and political power is represented within these “texts” and how they have been used or continue to be
used to construct a certain reality and thus authenticate an institution or belief (Crowe, 2005; Fairclough, 2003; Parker, 1994; Titscher, Meyer, Wodak, & Vetter, 2000; Traynor, 1996). “People in complex societies understand and re-enact in speech” or written text, visual image or sound effect “the power differences that pervade those societies” (Bernard & Ryan, 2010, p. 222). CDA focuses on “how the content of discourse establishes, reflects, or perpetuates power differences between actors in society” (Bernard & Ryan, 2010, p. 222). Thus CDA is concerned with revealing the social and ideological effects of “text” and how the explicit and implicit meanings imbedded in “text” bring about change in peoples’ knowledge, beliefs, attitudes, values and understanding toward and about power, domination and exploitation (Fairclough, 2003).

Choice of a CDA approach for data analysis enables the researcher to situate the chosen texts within their social, political, cultural and historical contexts and reveal the underlying discourses evident within these texts. The CDA process assists in revealing the social and ideological effects of the chosen “texts” and how the explicit and implicit meanings imbedded in these “texts” have brought about change in peoples’ knowledge, beliefs, attitudes, values and understanding toward and about self-management of a long-term condition within the New Zealand context.

Data analysis for the three documents was undertaken using Fairclough’s checklist for textual analysis (Fairclough, 2003). This checklist, which consists of questions a researcher may ask themselves, is akin to a tool box, where some or all of the tools may be used for a project. The first stage of analysis involved reading the three documents individually and then researching the sociocultural and historical context for each of the documents on the internet. Questions from the toolbox considered social events the texts are a part of and allowed identification of the context for the documents. Research was followed by write up of the sociocultural context for each document and commenced with Whanau
Ora followed by Meeting the needs of people with chronic conditions and then the Flinders Program™.

The next stage of analysis encompassed examination of each text individually, in order to identify underlying discourses. Toolbox questions considered discourses drawn on by the documents. The executive summaries and definition of self-management within each document were closely examined to gain an overall impression of discourses embedded, textured and mixed within the documents. Once discourses had been identified and discussed with a supervisor (MC), research, reading and writing was undertaken around each identified discourse, commencing with the Whanau Ora document and then Meeting the needs of people with chronic conditions and Flinders Program™ documents.

The third stage of analysis was textual analysis and tools utilised were difference, intertextuality, assumption and semantic and grammatical relations between sentences. In this stage the researcher closely examined the minutiae of each of the texts and in particular the definitions of self-management. Texts were examined for structure and strategies of intertextuality and claim to authority along with use of graphics and other textual features. The self-management definitions underwent both semantic and thematic analysis in order to pull apart the definitions and describe processes evident within the definitions provided by each of the documents. Analysis was followed by descriptive write up for each of the three documents. The researcher then returned to the key documents in order to extract excerpts from these to illustrate and illuminate embedded discourses.
Interviews
This section discusses aim, design, sample, recruitment process and data collection and analysis methods utilised for interviews with individuals living with long-term conditions, a focus group held with nurses and individual nurse interviews.

Individual interviews - individuals living with long-term conditions

**Aim**
The aim of this segment of the research was to elicit, via a semi-structured interview;

1. how individuals living with a long-term condition view, define, interpret and experience individual expertise in self-management; and,
2. beliefs that enhance or impede the development of ability to self-manage a long-term condition.

A further aim of this section of the research was development of open ended questions for the e-survey segment of the research. These questions were generated from recurring statements evident within these interviews.

**Design**
Qualitative semi-structured interviews were undertaken to gather the participants’ experience of living with a long-term condition as this form of interview allows for exploration of individual attitudes, feelings, ideas and thoughts (D. Jackson, et al., 2003). The interview guide was based on a guide developed by Patricia Wilson and used in her doctorate which was completed in the United Kingdom. This researcher emailed Wilson after reading a number of her published articles (Wilson, 2001, 2005; Wilson, et al., 2006, 2007) explaining the proposed New Zealand study and asking if she would consider sharing the interview guide she used for her study. Wilson kindly emailed her complete doctorate and the interview guides she used (P. Wilson, personal communication, August 3, 2009). These were used to form the basis of the guide with a few extra questions created by the researcher (Appendix 10). Questions
were designed to capture individuals’ views, definitions, interpretations and experiences of expertise in self-management; beliefs that enhance or impede the development of ability to self-manage, and; barriers and facilitators for participation in self-management. The guide was trialled on a colleague and then questions rearranged in order to improve flow.

**Sample**
Up to ten adults from the Christchurch region, aged 18 years and older, living with a long-term condition/s (e.g.: asthma, arthritis, diabetes, bipolar disorder, emphysema, COPD, other lung disease, heart disease or other long-term conditions) and willing to take part in an interview were sought.

**Recruitment process**
To obtain a sample of individuals living with long-term conditions the researcher utilised the qualitative sampling strategies of convenience, snowball and purposive sampling in order to locate suitable participants (D. Jackson, et al., 2003). A small message was placed in the Northwest edition of Coffee News “What's Happening” section inviting individuals with Type 2 Diabetes to contact the researcher if they were interested in talking about their experience of living with diabetes. One person responded to this message. The second person was found through snowball sampling (D. Jackson, et al., 2003). The first participant passed study details on to a friend, who contacted the researcher and indicated a willingness to participate in an interview.

The researcher then used knowledge of the population living with long-term conditions to approach participants (Schneider, 2003). Another study, being hosted by the Centre for Postgraduate Nursing Studies provided two further possible participant’s names. Individuals were approached by the primary investigator of that study and names and contact details were only provided to this researcher after these individuals had indicated they were interested in finding out more about this study. Both agreed to participate. Another
participant, known to the researcher, volunteered to participate after informal
discussion about this study.

In order to obtain a mix of individuals with long-term conditions, a Clinical
Nurse Specialist (CNS) was approached for names of individuals who might be
physically able and interested in participating in an interview. The CNS
approached individuals about the study and requested permission to pass on
contact details. The researcher was given contact details for three people. One
individual and partner agreed to participate in an interview. The other two were
approached by telephone and information sheet about the study posted out but
were either ill or in hospital and unable to participate on follow up. One further
participant was recruited via a colleague who heard about this study and passed
on study information.

All individuals who indicated they were interesting in participating were sent an
information sheet and consent form either by electronic mail or post. The
researcher telephoned the individual a week later and answered any further
questions, and if still interested in participating, set up a suitable time and place
for the interview.

**Data collection**
All participants requested interviews be held in their homes. On arrival the
researcher introduced herself, checked again that the individual wished to
continue with the interview and thanked the participant for their time and for
agreeing to be interviewed. The researcher then explained the interview process,
went over the study and information sheet with the participant to ensure any
questions had been answered to their satisfaction, obtained a signed consent
form, or provided the participant with a new consent form for signing, before
asking permission to start the interview. All interviews were digitally recorded
and lasted between half to one and a half hours.
Nurse - focus group and interviews

Aim
The aim of this section of the research was to elicit, via a focus group and two individual semi-structured interviews;

1. how individual expertise in self-care/management is viewed, interpreted, defined and experienced by nurses working with individuals who live with long-term conditions.

2. beliefs held by nurses working with people living with long-term condition/s that enhance or impede the development of an individual’s ability to self-care/manage.

Focus Group

Design
A focus group interview was specifically chosen to gather nurse interpretations, views, experience and beliefs around individual expertise in self-care/management as it allows interaction between participants (Kitzinger, 1994; Morgan, 1998) and exploration of what is thought but also the how and why behind those beliefs (Kitzinger, 1995). A focus group guide was developed with ten key questions by the researcher in conjunction with the supervisors (Appendix 11).

Sample
Six to ten primary healthcare and specialist nurses working with individuals living with long-term conditions were sought to participate in the focus group.

Recruitment process
The Centre for Postgraduate Nursing Studies offers two postgraduate papers in long-term condition management (University of Otago Christchurch, n.d.) and it was suggested this researcher approach the paper convenor about the possibility of running a focus group within one of the block courses scheduled for one of the papers – Long-term condition management (Advanced). The paper convenor was willing to support a focus group and sent out, on behalf of this researcher,
an email inviting participation, with information sheet and consent form to the twelve students registered for the course.

**Data collection**
The focus group was held in a room at the Centre for Postgraduate Nursing Studies. Lunch was offered to participants as they were on a block course and in at the Centre for a number of days. On arrival, the researcher made participants welcome and thanked the participants for their time and for agreeing to be part of the group. The researcher introduced herself, then explained the focus group process, recapped the study and got members to introduce themselves, state where they worked and which long-term conditions they encountered during the course of a day. The focus group was digitally recorded with three recording devices and lasted approximately forty five minutes.

**Individual nurse interviews**

**Design**
Qualitative individual semi-structured interviews were utilised and questions were designed to capture nurse views, definitions, interpretations and experiences of individual expertise in self-management and nurse beliefs that enhance or impede the development of an individual’s ability to self-manage a long-term condition. The interview guide was again based on a guide developed by Wilson with a few additional questions created by the researcher (Appendix 12).

**Sample**
Primary healthcare and specialist nurses working with individuals living with long-term conditions were sought to participate in individual interviews.

**Recruitment process**
The researcher utilised the qualitative sampling strategy of purposive sampling (D. Jackson, et al., 2003) and directly approached two senior registered nurses who work with individuals living with long-term conditions to ascertain their interest in participating in an interview. Both were interested in finding out more
about the study. The researcher emailed an information sheet, interview guide and consent form to these individuals and followed up with a telephone call a week later to answer any further questions and ascertain if still interested in participating. A suitable time and place was set up for the interview during this call.

**Data collection**

Interviews were held at the Centre for Postgraduate Nursing Studies. On arrival, the researcher made the participant welcome, obtained a drink for the participant and thanked the participant for their time and for agreeing to be interviewed. The researcher then explained the interview process, went over the study and information sheet with the participant to ensure any questions had been answered to their satisfaction, obtained a signed consent form, or provided the participant with a new consent form for signing, before asking permission to start the interview. Interviews were digitally recorded and lasted approximately one and a half hours.

**Data analysis**

All individual interviews, nurse interviews and focus group were transcribed by this researcher. The nurse focus group was conducted and transcribed first, followed by individual interviews with participants living with long-term conditions. Transcription of these interviews was undertaken as close to the interview as possible. Nurse interviews and transcription of the recordings were undertaken last. Data analysis of transcripts was conducted in the following order - individual interviews, nurse focus group and finally individual nurse interviews and utilised the process of thematic analysis.

Thematic analysis is an analytic process used in qualitative research (Braun & Clarke, 2006) which assists “the researcher in the search for insight” when dealing with data (Boyatzis, 1998, p. vi). It involves searching for and identification of common threads within or across interviews to facilitate analysis and description of the data (Boyatzis, 1998; Braun & Clarke, 2006;
Morse & Field, 1995). It is an inductive process that works from specific observations or phrases toward broader generalisations or common themes.

Inductive theory is directed toward bringing knowledge into view. It is generally descriptive, naming phenomena and positing relationships. It is frequently conducted in the naturalistic setting and considers context as part of the phenomena. The researcher’s goal is to identify patterns or commonalities by inference through the examination of specific instances or events. During analysis, the researcher moves from specific instances or datum, to more abstract generalisations extending from the synthesis of data, eventually resulting in the identification of concepts and theory development (Morse & Field, 1995, p. 8).

A theme is made up of a name, definition, description of the theme, qualifications or exclusions for identifying the theme and examples of these. Themes are patterns that may either describe and organise an observation or interpret aspects of the phenomenon. A theme may be directly observable in the data (manifest level) or lie beneath the data (latent level) (Boyatzis, 1998). DeSantis and Ugarriza (2000, p. 351) suggest the “concept of a theme is critical to the accurate interpretation of qualitative data” and as such the researcher needs to have a clear understanding of what constitutes a theme. A theme is “an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole” (DeSantis & Ugarriza, 2000, p. 362). Themes consist of form, they unify, are woven throughout a text, “are the underlying factor, web, essence, or meaning of an experience” and “themes exist apart from their individual properties” (DeSantis & Ugarriza, 2000, p. 367).

Identification of themes within the data were driven by the data itself. Each transcript was individually read and then re-read in order to obtain a sense of the whole (Morse & Field, 1995). Phrases or words that related directly to the research question and aims were underlined and the researcher’s thoughts jotted in the margin. Reduction of the raw information was then undertaken and involved transferring the underlined and interesting phrases from each transcripts to another document along with page number and tape time.
Once all phrases were transferred, further reading was undertaken in order to identify themes within each transcript (Boyatzis, 1998; Morse & Field, 1995).

The researcher then looked for common themes across the transcripts (Boyatzis, 1998). To assist with this process, the researcher printed out the document and separated each phrase with its associated theme. Further reading of the phrases, thinking and sorting was undertaken until groups of common themes became evident. When this was complete, the researcher utilised “cut and paste” from “document two” to a third document for each of the groups of common themes. Discussion was then undertaken between the supervisors and this researcher in order to identify significant concepts that appeared to link the common themes and the groups of interviews together (Boyatzis, 1998; Morse & Field, 1995).

The researcher then investigated meanings of potential naming words for the identified themes through the use of online dictionaries and thesaurus (Merriam-Webster, 2013). Further reading of the participant quotes, the researcher’s thoughts and potential themes was undertaken to establish that the names and descriptors for the themes fitted and adequately described the data. Descriptive write up of the findings was then undertaken and included naming, defining and describing the identified themes and illustrating these themes with supporting quotes from participant transcripts (Boyatzis, 1998). Thematic analysis enabled this researcher to gain understanding, identify common threads within and across interviews and then across the multiple qualitative data sources in order to draw all the data into a coherent whole (Boyatzis, 1998; Braun & Clarke, 2006; Morse & Field, 1995).
E-survey
This section discusses the aim, design, sample, recruitment process, and research instruments used to collect data for the electronic survey (e-survey).

Aim
The aim of this survey was to elicit, via an e-survey a snapshot of what it is like to live with a long-term condition in New Zealand. A further aim was to extrapolate themes that arose from the individual interviews to ascertain if a wider audience agreed or disagreed with these. Additionally analysis of the data aimed to:

1. describe respondent demographics (age, sex, ethnicity, marital status, living arrangements, religious affiliation, income sources, highest educational qualifications, response by region, urban/rural split, number of long-term conditions and number of specific long-term conditions);
2. report self-reported health status, self-management behaviour and self-efficacy of New Zealand individuals living with long-term conditions;
3. compare e-survey mean and standard deviation scores with published data from Stanford and other studies (who have used Stanford);
4. test relationships from e-survey data between groups (male/female, urban/rural and long-term conditions) with each of the Stanford Scales; and,
5. test relationships from e-survey data between Stanford Scales, age, and number of long-term conditions.

Design
An online or e-survey design was chosen utilising a traditional research and paper based cross sectional survey design. An e-survey is “one in which a computer plays a major role in both the delivery of the survey to potential respondents and the collection of survey data from actual respondents” (Jansen, Corley, & Jansen, 2007, p. 2). There are three main types of e-survey (Jansen, et al., 2007; Sue & Ritter, 2007):
1. point of contact – a survey is filled out by a participant on a computer supplied by the researcher;
2. email based – around since the 1980’s (Evans & Mathur, 2005). A survey, sent as an attachment, is delivered by electronic mail to an email address list via the internet or corporate intranet; and,
3. web-based – the survey instruments are hosted on a network server, connected to the internet and can be accessed through a web browser from any computer. The earliest web-based surveys were first hosted in the 1990’s (Evans & Mathur, 2005; Roberts, 2007). Participants for web based surveys are either chosen using a traditional quantitative sampling method and then alerted to the opportunity to participate by directing the participant to the website hosting the survey or self-selected (Jansen, et al., 2007). Those who self-select are not directly recruited by the researcher but find the survey through browsing the web (Jansen, et al., 2007).

This type of research design is used for collecting data on specific variables using a representative group at defined point in time and is often used in health research (Elliot & Hayes, 2003; Last, 2011).

Design also encompasses the physical layout and presentation of a survey. A number of guidelines exist for the physical design or layout of paper based questionnaires but few for e-surveys (Lumsden, 2007). To integrate the three separate sections of the survey, the researcher employed an independent software technician to create the online version and LimeSurvey® software was used to support the design. LimeSurvey® is a web-based open source software tool for creating internet surveys (Schmitz, n.d). Email conversations with the software technician and use of LimeSurvey® allowed for the inclusion of a welcome page, multipage format and other layout requirements. The e-survey was designed to take approximately 20-30 minutes and was voluntary, allowing respondents to cease participation at any stage. The e-survey was pretested using a number of different computers, web browsers and users to trial its ease of use.
and question format. Undertaking the survey online has provided the researcher a useful advantage in that data can easily be exported in the format required to analysis software (Statistical Package for the Social Sciences now IBM SPSS (SPSS)) for data analysis (Sue & Ritter, 2007).

**Sample**

A non-probability convenience sampling strategy was used as it is an easy way for a researcher to obtain participants but this form of sampling strategy has a number of limitations; limited generalisability to the wider population and a high risk of bias from self-selection (Schneider, 2003; Sue & Ritter, 2007). It is difficult to ascertain a suitable sample size for an online non-probability sample because the researcher is unable to determine the exact size of the parent population (R. Hill, 1998). The following suggestions were taken into account when deciding how large the sample should be for this e-survey.

1. Sample size – little justification for less than thirty or larger than 500 (Hill (1998) suggests little gained over 380 cases if a finite population) (Dr. M Collins, personal communication, 11 March 2012; Sue & Ritter, 2007).

2. For descriptive research, it is suggested the sample population should be about 10% of the estimated parent population and for correlational research, at least thirty subjects are required to establish a relationship (R. Hill, 1998; Sue & Ritter, 2007).

3. Select the largest sample you can afford (considering time and energy as well as money) as larger samples are better than smaller ones (R. Hill, 1998; Sue & Ritter, 2007).

4. It is important that the sample be representative of the population from which it is drawn (Sue & Ritter, 2007).

Based on these suggestions a sample size of 200 was sought for the e-survey.

The relevance of e-survey to this research encompasses geographic spread of the potential sample around New Zealand (Sue & Ritter, 2007), the strengths of e-surveys, Internet usage rates and access by age groups to be included in this
study and use of the Internet for obtaining health information. Internet usage in the world was estimated to be 2,267,233,742 users as at 31 December 2011, a population penetration of just over 32% (Internet World Statistics, 2012). North America had the highest population penetration (78.6% of the population), followed by Oceania/Australia (67.5%) and Europe (61.3%) with Africa at 13.5% (up from 2.5% in 2006 (Whitehead, 2007)) (Internet World Statistics, 2012). In New Zealand in 2009, it was estimated 83% of New Zealanders used the internet (Bell et al., 2010) with 75% of households having access to the internet at home (Statistics New Zealand, n.d.) and population penetration showing a small rise at 31 December 2011 to 84.5% (Internet World Statistics, 2012). Internet usage across all ethnicities within New Zealand has risen since 2007 with Maori and Pasifika Internet usage showing the greatest increase, resulting in a decrease in differences across ethnicities (Bell, et al., 2010).

The age of an individual is considered an influential factor in access and use of the Internet with use decreasing as age increases (N. Adams, Stubbs, & Woods, 2005; Choi, 2011; Selwyn, Gorard, Furlong, & Madden, 2003; P. Smith et al., 2010). However, in a recent Pew Report (America), Internet access for a number of activities was shown to be more evenly spread across all age groups than in the past (Zickuhr, 2010). Research shows older adults utilise the Internet to gain health information (K. Flynn, Smith, & Freese, 2006; Harrod, 2011; L. Wagner & Wagner, 2003; T. Wagner, Baker, Bundorf, & Singer, 2004; Ybarra & Suman, 2008; Zulman, Kirch, Zheng, & Lawrence, 2011). Other studies have shown that individuals are interested and willing to interact with technology to complete clinic computer based health assessments (Koestler, Libby, Schofferman, & Redmond, 2005), self-administered electronic pre-operative surveys (VanDenKerkhof, Goldstein, Claine, & Rimmer, 2005) and participate in research surveys via the Internet (Beling, Libertini, Sun, Masina, & Albert, 2011). With the potential sample spread out around New Zealand, approximately 83% of New Zealanders accessing the internet and an increase in broadband connectivity amongst older users (50-59 years - up from just over
60% in 2007 to just over 80% in 2009; 60-69 years – 60% to 80% from 2007-2009; 70+ - from 41% in 2007 to 65% in 2009 (Bell, et al., 2010), an e-survey was deemed a valid way to collect data for this section of the research.

Thus, the e-survey was made available to as many adult individuals, aged 18 and over, living in New Zealand with a long-term condition such as asthma, arthritis, diabetes, bipolar disorder, emphysema, COPD, other lung disease, heart disease or other long term condition/s as possible.

**Data collection**
A search of the internet was conducted to find contact names and details for Asthma New Zealand, New Zealand Heart Foundation, Arthritis New Zealand, Diabetes New Zealand and Balance New Zealand. District Health Board websites were searched to locate suitable community newsletters and contact details for Communications/Media departments. Each contact was emailed an introductory letter (Appendix 13) during May 2011 explaining the research and survey and asking if would be possible to advertise the survey on their website or in their respective community newsletters. Further contacts for Coffee News and Health Navigator were also emailed. Whilst waiting for responses to this introductory email, the researcher created a web and print friendly invite (Appendix 14). Eight positive responses were received and after providing further information as requested, these eight agreed to support the research through posting a link on their website or including the invite within their newsletters as and when they could. Two further emails were sent to a reference group of diabetes specialist nurses in the lower North Island and the College of Nurses. Appendix 15 outlines positive, negative or no response to advertising emails. The e-survey went “live” on 1 June 2011.

On 9 June 2011, an email was received from a participant noting that the marital status question had no option for “widowed”. After discussion with the supervisor, the software technician was asked to add the option of “widowed/widower or surviving civil union partner” to the marital status
question. This was done in the early hours of the morning, when the website was quiet and all initial entries were imported back into the survey. No further issues were reported to the researcher by participants.

In early July, a review of responses to the e-survey showed most respondents were from the North Island, so a key South Island contact was emailed to generate further possible avenues for advertising the survey more widely in the South Island. Other contacts, suggested by initial email contacts, were also followed up resulting in a further two contacts who agreed to advertise a link to the e-survey in their newsletter or via an email network. In November 2011 the researcher undertook a tally of the spread of conditions which revealed small samples for categories of “Emphysema/COPD” and “Other Lung Disease”. It was discovered the only way to reach individuals with these conditions is through the Asthma Foundation of New Zealand, so the researcher emailed eleven regional asthma group contacts as listed on Enable New Zealand Weka/Disability website with two supportive responses. Appendix 16 outlines response level to the e-survey over the nine months.

The e-survey was deactivated on 10 February 2012. The LimeSurvey® data file was condensed and sent to the researcher’s email address. A summary of the e-survey using Eysenbach’s (2004) checklist for reporting results of Internet e-surveys (CHERRIES) is provided in Appendix 17 and 24. Appendix 17 summarises design, ethics, development and pretesting, recruitment and survey administration, and Appendix 24 outlines response rate, prevention of multiple entries and analysis decisions. A further table, evidenced in Appendix 18, summarises month by month unique visitors, number of visits, visit to visitor ratios, number of pages viewed, pages per visit and visit duration.

**Research instrument**

The e-survey was designed in three parts. The first contained fourteen demographic questions with a further thirteen adaptive questions (Section (S)1, Question (Q)1-27), the second was constructed from pre-existing Stanford tools
(S2,Q28-36) (Stanford School of Medicine, 2007), and the third contained eight open-ended questions (S3,Q37-45) created from themes that arose from the individual interviews (See Appendix 19).

Section 1: Demographic questions
This section of fourteen questions contained key demographic questions that sought information on gender, age and ethnicity. Further questions around marital status, people living in household, religion, secondary qualification and income sources were derived from another study and New Zealand census questions. A question on New Zealand residency was included to ensure inclusion criteria were met. Post code and area lived in were included to assist in matching of demographic data to measures of socio-economic status as research shows long-term conditions are linked with socio-economic status (Glover, Hetzel, & Tennant, 2004; Hayward, Miles, Crimmins, & Yang, 2000; Ministry of Health, 2009b; National Health Committee, 2007; Salmond, Crampton, King, & Waldegrave, 2006). One question asked participants to indicate which long term condition/s they live with and was modified from a Stanford question (Stanford School of Medicine, 2007). Cancer was listed and was included to ensure inclusion and exclusion criteria were met for this study as cancer has not been included as a “long-term condition”. This was a clear choice as living with cancer is more about survivorship over time than self-management of a long-term condition (Aziz, 2008; Mullan, 1985).

Adaptive questioning was used within this section. Adaptive questioning is where certain questions, based on response, leads to potentially different questions. The aim of adaptive questioning is to present respondents with questions relevant to them, thereby reducing the complexity and number of questions in a survey (Eysenbach, 2004; Sue & Ritter, 2007). Adaptive questions were:

Q6: Which ethnic group do you belong to? If the response was Maori, then the respondent was presented with “My Iwi is: Please write your answer here”.

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Q11: What is the highest qualification you obtained at secondary school? If the response was “Other NZ secondary qualification” then the respondent was presented with “Please state other NZ secondary school qualification: Please write your answer here”.

Q16: Please indicate which long-term conditions you are living with – Please choose all that apply. Depending on response, adaptive questioning may have taken the respondent in a number of directions.

1. If the response was Diabetes, then the respondent was asked “How is your diabetes controlled: Please choose all that apply – diet, tablet, insulin and other”.

2. To enable further data analysis and comparison between groups an adaptive question about length of time since diagnosis was “behind” each of the choices in Q16.

3. If the response to Q16 was “Cancer”, the respondent was asked to specify which type of cancer.

4. If the response was “Other” to Q16 then adaptive questioning asked for the respondent to specify which other long-term condition/s they lived with.

Section 2: Stanford questions
The Stanford Patient Education Research Centre, Department of Medicine at the Stanford University School of Medicine, Palo Alto, California, America has developed, adapted and tested various scales for research which are available to use without permission and at no cost (Stanford School of Medicine, 2011c). These scales are able to be self-administered, are available in English and Spanish and are for research participants living with long-term conditions. The Stanford Patient Education Research Centre provide online the items, properties (when available), coding and scoring instructions (Stanford School of Medicine, 2011b). These instruments have been trialled by the Patient Education Research Centre, as part of the Chronic Disease Self-management Program, in a paper based format in English and Spanish (Lorig, Ritter, & Gonzalez, 2003; Lorig, Ritter, & Jacquez, 2005; Lorig et al., 2001; Lorig, Sobel, Ritter, Laurent, &
Scales downloaded from the Stanford Patient Education Research Centre site were used to create this section of the survey and explore topics of self-management behaviours, self-efficacy and health status (Stanford School of Medicine, 2007, 2011b). Specific tools used were:

**General Health – Self-Rated Health (SRH)**
The General Health – Self-Rated Health (S2,Q28) is a single question five-point Likert item ranging from one (excellent health) to five (poor health). A higher score is suggestive of poorer health (Lorig, et al., 1996; Stanford School of Medicine, 2007). This scale is from and used in the National Health Interview Survey in America (Lorig, Sobel, et al., 2001).

**Symptoms – Health Distress (SHD)**
This scale (S2,Q29) consists of four questions with a six-point Likert scale ranging from zero (none of the time) to five (all of the time). The total scale score is the mean of the four items with a higher score indicating more distress about health. The Symptoms – Health Distress scale assesses how much time during the past two weeks a participant has been discouraged, fearful, worried or frustrated by their health problems. The scale was modified from the Medical Outcome Study health distress scale (Lorig, Sobel, et al., 2001; Lorig, et al., 1996; Stanford School of Medicine, 2007). The Symptoms – Health Distress scale has good internal consistency with a reported Cronbach alpha coefficient of 0.87 (Lorig, et al., 1996).
Daily Activities – Social/Role Activities Limitations (DASRA)
The Social/Role Activities Limitations scale (S2,Q30) consists of four questions with a five-point Likert scale and measures how much a long-term condition interferes with activities. Each item is rated from zero (not at all) to five (almost totally). The scale score is the mean of the four items with a higher score indicating greater activities limitations. Lorig et al. (1996) reported good internal consistency and a Cronbach alpha of 0.91.

Medical Care – Communication with Physicians (MCPHY)
Three items (S2,Q31) with a six-point Likert scale ranging from zero (never) to five (always). The mean of the three items provides the total score for this scale with a higher score showing better communication with physicians (Lorig, et al., 1996; Stanford School of Medicine, 2007). The Medical Care – Communication with Physicians scale has good internal consistency with a reported Cronbach alpha coefficient of 0.73 (Lorig, et al., 1996).

Self-Efficacy for Managing Chronic Disease 6-Item Scale (SEMCD)
This scale (S2,Q32) has six items and was created from larger self-efficacy scales developed for the Chronic Disease Self-management study. This scale has been used in Stanford internet studies and explores domains common to many chronic diseases (symptom control, role and emotional function and communicating with physicians). It is presented as a ten-point Likert scale from one (not confident at all) to ten (totally confident), the total score is the mean of the six items with a higher score indicating higher self-efficacy (Lorig, Sobel, et al., 2001; Stanford School of Medicine, 2007). The Self-efficacy – Managing Chronic Disease 6-Item Scale has good internal consistency with a reported Cronbach alpha coefficient of 0.91 (Stanford School of Medicine, 2007).
Chronic Disease Self-Efficacy Scales
The following scales were developed and tested for the Chronic Disease Self-management study (Lorig, et al., 1996; Stanford School of Medicine, 2007).

*Get Information about Disease Item (SEGIAD)*
A single question (S2,Q33) rated on a ten-point Likert scale from one (not at all confident) to ten (totally confident). Higher score indicates greater self-efficacy.

*Obtain Help from Community, Family, Friends Scale (SEOHCFF)*
This scale (S2,Q33) consists of four items with scoring rated on a ten-point Likert scale from (not at all confident) to ten (totally confident). The score is the mean of the four items with a higher mean score indicating higher self-efficacy. According to Lorig et al. (1996), the Self-efficacy – Obtain Help from Community, Family, Friends Scale has good internal consistency, with a Cronbach alpha coefficient reported of 0.77.

*Communicate with Physician Scale (SECPHY)*
A three question scale (S2,Q34) rated on a ten-point Likert scale from one (not at all confident) to ten (totally confident). The scale score is the mean of the three items with a higher number indicating greater self-efficacy. This scale is similar to the Medical Care – Communication with Physicians scale but asks two different questions which were felt to be relevant to the research question, so the complete scale was included. The Self-efficacy - Communicate with Physician Scale has good internal consistency with a reported Cronbach alpha coefficient of 0.90 (Lorig, et al., 1996).

*Manage Disease in General Scale (SEMDG)*
Consisting of five questions (S2,Q35), each rated on a ten-point Likert scale from one (not at all confident) to ten (totally confident). Higher self-efficacy is indicated from a higher score generated from the mean of the five items within the scale. According to Lorig et al. (1996), the Self-
efficacy – Manage Disease in General Scale has good internal consistency, with a Cronbach alpha coefficient reported of 0.87.

Do Chores Scale (SEDC)
This scale consists of three items (S2,Q36) with scoring rated on a ten-point Likert scale from (not at all confident) to ten (totally confident). The score is the mean of the three items with a higher mean score indicating higher self-efficacy. The Self-efficacy – Do Chores Scale has good internal consistency with a reported Cronbach alpha coefficient of 0.91 (Lorig, et al., 1996).

Social/Recreational Activities Scale (SESRA)
Two items (S2,Q36) with a ten-point Likert scale ranging from one (not at all confident) to ten (totally confident). The mean of the two items provides the total score for this scale with a higher score showing better self-efficacy. According to Lorig et al. (1996), the Self-efficacy – Social/Recreational Activities Scale has good internal consistency, with a Cronbach alpha coefficient reported of 0.82.

Section 3: Open ended questions
This section (S3,Q37-45) was free text and allowed respondents to answer the questions if they wished. Questions were derived from recurring statements evident within interviews undertaken with individuals living with long-term conditions. A colleague with experience in counselling and the researcher sat together and designed the questions in order to elicit views, beliefs and barriers and facilitators for living with a long-term condition. A total of eight questions were created, along with an additional comment space (See Appendix 19).

Data management
The downloaded LimeSurvey® file was imported into SPSS in order to define the variables, prepare a code book, screen, clean and analyse the data. A code book was prepared documenting each variable, its name and SPSS name, corresponding question number from the e-survey and coding instructions for the variable. Once the code book was completed the researcher undertook data
screening. Data screening enabled the researcher to locate values within the data that were inconsistent with the possible range for any given variable (Pallant, 2011). For example, the “Postcode” (S1,Q2) and “Region” (S1,Q3) variables where responses were outside the required range for these answers (i.e. respondents gave full address instead of a numerical postcode, entered three digit postcodes or chose “Other” or entered “this question is redundant” rather than the relevant post code or region they resided in). Other variables tidied up (capital letters, spelling, terminology used) in order to group similar responses were “Ethnicity Other Explain” (S1,Q6), “Iwi” (S1,Q7), “Who Lives in Same Household as You Explain” (S1,Q9), “Religion Other” (S1,Q10), the education questions (S1,Q11-14), “Other Income Explain” (S1,Q15), “Type of Cancer Explain” (S1,Q18) and “Other Long-term Condition Explain” (S1,Q19).

During the data screening process the researcher noted that the option for “How Diabetes is controlled – Other” (S1,Q17) held no data. Cross checking with the LimeSurvey® file revealed that two participants had entered a response but the data had not transferred to SPSS. Data for these responses was hand entered and a cross-check of the SPSS file with the LimeSurvey® file was undertaken of all the “Other” variables within the Demographic section and the complete Stanford section13. No further data was found to be missing.

**Data analysis: Section 1 & 2**

The programme SPSS Version 19-x for Windows was used to analyse data. Responses were included for analysis when respondents had completed the demographic section of the survey plus at least the first Stanford scale (Self-Rated Health). Reliability, normality and homoscedasticity of the data were ascertained prior to running descriptive and non-parametric tests (Mann Whitney-U and correlations). Additionally, instructions provided by Stanford

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13 Cross checking was undertaken through comparing summaries from both LimeSurvey® and SPSS (n=305) for each answer through the frequency of each response or through list comparison
School of Medicine (2007) regarding scoring the scales and dealing with missing data from the scales was followed. To facilitate a comparison of the highest scoring respondents with those respondents who indicated they had less self-efficacy, poorer self-management behaviours or health status, a one-third cut off was established for data obtained from each of the Stanford Scales. This was achieved by counting up the number of entries in the “valid” column for each scale from the frequency table output from SPSS. This number was then divided by three to establish the cut off mark in the valid column and percentages were then worked out from the cumulative percent column. Self-rated Health and Self-efficacy – Get Information About Disease are one item scales so groups were established as “excellent and very good” with “good, fair and poor”; and, 1-7 with 8-10, respectively. Mean scores were used to report e-survey data and this enabled comparison of e-survey data with published data from Stanford and by other authors who have used Stanford Scales.

Data analysis: Section 3 – open-ended questions
E-survey responses were copied from SPSS to a Word document for each of the eight questions. The process of data analysis for each question was thematic (Boyatzis, 1998) and derived from the raw information provided by the e-survey respondents. To begin, answers for each question were individually read and re-read in order to obtain a sense of the whole (Morse & Field, 1995). Phrases or words that related directly to the question were underlined and the researcher’s thoughts jotted in the margin. Reduction of the raw information was then undertaken and involved grouping the underlined and interesting phrases from each question along with respondent’s identification number allocated by SPSS into common themes. This was followed by identification of significant concepts that appeared to link the common themes and the original questions together (Boyatzis, 1998; Morse & Field, 1995). Saturation of common themes was noted

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14 For example Symptoms Health Distress scoring instructions state “score each item as the number circled. If two consecutive numbers are circled, score the higher (more distress) number. If the numbers are not consecutive, do not score the item. The scale score is the mean of the four items. If more than 1 item missing, set the value of the scale to missing. Scores range from 0-5; higher score indicating more distress about health” (Stanford School of Medicine, 2007, p. 2).
after four or five pages; however the entire eight word documents were read to ensure no extra or different themes were found.

The researcher then investigated meanings of potential naming words for the identified themes through the use of an online dictionary and thesaurus (Merriam-Webster, 2013). Further reading of the respondent answers, the researcher’s thoughts and potential themes was undertaken to establish that the names and descriptors for the themes fitted and adequately described the data. Descriptive write up of the findings was then undertaken and included naming, defining and describing the identified themes and illustrating these themes with supporting quotes from the respondent’s answers (Boyatzis, 1998).
Chapter 4 : Results

Critical discourse analysis of
Meeting the needs of people with chronic conditions,
The Flinders Program™
and Whanau Ora documents

Self-management is being able to manage your long-term condition yourself. That you have the responsibility to yourself, and in the long run, the community at large (E-survey, 342).

Introduction
This chapter provides a discourse analysis of three documents The National Health Committee: Meeting the needs of people with chronic conditions (National Health Committee, the Committee and Meeting the needs of people with chronic conditions); The Flinders Chronic Condition Management Program™ (Flinders Program™), and; Whanau Ora: Report of the Taskforce on whanau-centred initiatives (the Taskforce and Whanau Ora) using Fairclough’s critical discourse analysis approach. This approach to discourse analysis views language as “social practice, rather than purely individual activity or reflex of situational variables” (Fairclough, 1992, p. 63), and an “irreducible part of social life, dialectically interconnected with other elements of social life, so that social analysis and research always has to take account of language” (Fairclough, 2003, p. 2). Fairclough argues that language contributes to construction of various “types of self”, the social relationships between people, and underlying belief and knowledge systems (Fairclough, 1992).

In order to expose how language has contributed to construction of a text, it is important to gain an understanding of the historical, political, social, economic
and institutional contexts contributing to the environment in which a text was produced. Contextual knowledge of the environment surrounding genesis of a text facilitates analysis of underlying dominant ideologies and discourses of the given time, and also enables examination of how these have contributed to shaping the content of the text (Crowe, 2005; Fairclough, 1992, 2003; J. Smith, 2007). Analysis at the textual level focuses on structure, vocabulary and style, and how these are put together to produce meaning, meaning that can only be understood when it is situated within sociocultural and discourse practice levels (Crowe, 2005; Fairclough, 1992, 2003; J. Smith, 2007). The discourse practice level enables the analyst to understand and discuss how the document, when linked with their textual and sociocultural levels, has been used to create, define, shape and influence the phenomena of interest, those of the self, social relationships and or underlying belief and knowledge systems (Crowe, 2005; Fairclough, 1992; J. Smith, 2007).

Fairclough (1992) suggests the analyst also needs to take into consideration three tendencies of change; democratisation, commodification and technologisation, which shape the form discourse takes within a text. The discursive tendency of:

- democratisation is characterised by “the removal of inequalities and asymmetries in the discursive and linguistic rights, obligations and prestige of groups of people”;
- commodification is a process whereby “social domains and institutions, whose concern is not producing commodities in the narrower economic sense of goods for sale, come nevertheless to be organized and conceptualized in terms of commodity production, distribution and consumption”; and,
- technologisation is characterised by a “tendency toward increasing control over more and more parts of people’s lives” (Fairclough, 1992, pp. 201, 207, 215).
These discursive tendencies of change provide “a way into identifying patterns in the complex and contradictory processes of ongoing discursive change”, and may interact with and or cut across each other within a text (Fairclough, 1992, p. 200). All three tendencies may or may not be evident within a given text.

The chapter commences with rationale and reason for choice for each of the three texts. Analysis is then structured around Fairclough’s (1992) principles of the sociocultural context in which the texts were produced (sociocultural level), textual techniques used within the texts (textual level), and how the text reflects underlying discourses (discourse practice level) and in turn shapes the definition and understanding of self-management (Crowe, 2005; J. Smith, 2007). Where appropriate, Fairclough’s discursive tendencies are discussed in relation to the discourse process evidenced within the texts.

**Choice of texts and rationale**

The research question drives the choice of text/s (Crowe, 2005) and the research question for this section of the thesis was:

> what are the underlying discourses embedded within New Zealand health policy and New Zealand postgraduate nurse education documents regarding self-management, and how may these impact/influence an individuals’, their family/whanau and nurses’ understanding of long-term condition self-management?

The chosen documents (texts) and reasons for choice were:

- *Meeting the needs of people with chronic conditions*, a seminal New Zealand document, and currently the only “framework” for long-term condition management within New Zealand (National Health Committee, 2007);

- The *Flinders Program™*, training used for New Zealand nurses at the postgraduate level to increase knowledge around the principles of self-
management (Flinders Human Behaviour & Health Research Unit, 2011), and;

- *Whanau Ora: Report of the Taskforce on whanau-centred initiatives*, another seminal document that sets out a uniquely Maori perspective and approach to meeting the social, economic, health and cultural needs of Maori and through the Treaty of Waitangi and government, all New Zealanders (Ministry of Social Development, 2010).

**Sociocultural, textual and discourse practice contexts**

It is important to establish the context in which the three documents were produced, the purpose for their production, and the underlying discourses embedded within (Crowe, 2005). This section provides an overview of each of these contexts for each of the three documents, starting with *Meeting the needs of people with chronic conditions*, followed by *The Flinders Program™*, and concluding with *Whanau Ora*. Within each section, the sociocultural milieu is provided, followed by structure and style of the document (textual level). The main identified discourses are discussed, and quotes, drawn from the document, are used to illustrate these underlying ideologies. This is followed by the document’s definition of self-management with supporting quotes, again drawn from the document, and used to illustrate underlying discourses.

**National Health Committee:**

**Meeting the needs of people with Chronic Conditions**

**Sociocultural context**

The period leading up to the production of the document *Meeting the needs of people with chronic conditions*, was a period of fundamental change for New Zealand’s health system, politics and public policy. Central to these changes were “the application of neoliberal, or market orientated, philosophies to drive policy development and service organisation” (Gauld, 2009a, p. 1). These radical reforms altered social and health service structures, from a social
democratic version of the welfare state to restricted welfare provision of the liberal market model, and were hidden amongst an effort to reduce and contain spending on health and social services (Boston, 1992; Gauld, 2009b; N. Rose, 1996).

The National Advisory Committee on Health and Disability, initially named the National Advisory Committee on Core Health Services, was established in 1992 specifically to identify core services to which “everyone should have access, on affordable terms without unreasonable waiting time”, but also to provide a framework for purchasing, rationing and prioritisation of services (Gauld, 2009b; Upton, 1991, p. 75). Defining “core services” proved next to impossible and the Committee moved to provide guidelines and information aimed to assist purchasing priorities, service provision and promotion of best practice (Gauld, 2009b; Ham, 1997). The Committee was established in law in 1993 under the Health and Disability Services Act (Gauld, 2009b; National Health Committee, 2011, 2012), and the Committee’s brief was expanded to include public health advice as further adjustments to the health system continued. It was during this time the Committee sought to bring to policy makers attention the impact of health determinants, particularly social, economic and cultural conditions, and the inequalities these create (National Advisory Committee on Health and Disability, 1998; Woodward & Kawachi, 1998). As Gauld (2009b) notes, these reports were dismissed, arguably because “the underpinning philosophy of the papers was egalitarian and interventionist, which contrasted with the government’s broad commitment to market-orientated policy” (p. 154).

Further major restructuring occurred with another change of government in 199915, and underlying ideologies shifted from profit driven system to focus on patients, and the core determinants of health, alleviation of poverty and unemployment (Gauld, 2009b). A number of health strategies were introduced

15 Gauld (2009b) suggests this restructuring was as substantial as the changes of the 1993 health reforms.
(e.g., New Zealand Health Strategy, Primary Healthcare Strategy, New Zealand Disability Strategy and He Korowai Oranga: Maori Health Strategy) along with legislation (New Zealand Public Health and Disability Act, 2000 (NZPHD Act) which replaced the Health and Disability Services Act) pursuing, for all New Zealanders, improvement, promotion and protection of health; inclusion, participation and independence of people with disabilities; the best care and support for those in need of services; reduction of health disparities for Maori and other population groups; provision of community voice in personal, disability and public health services and provision of information aimed at delivering appropriate, effective and timely personal and public health services (New Zealand Government, 2000).

The National Health Committee is appointed by and reports to the Minister of Health (National Health Committee, 2012)\(^1\), and its statutory purpose, as defined by Section 13 under the NZPHD Act\(^1\), is to provide advice to the Minister of Health (Parliamentary Counsel Office - New Zealand Government, 2000) on matters relating to the:

- a) kinds and relative priorities of personal health, disability support and public health services that should, in the Committee’s opinion, be publicly funded; and
- b) other matters relating to public health including,
  - i. personal health matters relating to public health; and
  - ii. regulatory matters relating to public health; and
- c) any other matters that the Minister specifies by notice to the NHC (National Health Committee, 2011, p. 1).

The Committee was reconfigured in 2011, after the election of the Key led National government in 2008 and review of health services by the Ministerial Review Group in 2009 (Ministerial Review Group, 2009). The National Health Committee’s mandate, while still within the confines of the NZPHD Act 2000,

\(^{16}\) Member appointments are for a term of up to three years. Reappointment is not automatic and depends on NHC work programme, skill mix and experience

\(^{17}\) Statutory purpose was the same under the Health and Disability Services Act of 1993 and the 1995 amendment.
has been refocused on “contributing to improved value for money and fiscal sustainability in the health and disability sector” (National Health Committee, 2011, p. 2), rather than its previous focus on other matters (i.e., the social, cultural and economic determinants) relating to personal and public health (National Advisory Committee on Health and Disability, 1998; National Health Committee, 2007).

The document, *Meeting the needs of people with Chronic Conditions* was produced by the National Health Committee of 2006. The National Health Committee outlined how, what it calls, the “NHC project on chronic conditions” came about but also how the Committee built on previous work by the National Advisory Committee on Health and Disability (1998) and Woodward and Kawachi (1998). The 2002 Committee attended a presentation by providers in South Auckland on the Counties Manukau Chronic Care Management Programme (National Health Committee, 2007; Wellington, Tracey, Rea, & Gribben, 2003). This visit and presentation brought to the Committee’s attention the “high incidence of chronic conditions and links between this and issues of health inequalities and access for Maori and Pacific peoples”, and was followed by a commitment from the Committee to “investigate the significance of chronic conditions in New Zealand and determine what changes needed to occur to better address the needs of people with chronic conditions” (National Health Committee, 2007, p. 6).

The NZPHD Act 2000, Section 13(2), requires the Committee to consult widely with high levels of engagement and participation from members of the public, and service providers and funders (Parliamentary Counsel Office - New Zealand Government, 2000). To this end, the Committee undertook initial meetings with stakeholders; held focus groups with people with long-term conditions; member checked through a draft discussion paper, further case studies and meetings with Maori and Pacific organisations and networks, before final submission of the document, *Meeting the needs of people with chronic conditions*, with its

**Textual context**
The document is available on the National Health Committee website\(^{18}\) under “publications, archived publications, NHC pre-2011 and *Meeting the needs of people with chronic conditions*”.\(^{19}\) Situated within a government department website provides weight to the document, legitimising it, its content and authors, and establishing the document’s claim to authority (Crowe, 2005). The online and hard copy of the document has been presented as a formal report containing acknowledgement/publishing page, preface from the Chair of the Committee, contents, executive summary, the report proper (split into: Meeting the needs of people with chronic conditions – Section One; and, National Health Committee case studies - Section Two), appendices, glossary, bibliography and references.

Throughout the document, the authors have utilised specifically New Zealand images such as toetoe\(^{20}\), Maori translations for major headings such as the title “*Hapai te whanau mo ake ake tonu*”, Maori proverbs with English translation, and findings from local New Zealand case studies with quotes from participants, to portray the document as inclusive of the opinions of and accessible to New Zealanders. Equally, the authors have given weight to the document through its presentation as a formal report and through incorporation of international research, as the primary intended audience was reported in the preface of the document as “the sector” (with further elaboration to include all health workers, primary health organisations, non-government and community providers, district health boards, etc.) and government departments and agencies.

\(^{18}\) Part of the Ministry of Health  
\(^{19}\) Documents are sorted by year and Meeting the needs of people with chronic conditions is located on page 2 of the NHC pre-2011 archived documents  
\(^{20}\) Toetoe was traditionally used to line inner walls, roofs and partitions of houses. The flowering stem, kakaho, was and is used in tukutuku panels as the vertical stakes of the panels (Auckland Museum, 1997; Landcare Research 2012).
This use of various “texts” within the document, are examples of what Fairclough refers to as intertextuality, the integration of external texts into a new text through the use of direct or indirect quotes thereby giving authority to the new document (Fairclough, 2003). The text also appears to endeavour to present “an openness to, acceptance of, recognition of difference; an exploration of difference”, but also “an attempt to resolve or overcome difference” and “a bracketing of difference, a focus on commonality, solidarity” through the incorporation of images and proverbs specifically drawn from Maori culture (Fairclough, 2003, pp. 41, 42).

Ko koe ki tena,
Ko ahu ki tenei
Kiwai o te kete

You hold that handle
And I’ll lift this handle
And together we can carry the kete (National Health Committee, 2007, p. 5).

The incorporation of images and Te Reo Maori within the document may also represent Fairclough’s discursive tendency of democratisation in that these are attempting to portray how Maori culture has “come to be accepted to some degree as compatible with discourse practices with which they have hitherto been seen as incompatible” (Fairclough, 1992, p. 202), that is white New Zealand European culture.

**Discourse practice level**

**Biomedicine and New Public Health**

Underlying the document, *Meeting the needs of people with chronic conditions*, is the discourse of new public health (NPH). NPH arises from western understanding of medicine and the genesis of NPH appears to be in response to challenges, problems and issues unable to be addressed by its parent,
biomedicine (Salmon & Hall, 2003). Simplistically, biomedicine\textsuperscript{21} is a way of understanding, diagnosing and treating illness and as such is reductionist because it considers biologic factors for causation of illness or disease over social, cultural and biographical explanations (Conrad, 2005; Dixon-Woods, 2001; Mehta, 2011; Nettleton & Gustafsson, 2002; Salmon & Hall, 2003). As understanding about causative factors of illness, diagnosis and treatment have developed and epidemiology of disease changed, new ways of addressing these issues were required (Baum, 2008), however, the solutions, packaged as NPH, were ones that remained firmly within the jurisdiction of biomedicine.

The term NPH appeared as early as 1916 and Baum suggests the history of public health for most industrialised countries is similar. This history can be summarised as the eras of indigenous control; colonisation (pre 1890’s); nation building (1890-1940); affluence, medicine and infrastructure (1950-1970); lifestyle and impact on health (1960-1980); new public health, influenced by WHO policies (Alma Ata and Ottawa Charter) (1980-1990) and global new public health (1990 – ) (Baum, 2008). Others contend the origins of NPH arise from the failure of industrialised nations to implement the WHO strategy - Health for All by 2000, key issues such as ageing populations, increased health service demand with less available funds, quality concerns and research and fresh thinking about improved performance and organisation of health systems (Baum, 2008; Gauld, 2009a; World Health Organisation, 1978). The Ottawa Charter is considered the foundation of NPH and the Charter managed to bring together the ideological and theoretical perspectives embedded within the individual (behavioural and lifestyle) versus system (social and economic)

\textsuperscript{21} Historically, Descartes idea of the body and mind being separate entities (Cartesian Dualism) challenged the then prevalent orthodox view of the mind body relationship of the human as a spiritual being, i.e., the body and soul as one entity allowing “doctors to dissect and manage the body without challenging the dominion of the church over the soul” (Mehta, 2011; Salmon & Hall, 2003, p1970). The acceptance of the Cartesian dualistic view of the body and mind led to reinterpretation and understanding of the body and the eventual rise of positivism and the scientific revolution (Mehta, 2011). It is through Cartesian Dualism and positivism that biomedicine has arisen.
approaches to health promotion (Baum, 2008; World Health Organisation, 1986).

Today NPH encompasses health promotion and education, social marketing, epidemiology, biostatistics, diagnostic screening, immunisation, community participation, healthy public policy, inter-sector collaboration, ecology, health advocacy and economics but still utilises “old” public health strategies of quarantine, isolation and sanitary inspection (Petersen & Lupton, 1996; Tulchinsky & Varavikova, 2010). Accordingly Meeting the needs of people with chronic conditions sets out the challenges of chronic disease through emphasising the economic and epidemiological impact of long-term conditions for people and the inter-sector collaboration required to “prevent and manage chronic conditions” (National Health Committee, 2007, pp. 1, 7, 9, 12, 39, 47, 49, 108). For example, the National Health Committee reference the World Health Organisation on the financial and social costs associated with long-term conditions and then go on to suggest these costs have an impact across every level of society through the

major financial and social costs associated with the rising incidence of chronic conditions (WHO 2003). These costs have implications for individuals with a chronic condition, family/whanau, carers, the health sector and society as a whole (National Health Committee, 2007, p. 9).

An example of NPH’s epidemiological thread is evidenced where the Committee notes a higher proportion of morbidity and mortality among Maori, Pacific Islanders and people on low incomes and to reinforce this, predicts prevalence rates for diabetes among Maori and Pacific Islanders for 2011.

Chronic conditions account for a higher proportion of illness and deaths among Maori, people on low incomes and Pacific peoples than among the general population. ... For example, by 2011, the prevalence of diabetes is predicted to increase by 148 percent among Pacific peoples and 132 percent among Maori (National Health Committee, 2007, p. 1).
Tenets of NPH are underscored by the Committee’s whole-of-government approach, it is a theme that runs throughout the document and was also drawn from submissions to the Committee.

_Tackling the burden of chronic conditions in New Zealand is not an issue for the health system alone. It requires a whole-of-government approach with a commitment from the health sector to work closely together as well as intersectorally with agencies such as the Ministry of Social Development and Housing New Zealand (National Health Committee, 2007, p. iii)._ 

NPH appears to be philosophically grounded in both socialist\(^{22}\) and neoliberal\(^{23}\) ideologies (Baum, 2008; Giddens, 1998; Petersen & Lupton, 1996) as the fundamental policy of NPH is based on “responsibility and accountability of national, regional and local governments for the health and well-being of society” but “also involves self care by the individual and the community” (Tulchinsky & Varavikova, 2010, p. 26). The document evidences these NPH ideologies of national and local government responsibility and accountability and individual and community self-care when it:

- discusses socially determined factors contributing to development of long-term conditions
  
  \[
  \text{many of the modifiable factors affecting whether people develop chronic conditions and how effectively they are managed lie outside the health sector, for example in housing, income, transport, local government, education and social services (National Health Committee, 2007);}
  \]
  
- includes discussion around community engagement through service delivery models aimed at minimising fragmentation of healthcare

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\(^{22}\) Socialism – group or state owned for the good of the group or country. Collectivism the opposite of individualism emphasises interdependence (key principle is paternalism – restricting liberty of individuals, without consent, where potential harm created by the individual, is prevented or some benefit is produced that the individual may not have obtained for themselves) (Baum, 2008; Giddens, 1998).

\(^{23}\) Neoliberalism – simplistically the market is self-regulating (not state owned) and the way to human progress is sustained economic growth (capitalism). Neoliberalism changes the perception of public and community good to individualism and individual responsibility. Individualism (key principle is autonomy – individual capacity to make free choices and control direction of own life) (Baum, 2008).
Chronic care models often refer to integrating policy at a community level, since this has the potential to minimise fragmentation of the health care system (National Health Committee, 2007, p. 49);

- incorporates findings from international research underscoring inclusion of input from family/whanau for practical and emotional well being

  shows the benefit for people with chronic conditions of having support from family/whanau for both practical assistance and wellbeing (National Health Committee, 2007, p. 48), and;

- concludes the document with one of the recommendations supporting a

  self-management approach of partnership between health professionals, patient, family/whanau and carers (National Health Committee, 2007, p. 76)

  shifting the onus of healthcare from the state to the health professional and the individual, their family or carer.

It is argued that NPH builds on the past lessons and history of public health to embrace a comprehensive range of social, economic and political activities with a commitment to community participation (Baum, 2008) and is a “contemporary application of a broad range of evidence-based scientific, technological, and management systems implementing measures to improve the health of individuals and populations” (Tulchinsky & Varavikova, 2010, p. 25). However, Petersen and Lupton suggest NPH is purely a moral enterprise involved in “prescriptions about how we should live our lives individually and collectively” (Petersen & Lupton, 1996, p. xii). In fact, they argue NPH is “a set of discourses focusing on bodies, and on the regulation of ways in which those bodies interact within particular arrangements of time and space” (Petersen & Lupton, 1996, pp. 11-12) and that these discourses endeavour to change individuals’ understanding so they become self-regulating (Dew, 2007). It is this focus by NPH on ‘the body’ that requires an exploration of what “the body” is and how it has become what Rose (1992) terms the “modern enterprising self”.

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The modern enterprising self
There are a number of ways to conceptualise “the body” and these arise from physiological, cultural, social constructs or a combination of these. Hippocratic Greek medicine understood the body as a dynamic, harmonious, balanced system and in Medieval times the body was believed to be a force that one could not fully control (Styhre, 2004). From a cultural perspective the body is viewed as a system of signs that carry meaning and symbolism thus conveying the culture, social equilibrium and order of a particular given period of time (Crawford, 1985; Douglas & Wildavsky, 1982; Turner, 1994). Another view sees the body as a social construction of power relations, evident in feminist and medical sociological works exploring social transformation of understanding about “the body” (Turner, 1994). The body may also be viewed as a subject for disciplinary actions (Styhre, 2004), or as a set of social practices, that is the body is socially constructed (Turner, 1994). This socially constructed body “has to be constantly produced, sustained and presented in everyday life, and that therefore the body is probably best regarded as a potentiality which is realised or crystallised through a variety of socially regulated practices” (Turner, 1994, p. 21). Thus the body is physically, culturally and socially constructed and as such is a “concrete, material, animate organization of flesh, organs, nerves and skeletal structure, which are given unity, cohesiveness, and form through the physical and social inscription of the body’s surface” (Grosz, 1995 as cited in Styhre, 2004, p. 104).

The body may also be understood as a target or channel of social disciplines. This view of the body has been influenced by critical theory and Foucault’s analysis of body disciplines and how power creates, shapes and utilises “human beings as subjects” (N. Rose, 1992, p. 144; Turner, 1994). The body is “increasingly seen as being based in its capacities, its ability to undertake various operations and actions, i.e. as a performing body” (Styhre, 2004, p. 104 emphasis in original) that is the body has become an unending project managed by the individual (Giddens, 1991; Petersen & Lupton, 1996). Meeting the needs of people with chronic conditions seems to underscore this “performing body”
when it suggests in its definition of self-management that people with chronic conditions need to have “greater control in looking after themselves” (National Health Committee, 2007, p. 26). Thus the body or the entrepreneurial self becomes the way of revealing the truth about the self and truth is achieved through either self-discipline or other ways such as surveillance and regulation (Turner, 1994).

**Risk, healthism, individual choice and moral duty**

The idea of risk has become one of the central characteristics of contemporary Western society (Beck, 1992; Douglas & Wildavsky, 1982; Giddens, 1991; Renn, 1992; Robertson, 2000). Risk can be defined as:

- the possibility of loss, damage, injury (harm) or death (peril or jeopardy) to something or someone;
- a source of danger created by something or suggested by someone (hazard);
- something that happens unpredictably without human intervention or observable cause (chance); and,
- as a venture – choosing to expose something or someone to a known hazard (Merriam-Webster, 2013).

The concept of risk can be understood from a variety of disciplines and conceptualised as an objective entity, a socially mediated construct or socially constructed (Zinn, 2008). Renn (1992) outlines seven different ways (actuarial, epidemiological, engineering, economic and psychological approaches plus social and cultural theories of risk) to conceptualise, define and assess risk. He suggests a definition of risk can be reached through analysis of three elements of undesirable outcomes, possibility of occurrence and the state of reality. Each of these approaches has different ways to measure uncertainty, define undesirable outcomes and reality and can be summarised as technical, economic, psychological, sociological and cultural perspectives of risk (Renn, 1992). All of these perspectives contribute to the knowledge, understanding and definition of risk in today’s society.
Contemporary neoliberal governance is underpinned by minimal state interference, market fundamentalism, risk management, individual responsibility and the resultant inevitability of inequality due to poor choice (Ericson, Barry, & Doyle, 2000; Galvin, 2002). Active management of choice lies at the heart of the discourse of risk (Ericson, et al., 2000) and through the lens of NPH, the discourse of risk can be viewed as either an environmental hazard, external to individuals who have little control over the risk or consequences of lifestyle choices and therefore able to be controlled by the individual through a change in behaviour (Lupton, 1993). Foucault’s work on the political relations of power can be used to explore how the subject, the “modern enterprising self” (the body), is positioned within and shaped by current neoliberal thinking and policy (N. Rose, 1992). This exploration employs two distinct but integrated political technologies, “disciplinary technologies” and “technologies of the self” operated by neoliberal governments in order to subtly “control” people (Galvin, 2002; N. Rose, 1992).

“Disciplinary technologies” or as Foucault termed it, “governmentality” frame “the complex of notions, calculations, strategies and tactics through which diverse authorities - political, military, economic, theological, medical, etc.” seek “to act upon the lives and conducts of each and all in order to avert evils and achieve such desirable states such as health, happiness, wealth and tranquillity” (N. Rose, 1992, p. 143). Risk from an environmental hazards perspective utilises a form of coercion that brings self-governing people into line with political objectives through the use of “disciplinary technologies” such as surveillance, evaluation and discipline via government programmes and construction of knowledge (Galvin, 2002; Hamann, 2009; Lupton, 1995; N. Rose, 1992). The Committee couch “active management” of risk amongst the rhetoric of “more proactive and coordinated health care to better meet the needs of people with chronic conditions” while at the same time incorporating quotes from the consultation period emphasising that “[c]oordinated health care for people with chronic conditions requires a fundamentally different approach”
because “[c]urrent models focus on managing the condition, not on helping the person to manage their life in spite of the condition. (NGO, NHC consultation)” subtly shifting management of healthcare to the individual (National Health Committee, 2007, p. 13).

“Governmentality” also incorporates the idea that the capabilities of individuals are a resource and therefore need to be harnessed, utilised, directed or “ruled” in some way (Hamann, 2009; N. Rose, 1992). The Committee appear to refer to this “resource” when they suggest “[m]any people self-manage to some degree” and then note “[h]owever, these people can be supported to be more effective” (National Health Committee, 2007, p. 27). These comments are then reinforced through incorporation of research literature supporting evidence for effectiveness of self-management, for improved health outcomes, and economic and health system efficiencies.

Self-management has been shown to:

- improve clinical outcomes: improve physical functioning, lead to fewer and less severe symptoms, slower progress of disease and fewer complications, improve health behaviours, improve patient satisfaction (Singh 2005; Kane et al 2005; Bodenheimer et al 2002b; Department of Health 2001)

From the lifestyle perspective of risk management evident in NPH discourse, individuals “engage in particular health practices as ‘self-care’ strategies for managing their perceived risk” (Robertson, 2000, p. 230). These personal health practices are what Foucault termed “technologies of the self” (Galvin, 2002). “Technologies of the self” are more imperceptible than the “disciplinary technologies” but impact the “modern enterprising self” so that s/he changes (often unknowingly) choices or desires so they align with current political
Evidence of “technologies of the self” within the document are subtly expressed through inclusion of community and self-management support strategies which appear to specifically target aligning individual choices with the current political agendas through statements such as

*Communities play an important role in bridging clinical care and everyday life. They can support a person’s health care through messages of prevention ... and promotion of positive attitudes to managing and living with chronic conditions* (National Health Committee, 2007, p. 21), and:

*People with chronic conditions and their family/whanau have a vital role in managing the condition(s). Family/whanau meet a wide range of practical and emotional needs for people with chronic conditions. When involved in care planning, family/whanau may also support behaviour and lifestyle changes* (National Health Committee, 2007, p. 23).

Crawford (1980) labelled “engagement with particular health practices” healthism, and suggested healthism was “the preoccupation with personal health as a primary – often the primary – focus for the definition and achievement of well-being; a goal which is to be attained primarily through the modification of life styles, with or without therapeutic help” (p. 368 emphasis in original). Healthism is a facet of what Crawford (1980) understood as the “new health consciousness” which focuses on holistic health, self-care and environmental and occupational health concerns (or risks).

Healthism and risk are linked because risk has now come to be understood as individual responsibility and healthism is embedded in a risk averse society that “produce[s] at risk individuals and behaviours. Healthism leaves people at risk” (Crawford, 1980, p. 385). Healthism “situates the problem of health and disease at the level of the individual” and therefore solutions to health problems “lie within the realm of individual choice” (Crawford, 1980, pp. 365, 368). This view “assumes human responsibility and that ‘something can be done’ to prevent misfortune [or ill health]” (Lupton, 1999, p. 3). The reduction of health
problems to individual responsibility and choice enables categorisation of individuals into “those at risk” and “those posing a risk” creating for the individual, an obligation to make a choice about how they will (or will not) mitigate or manage the real or perceived risk (Lupton, 1993). However it is argued if the individual ignores the risk, he or she places themselves “in danger of illness, disability, and disease, which removes them from a useful role in society and incurs costs upon the public purse” (Lupton, 1993, p. 429). Ultimately, for the individual this obligatory choice results in choice based upon a moral duty to do the “right thing” by and for themselves, their family and the wider society (Petersen & Lupton, 1996).

Definition of self-management
Sub-section 3.5 “Evidence for the use of self-management” (National Health Committee, 2007, pp. 26-31) puts forward a definition of self-management provided by the National Health Committee discussion document from 2005. The section also discusses principles of self-management, who self-management is for, self-management initiatives, evidence on self-management covering delivery, workforce, outcomes and effectiveness and gives examples of four self-management initiatives in New Zealand. The National Health Committee has defined self-management as:

people with chronic conditions having greater control in looking after themselves, with the support of their families/whanau (where desired), and in partnership with health professionals and community resources (National Health Committee, 2007, p. 26).

Scrutiny of the choice of language utilised by the Committee for their definition highlights a number of ambiguities and raises a few questions. The definition commences with a noun, the word “people” which may refer to humans in general, a collective group or be a politically correct way to refer to individuals without actually referring to them as individuals. This notion of “individuality” is followed up by the use of the word “themselves” reinforcing “individual-ness” as opposed to the collective group idea. The definition then uses the words “greater control” possibly suggesting people do not currently have enough control or that control needs to be shifted from somewhere (e.g. health system,
doctors, nurses, etc.) and “given” to the individual. This also raises the question of who has decided people do not currently have enough control. Connecting these two ideas of individual and control is the verb “having” (a present participle of “have”) meaning to possess or hold. Also of interest is the choice of words “chronic” and “conditions” used to delineate which “people” are being talked about. Use of the word condition is suggestive of “an attempt to create an umbrella term … inclusive of the different understandings of chronic ailments” in order to “link different audiences” and focus these on “the overarching issues related to chronicity” (Wellard, 2010, p. 3).

The second phrase “with the support of their families/whanau (where desired)” seems to indicate self-management should be an individual process and the individual will ask family for help as and when required as indicated by the bracketing of “where desired”. Health professionals and community resources are incorporated within the definition through the use of the word “partnership”. Partnership suggests some sort of relationship between individuals or groups characterised by mutual cooperation and responsibility for the achievement of a specific goal (Merriam-Webster, 2013). What the goal is, or how it is achieved and how “co-operation and responsibility” are negotiated is left to the reader’s imagination, understanding and discretion.

Stripped down, the definition provided by the National Health Committee seems to suggest that self-management is about individuals having control. Self-management defined thus, seems to shift the onus from the state to the individual, and implies knowledge of risk and therefore an obligatory choice about what to do about how to live one’s life responsibly and morally. As Galvin maintains

the belief we can freely select our ways of living is fundamental to the claim that illness results from behaviours associated with faulty lifestyle ‘choices’. It is in this way that chronic illness becomes defined as an instance of personal moral failure in contemporary times, for if we can choose to be healthy by acting in accordance with the lessons given us by epidemiology and
behavioural research, then surely we are culpable if we do become ill (Galvin, 2002, p. 119).

The document’s stated definition is therefore underpinned by the discourse of NPH incorporating individual choice, risk and moral duty.

The Flinders Chronic Condition Management Program™

Sociocultural level
The Flinders Chronic Condition Management Program™ (Flinders Program™), originally called the Flinders Model, is an Australian programme that originated from the South Australian HealthPlus Coordinated Care trials of 1997-1999. The trials were set up to test models of service delivery for Australian people with chronic illnesses (Battersby, et al., 2007; Hurley, Whitford, & Kalucy, 2000). The trials allowed for the creation and testing of an outcomes-based model, a fundamental shift in health service delivery for Australia (Battersby, et al., 2007). The lack of coordinated funding was seen as major issue because state and commonwealth governments funded different portions of the health system (hospitals and primary care respectively), creating financial and clinical barriers to appropriate services for people with long-term conditions requiring multiple services (Battersby, et al., 2007; Battersby & SA HealthPlus Team, 2005; Hurley, et al., 2000). A mid-trial review showed health benefits from coordinated care depended more on the “patient’s self-management capacity, not just the severity of his or her disease; that is, self-management capacity may provide a method of determining who requires coordinated care” (Battersby, et al., 2007, p. 58). It was this finding that gave rise to the development of the Flinders Program™ by the Flinders Human Behaviour and Health Research Unit, Flinders University, Adelaide, Australia (Flinders Human Behaviour & Health Research Unit, 2011).

The programme is based on cognitive behaviour therapy, motivational interview techniques and problem solving and is a care planning process designed for health professionals to assist in delivery of patient-centred care (Flinders Human
Behaviour & Health Research Unit, 2011). The programme provides the health professional with a “structured process that allows for assessment of self-management behaviours, collaborative identification of problems and goal setting leading to the development of individualised care plans” when working with individuals with long-term conditions (Flinders Human Behaviour & Health Research Unit, 2007, p. ii). The manual outlines six important principles for self-management:

1. Have knowledge of your condition,
2. Follow a treatment plan (care plan) agreed with by your health professionals,
3. Actively share in decision making with your health professionals,
4. Monitor and manage signs and symptoms of your condition,
5. Manage the impact of the condition on your physical, emotional, and social life, and
6. Adopt lifestyles that promote health

and uses self-assessment of self-management skills by the individual with the long-term condition and an interview, allowing the healthcare provider to assess the individual’s self-management skills and barriers (Regan-Smith, Hirschmann, Iobst, & Battersby, 2006, p. 60). From these two sets of self-management scores, discrepancies are discussed and agreed. Main life problems and goals are identified by the individual and these plus the self-management issues form the basis of the negotiated care plan (Flinders Human Behaviour & Health Research Unit, 2007; Regan-Smith, et al., 2006). Information about the Flinders Program™ is available on the Flinders University website. The Flinders Human Behaviour and Health Research Unit is part of the School of Medicine’s Department of Psychiatry in the Faculty of Health Sciences at Flinders University (Flinders University, 2011).

The introduction of the Flinders Program™ in New Zealand appears to be in response to the advent of Care Plus services in 2004 and the need for training of primary healthcare providers (particularly nurses) in the delivery of a changed model of primary healthcare (Henty & Dickinson, 2007; Horsburgh, et al., 2010; National Health Committee, 2007). Care Plus was a new initiative arising from
the Primary Health Care Strategy\textsuperscript{24} (Ministry of Health, 2001c) that provided additional funding to primary health organisations (PHOs) to enable provision of improved management and care of people with long-term conditions or terminal illnesses (Henty & Dickinson, 2007; McKinlay, 2007; Ministry of Health, 2011b). The extra funding allowed primary healthcare nurses to take on new extended roles, such as nurse led consultations, in the management and monitoring of people with long-term conditions (Eggleton & Kenealy, 2009; J. Hill, 2010; McKinlay, 2007).

Use of the Flinders model and programme requires practitioners to undertake training with attainment of a Certificate of Competence in Chronic Condition Self-Management from Flinders University (Flinders Human Behaviour & Health Research Unit, 2007; Horsburgh, et al., 2010). For New Zealand nurses, the Flinders Certificate is embedded into three New Zealand university postgraduate primary healthcare and long-term condition management nursing programmes (Horsburgh, et al., 2010). As part of these courses, the nurse participates in a Flinders workshop led by a certified trainer. Successful completion of the workshop training and “three care plans with clients using the Flinders Program™” enables the nurse to be awarded a “certificate of competence” and licenses the nurse to use the Flinders Program™ (Flinders Human Behaviour & Health Research Unit, 2007, p. ii).

\textit{Textual level}

The programme’s claim to authority is evidenced through association with a university research unit, genesis in government funded quantitative research and its evident link with psychology, the scientific study of the human mind functions and behaviour. This is reinforced in the presentation of the manual, provided to those who have undertaken the Flinders course, in a white ring

\textsuperscript{24} Care Plus was the “brain child” of the Independent Practitioners Association Council (IPAC) to improve access to services for people who might have been disadvantaged by the establishment of the PHO funding formula (Eggleton & Kenealy, 2009).
binder with the sub-title “Flinders University, Flinders Human Behaviour & Health Research Unit” and main title “Flinders Model, chronic conditions self-management education and training manual”. Overlaid on the chequerboard, in the bottom right corner is the Flinders University crest25 (Flinders University, n.d.).

Reinforcement of authority continues on the inside of the manual with further use of the university name and the unit that produced the manual, university crest, followed by the title of the manual, developers of the manual, acknowledgements and contact details. Background to the model and information on certificate of competence, trainer accreditation and postgraduate study, licensing and use of the model, how to use the manual and learning objectives follows with the manual then segmented into five parts; theory and evidence, overheads for workshop sessions, practical worksheets, master copies of forms and other (containing The Partners in Health Handbook and information on motivational interviewing, role plays and structured problem solving). The manual’s process for claiming authority is further underscored through the use of intertextuality - direct and indirect quotes and graphics drawn from academic and research texts and incorporated into various sections of the manual along with presentation of practical worksheets and checklists for using the Flinders Program™ tools (Fairclough, 2003). It has also been adapted for use in New Zealand with the integration of New Zealand specific statistics drawn from the National Health Committee document, Meeting the needs of people with chronic conditions evidencing Fairclough’s strategy of intertextuality (Fairclough, 2003).

25 The university was established in 1966 and is named for Matthew Flinders, a 19th century English navigator, explorer and surveyor. The crest has a drawing of Flinder’s fully rigged ship, the Investigator, sitting on Flinders blues and white and below this on a dark blue shield, a drawing of an open book, representative of Flinders’ book “A voyage to Terra Australia” and a radiant sun at the base of the dark blue shield (Flinders University, n.d.).
Discourse practice level
Underlying the Flinders Program™ is the discourse of NPH and its parent, biomedicine. From these stem medicalisation, the consumer and managerial discourses. The manual itself evidences NPH discourse through the inclusion of statements such as “WHO identify chronic conditions as major health impact 2002-2003” when providing the history of the Flinders Program™ and through epidemiological and economic statistics drawn from the National Health Committee document (Flinders Human Behaviour & Health Research Unit, 2007, p. 3) (Appendix 20 evidences selection of slides from manual). The manual also discusses factors that may facilitate self-management. Through the use of intertextuality, the text incorporates the Ottawa Charter by stating “self-management programs primarily focus on developing personal skills, but consideration should be given to other areas that are highlighted by the Ottawa Charter” such as “development of healthy public policy; creation of supportive environments; strengthening community action, and reorientation of health services” (Flinders Human Behaviour & Health Research Unit, 2007, p. 10). Further evidence of NPH discourse is shown through the health promotion and educational focus of the manual presented within the learning objectives which outline the competencies the health professional undertaking the course can expect to achieve (see Appendix 21 for learning objectives).

Medicalisation and the consumer
Discourses of biomedicine, NPH and medicalisation provide context for the origin of consumerist and managerial discourses embedded in this text. Medicalisation is described as a process that occurs when previously non-medical issues become defined and treated as medical problems, illnesses or disorders (Conrad, 2007; Conrad & Leiter, 2004; Crawford, 1980). Solutions to these “new” problems, illnesses and disorders are found in advancing technology (i.e., pharmaceuticals and machines) (Netleton & Gustafsson, 2002) and it is these solutions that have facilitated the expansion of the responsibility of medicine and public health or medicalisation of what were previously non-

26 Refer to earlier discussion regarding biomedicine and NPH – pages 112-116
medical issues (Conrad, 2007; Crawford, 1980; Salmon & Hall, 2003; Tulchinsky & Varavikova, 2010). This shift in definition from a non-medical issue to a medical issue is argued to have been driven by decline of religious power, contraction and expansion of medical authority, change in health policy from access to cost control, the increasing power of social movements, influence of pharmaceutical and biotechnology companies, rise of the internet and direct to consumer advertising (Conrad, 2007). However, a consequence of medicalisation becomes the individualisation of issues that are effectively social problems and the obfuscation of “social forces that influence well-being” (Conrad, 2007, p. 152). Development of new medical markets facilitate medicalisation and the key to markets is existence of a medical product and consumer demand (Conrad & Leiter, 2004). It could be argued genesis of the Flinders Program™ would sit nicely within medicalisation of chronic illnesses and the resultant “change in health policy from access to cost control” for the Australian healthcare system and for New Zealand. Introduction of the Flinders Program™ can be linked with the shift in focus of chronic illness care from tertiary to primary care and with healthcare cost containment issues.

Salmon and Hall (2003, p. 1970) assert “new discourses of the person do not displace previous ones, but coexist and combine with them.” Thus, as Boote, Telford and Cooper (2002) contend, there are a number of different ways to conceptualise the “person” in relation to healthcare. They may be a consumer, a healthcare recipient, a patient, a service user, citizen, user, lay person, client, patient as agent, customer or modern enterprising self, etc., depending on who is describing the person, their agenda, the organisation using the term or the underlying philosophical beliefs (Boote, et al., 2002). The Flinders Program™ variously refers to individuals living with long-term conditions as “patients and persons” but in the main as “clients”27 suggestive of a customer who probably is dependent on, and a high user of, the services of a local doctor and or hospital.

27 Merriam-Webster (2011) define “client” as “one that is under the protection of another, dependent; a person who engages the professional advice or services of another; a customer; and, a person served by or utilising the services of a social agency”.

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Evidence of use of the term client within the manual starts early on in the slide presentation for healthcare professionals, for example:

*How does your current management of chronic conditions support clients to self-manage?*

*What does client/patient/person centred mean?*

and is continued through into the Partners in Health Scale where the “client” and the health professional both fill out the scale and then compare their ratings and any discrepancies in these as a basis for creating a plan of care

*Compares client and health professional ratings (Flinders Human Behaviour & Health Research Unit, 2007, pp. 1, 11, 16).*

Consumerism is argued to be a “political discourse which privileges a particular reading of power” and is “exercised by all of us when we make decisions concerning the consumption of goods and services, from washing machines to health care” (Crinson, 1998, p. 229). The idea of a consumer in healthcare has arisen from an “emphasis on market ideology … that recipients of health services (as consumers) deserved the same level of choice, value-for-money and satisfaction as consumers in more business-focused transactions” (Boote, et al., 2002, p. 222; Crinson, 1998). Underfunding of healthcare systems by governments, increasingly forces those who can afford it into the “market” to meet their personal healthcare requirements under the guise of “choice” and hidden in notions of “personal responsibility and moral duty” (Crinson, 1998; Ericson, et al., 2000). The Flinders Program™ underscores the consumerist discourse through suggesting it is the responsibility of the person living with a long-term condition to self-manage on a slide titled “Self-management: Who’s responsible?” followed by further slides discussing definition of a “good self-manager”, principles of self-management, benefits of self-management and characteristics of successful self-management support. Of these eleven slides, six relate to the person, two relate to successful self-management support and one each for who is responsible, summary of benefits and what self-management
is not (see Appendix 22 for slides). It is argued the consumerist discourse encourages

individualistic understandings of poverty [health] by promoting the view that the unemployed [chronically ill or those with long-term conditions] simply lack motivation and self-discipline. It encourages a distinction between an unmotivated, ‘undeserving poor [ill]’ who lack initiative and an entrepreneurial deserving poor [ill] who are willing to subject themselves to the most oppressive working conditions [health systems] yet have little freedom in the market (Ziguras, 2004, p. 139).

In fact, Ziguras (2004) contends individuals who have “shown an inability to discipline themselves in order to participate in the consumer society are subjected to … training courses, case-managers and seminars designed to inculcate them with the self-direction required in the workforce” (p. 139). The same sentiments could be expressed about healthcare. Introduction of the consumerist discourse into health has also given rise to managers who were required to make decisions around “the level of consumer health demands and providing the resources to then meet this need” (Crinson, 1998, p. 231).

**New Public Health and management**

What a manager is varies and is dependent on the historically, socially and culturally situated understanding of the “activity of management and the associated techniques and practices that bestow upon these a material reality” (du Gay, Salaman, & Rees, 1996, p. 265). The discourse of management is said to originate from late in the industrial revolution when industry required more capital to expand and owner-operated firms became companies with the introduction of shares and shareholders (Darcy, 2002). These new shareholders employed skilled people to run the businesses and deal with staff and technology on their behalf, thus creating a new profession of management that implied a “role of making decisions on behalf of someone else” (Darcy, 2002, p. 32).

Within a neoliberal governmentality, the discourse of management positions the manager as entrepreneurial and as such the manager is “charged with ‘leading’ their subordinates to ‘self-realization’ by encouraging them to make a project of
themselves” (du Gay, et al., 1996, p. 271). The role of management consequently becomes one of empowerment — providing workers with the information, training, authority and accountability to excel ... As workers take on more management tasks, managers must take on more leadership tasks - holding a vision of the business, articulating it to workers and customers, and creating an environment that truly empowers workers (Champy, 1994 as cited in du Gay, et al., 1996, p. 271).

These same attitudes appear to have been applied to self-management programmes such as the *Flinders Program™* and the manual certainly underscores the role of the nurse as manager through the training provided to nurses and set up of the programme used by nurses to motivate individuals living with long-term conditions to identify problems, identify and set goals and contribute to an agreed care plan for self-management. In fact the whole manual is geared toward the health professional learning to guide a “client” toward a negotiated self-management care plan as evidenced in this quote about motivational interviewing

*is person-centred, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence (and procrastination)* (Flinders Human Behaviour & Health Research Unit, 2007, p. 38).

The competency of the manager to empower workers to excel and sustain and build a successful business influences the financial return to the shareholders on their investment in the company (du Gay, et al., 1996). Consequently a company comes to depend on the ability and charisma of its managers and it is this dependency which has given rise to the development of management competences (du Gay, et al., 1996). This idea of competency goes hand in hand with assessment and audit to ensure continuation of profit to shareholders is maintained and improved (du Gay, et al., 1996). The idea of the nurse as manager is reinforced in New Zealand through The Nursing Council of New Zealand, the regulatory authority responsible for registration of nurses and monitoring of on-going competency of registered nurses (Nursing Council of
New Zealand, 2008c) and the Health Practitioners Competence Assurance Act 2003 which outlines the Council role and responsibility (Parliamentary Counsel Office - New Zealand Government, 2003). Ultimately, the Council’s main role is to protect public safety.

**Definition of self-management**
The manual outlines a number of definitions for self-management drawn from the literature and identifies issues raised in the literature. It then synthesises these together to provide a comprehensive definition of self-management suggesting self-management

> involves the individual with the chronic condition working in partnership with their carers and health professionals so that they can:
> 1. Know their condition and various treatment options;
> 2. Negotiate a plan of care i.e. care plan, and review/monitor the plan;
> 3. Engage in activities that protect and promote health;
> 4. Monitor and manage the symptoms and signs of the condition; and
> 5. Manage the impact of the condition on physical functioning, emotions and interpersonal relationships (Flinders Human Behaviour & Health Research Unit, 2007, p. 4).

Fairclough (2003) suggests “meaning relations” are evident “between sentences and between clauses (or ‘simple sentences’) within sentences” (p. 87). The definition starts with the transitive verb “involves” meaning to “engage as a participant”, “oblige to take part”, “occupy oneself absorbingly” or “commit oneself emotionally” (Merriam-Webster, 2013). This is then linked with “the individual”, identifying who is involved, followed by an adjectival prepositional phrase, “with the chronic condition”, identifying which individuals are being discussed\(^ {28}\). A noun, “working”, meaning “the action of doing work” is then

\(^{28}\) Again the appearance of the words “chronic” and “conditions” is suggestive of “an attempt to create an umbrella term … inclusive of the different understandings of chronic ailments” in order to “link different audiences” and focus these on “the overarching issues related to chronicity” (Wellard, 2010).
used (along with adverbial and adjectival prepositional phrases (*in partnership* and *with their carers and health professionals*)) and a coordinating conjunction “so” in order to get to the list of actions or work to be undertaken by “they” as recommended by the reviewed literature. The pronoun “they” usually refers to two or more people or things previously mentioned or identified. However, use of the word “they” in this definition is somewhat vague and could be understood as referring to only the individual or to encompass the individual, carer and health professionals. The relationship indicated through use of the word “partnership” between the individual, carers and health professionals has at least clearly defined goals as listed in numbers 1-5 within the definition, however negotiating mutual cooperation and responsibility may not be an easy task for any of the parties involved.

The use of “so that” within the definition indicates a semantic causal relation of purpose which foregrounds legitimation (Fairclough, 2003). Legitimation, in this instance, is for the purpose of steps 1-5 and the rest of the manual and suggests a strategy of rationality, that of behaving in a goal directed way (Fairclough, 2003). The reasons and purposes underlying the manual “evoke value systems which are taken for granted and constitute the ‘generalized’ motives … which are now widely used ‘to ensure mass loyalty’” (Fairclough, 2003, p. 99). The values drawn on relate to the moral obligation of the individual to self-manage a long-term condition and the legal obligations of healthcare professionals.

Pulling apart this definition reveals self-management could be understood as work and tasks an individual is said to need to undertake (according the literature) in order to effectively self-manage a long-term condition/s or self-management may be work that is undertaken by the individual, carers and health professionals. Self-management, then, has become an obligation, an emotionally absorbing occupation undertaken so that the individual (and carer

29 Partnership suggests a relationship between individuals or groups characterised by mutual cooperation and responsibility for the achievement of a specific goal (Merriam-Webster, 2011).
and health professional) can know, negotiate, engage, monitor and manage a long-term condition/s. The manual’s definition of self-management particularly reinforces the discourses of:

-NPH, through an individual having knowledge of their condition and treatment options;
-NPH and management, through an individual having a negotiated, reviewed and monitored self-management plan, by an individual personally monitoring and managing the physical signs and symptoms and impact of the long-term condition on physical functioning, emotions and interpersonal relationships; and,
-NPH and individual responsibility, through the individual engaging in activities to promote and protect health (which may also include monitoring of physical signs and symptoms).

At a deeper level of discourse analysis, both the National Health Committee and the Flinders Program™ documents evidence a process of convergence whereby the tendencies of commodification and democratisation seem to unite to “affect the constitution of subjectivity or “selfhood” by discourse, in the context of shifts that have been documented in the social constitution of the self in contemporary society. These shifts are towards a more autonomous, self-motivating self” (Fairclough, 1992, p. 219).

Whanau Ora: Report of the Taskforce on Whanau-Centred Initiatives

Sociocultural level
The genesis of the Whanau Ora document appears to have arisen from a supply and confidence agreement between the National and Maori Parties in 2008. This agreement occurred after Maori Party members won four of the Maori seats and the Key led National Party invited the Maori Party (along with other support parties) to form a government based on a Relationship of Confidence and
Supply (The National Party and Maori Party, 2008). Prior to this, the concept of Whanau Ora was a policy priority of the Maori Party outlined in He Aha te Mea Nui (What is the most important thing?) (The Maori Party, 2011b) and was evident within He Korowai Oranga; Maori Health Strategy (Ministry of Health, 2002) and embedded in Te Ao Maori (University of Otago, 2010), and the Treaty of Waitangi. The confidence and supply agreement led to the National Party agreeing to adopt and implement a number of policies being advanced by the Maori Party. From this, Cabinet approved the establishment of the Whanau Ora Taskforce in 2009 (Ministry of Social Development, n.d-b).

The six member Taskforce was charged with developing “a policy framework for a new method of government interaction with Maori service providers to meet the social service needs of whanau” (Turia, 2009). The particular purpose of the Taskforce was to “construct an evidence-based framework” that would lead to strengthening and enhancing whanau capabilities and wellbeing, broadening government and community relationships beyond contractual obligations and improve cost effectiveness and value for money (Turia, 2009).

The Maori Party entered into a further Confidence and Supply agreement with the National Party in 2011(The National Party and Maori Party, 2011), and has

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30 This was the first time a political party represented Maori people in government. Up until this point, individuals who identified as Maori worked within political parties such as National, Labour, Greens, New Zealand First etc., but were bound by those party mandates and could not easily advance a Maori way of thinking or Maori aspirations within those parties.

31 “Whanau-ora: restoring the essence of who we are; putting the vibrant traditions from our people at the heart of our whanau [extended family] (The Maori Party, 2011b, p 2). Whanau has been interpreted by the Taskforce as “a multigenerational collective made up of many households that are supported and strengthened by a wider network of relatives” (Ministry of Social Development, 2010, p 13).

32 The Maori world view comprised of three key facets, Te Reo (the language), Tikanga (protocols and customs) and Te Tiriti o Waitangi (The Treaty of Waitangi) (University of Otago, 2010).

33 Taskforce comprised of: Professor Mason Durie (Chair), Rob Cooper, Suzanne Snively, Di Grennell, Nancy Tuaine and Linda Grennell (with expertise in Maori wellbeing, social policy, research, government function, funding models, governance, health issues, family violence prevention, social services and welfare of women and children).
further advanced Whanau Ora through establishment of Whanau Ora within Te Puni Korkiri with its own minister (Tariana Turia), obtaining funding in the 2010, 2011 Budgets ($134m over four years and a further $30m), establishment of a governance group to support the implementation of Whanau Ora across government agencies and key stakeholders, establishment of Whanau Ora providers and securement of further funding ($6.6m) to enable providers to implement plans for overcoming the challenges in their areas (Te Puni Korkiri, 2011; The Maori Party, 2010, 2011a).

**Textual level**

To develop the framework and create the report, the Taskforce undertook twenty two hui around New Zealand, received over 100 written submissions from individuals and organisations, reviewed relevant literature and tapped into the experiences of health and social service agencies within New Zealand (Ministry of Social Development, 2010). In April 2010, the Taskforce reported back to Honorary Ms Turia, the then Minister for the Community and Voluntary Sector. The Taskforce report is located on the Ministry of Social Development website under “about us and our work, work programmes, initiatives, the Taskforce for Whanau-centred initiatives” (Ministry of Social Development, n.d-a). The web page provides background to the establishment of the Taskforce, the Taskforce members and a summary of the process undertaken by the Taskforce to produce the report. Links are provided to the report itself, frequently asked questions about the report, the Taskforce and its work, the Taskforce terms of reference and media releases from 2010 regarding Whanau-Ora. Situated within a government department website provides weight to the document but also the background states that Cabinet “approved” the establishment of the Taskforce, which as Crowe (2005) suggests, legitimises the document, contents and authors and establishes the document’s claim to authority.

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34 Te Puni Korkiri (the Ministry for Maori Development) is the only New Zealand Government department solely focused on realising Maori potential
35 A New Zealand Government department that aims to help “build successful individuals, and in turn build strong, healthy families and communities” (Ministry of Social Development. n.d-a).
To convey meaning, the report utilises graphics such as a full colour photograph of an unfurling koru (ponga or silver fern), the use of which could be interpreted through the discursive tendency of commodification. Fairclough argues the commodification process may use graphics as well as or instead of vocabulary. If the genre of graphics are used and done well the graphic may be “an effective way of making information available at a glance” and the visual may “project an enticing image for the ‘product’” (Fairclough, 1992, p. 211). If the image works it can “instantaneously create a world which potential consumer, producer and product can jointly inhabit, before a reader gets to read (or a viewer to hear) the language of the advertisement” (Fairclough, 1992, p. 211). The koru “conveys the idea of perpetual movement, and its inward coil suggests a return to the point of origin” (Royal, 2009a) and, for Maori, may capture a world where Maori aspirations are realised or be evocative of a return to guiding principles, values and traditions as a way forward for Maori.

The document also employs intertextuality, particularly assumption, that is implications of “what is ‘said’ in a text is ‘said’ against a background of what is ‘unsaid’, but taken as given” (Fairclough, 2003, p. 40). Although the document appears to have been formatted as a formal report, a waiata36 (Te Taura Whiri I Te Reo Maori, n.d) precedes the forward from the Taskforce. The waiata introduces a cultural element situating the document within a Maori world view. In doing so the authors have connected this “text” with other Maori “texts” and asserted their claims that “what is assumed has indeed been said or written elsewhere, that indeed one’s interlocutors [one who takes part in dialogue or conversation] have indeed heard or read it elsewhere” (Fairclough, 2003, p. 40). The remainder of the document contains contents page; a forward from the Taskforce; an executive summary; background; appendices and eight numbered

36 The waiata, composed by Te Inupo Farrar was used at many of the hui the Taskforce held. Waiata – a song, with poetic interpretation, but more specifically a chant, traditional in style, sung in unison and unaccompanied by musical instruments (Te Taura Whiri I Te Reo Maori. n.d; S. Pitama, personal communication, July 27, 2012).
sections (covering whanau context, principles, foundations and measures; whanau centred initiatives – perspectives and aspirations; case studies; whanau centred initiatives – the main goals; whanau services – key operational elements; and, implementation), however the document does not include references, reference page or a publishing information page.

As the report’s intended audience was Tariana Turia, the report seems to presume some common ground and understanding of Te Reo; therefore difference and dialogicality (Fairclough, 2003) have been reduced negating the need to translate or explain the waiata. Additionally, Maori is an official language of New Zealand (Milne, 2005) and it could be argued that although “assumption” has been utilised as a textual tool on the part of the authors, equally what is being highlighted here is “social difference” and “universality” (Fairclough, 2003) because Maori language, and to a lesser degree Maori world views, have become more prominent and integrated into mainstream in New Zealand culture and policy.

The presentation of voices of participants who participated in the process is also interesting. Their statements both written and oral are placed to the side of the text in the margin and are not integrated in the traditional way quotes are integrated and used to highlight or reinforce the points the report is making. This presentation of participant voices along with the lack of references, reference page or a publishing information page could be described as a strategy of the discursive tendency of democratisation, whereby the way they have been included (or not included) signals “a tendency towards informality of language” within the report itself (Fairclough, 1992, p. 201).

**Discourse practice level**

*New Public Health*

There appear to be two major discourses embedded within the *Whanau Ora* document – those of NPH and Kaupapa Maori. The document discusses how the
framework the Taskforce were charged with constructing, is based on “whanau aspirational aims consistent with the Whanau Ora philosophy” but asserts the framework is “especially concerned with social, economic, cultural and collective benefits” (Ministry of Social Development, 2010, p. 7). The report notes

*much of the focus during the consultation process was on social gains, the aspirational aims are premised on a balance between social gains (such as health, education and societal inclusion), economic gains (such as an expanding asset base), cultural gains (including participation in te ao Maori), and collective gains*

evidencing the mix of Kaupapa and NPH socialist discourses (Ministry of Social Development, 2010, p. 7). This mix of discourses, plus neoliberal ideology is further evidenced in the outcome goals identified by the Taskforce that the report suggests should underpin any future whanau-centred initiatives. The Taskforce suggest “the goals will be met when whanau are self-managing, living healthy lifestyles, participating fully in society, confidently participating in te ao Maori, economically secure and successfully involved in wealth creation and cohesive, resilient and nurturing” (Ministry of Social Development, 2010, p. 7). It is reference to “self-managing, living healthy lifestyles, participating fully in society and economically secure and successfully involved in wealth creation” that are suggestive of NPH ideology and discourses of the modern enterprising self, risk, healthism, individual choice and moral duty. Other links to NPH discourse are shown through inclusion of epidemiological trends on Maori birth (Maori fertility rates remain above replacement (around 2.4)), median age (22 years), ageing (increased life expectancy, 70.4 years males and 75.1 years females) and the mobility of the Maori population both nationally and internationally (Ministry of Social Development, 2010, p. 13).

*Kaupapa Maori*

The goals of “confidently participating in te ao Maori and cohesive, resilient and nurturing” appear to link to the discourse of Kaupapa Maori and the Taskforce acknowledge “a Maori cultural context ranks alongside social and economic
factors as a determinant of whanau wellbeing” (Ministry of Social Development, 2010, p. 17). The document incorporates statements by participants from the engagement process to underscore importance of Kaupapa Maori such as

*culture is at the centre of wellbeing to Maori – it is about caring, sharing, and looking after each other*

*Ae, I support the kaupapa, the korero and the whakaaro behind Whanau Ora, and;*

*Whanau Ora brings our whanau back into the collective. Back to simplicity and the amazing models from our tupuna (Ministry of Social Development, 2010, pp. 16, 28, 35).*

The term, Kaupapa Maori, is understood to differentiate Maori values, principles etc., from those held by non-Maori (Pihama, 2001; G. Smith, 2003). The word “kaupapa” has been defined by the online Maori dictionary as a noun meaning

1. “a topic, policy, matter for discussion, plan, scheme, proposal, agenda, subject, programme, theme and
2. level surface, floor, stage, platform, layer” (Te Whanake - Maori language online, 2012).

However, kaupapa has more depth of meaning than is evident within the English translation of this dictionary definition and is closely tied with other Maori words - tikanga, whakapapa, turangawaewae, maori and the importance of Papatuanuku – the land (Royal, 2000, 2009b, 2009c, 2009d, n.d.).

Kaupapa stems from two Maori words “kau” meaning “to appear for the first time, to come into view, to disclose” and “papa” meaning “ground or

37 Tikanga – ethical behaviour; solid, secure, dependable behaviours that others will wish to adhere.
38 Whakapapa – popularly, genealogy; literally to create a base or foundation.
39 Turangawaewae – popularly “a place to stand”; literally, turanga (standing place), waewae (feet). “Turangawaewae are places where Maori feel especially empowered and connected. They are our foundation, our place in the world, our home”.
40 The word “maori” has a number of meanings. Today “Maori” is used as an ethnic and cultural category. Historically, “maori” is understood to mean “pure” and “natural” (waimaori – pure and fresh water) and conveys ideas of clarity, transparency and cleansing or as in whakamaori – “to make clear” - explain. The word “maori” may also mean “mortal”.
41 Earth mother (Te Ahukaramu Charles Royal. 2009. Papatuanuku – the land – Papatuanuku – the earth mother.)
foundations” and it conceptually equates to the English “principles or values” (Marsden & Henare, 1992; Pihama, Cram, & Walker, 2002; Royal, 2000).

Marsden describes kaupapa as a process whereby “Maori when contemplating some important project, action or situation that needs to be addressed and resolved the tribe in council would debate the kaupapa, - the rules and principles by which they should be guided” (Marsden & Henare, 1992, p. 14). One of the participant statements reinforces the importance to Maori of guiding principles through stating

it [the framework] should not be a structure that oppresses, it has to be underpinned by principles (Ministry of Social Development, 2010, p. 22).

Kaupapa are the “process of holding firmly to one’s fundamental foundations” (Pihama, 2001, p. 78) and the base from which Te Ao, the Maori world, may be considered (Pihama, et al., 2002). Kaupapa Maori explains the body of knowledge obtained from the experience of Maori people, past and present, and generated via an oral tradition. It is a collective wisdom. Kaupapa Maori is the “systematic organisation of beliefs, experiences, understandings and interpretations of the interactions of Maori people upon Maori people, and Maori people upon their world” (Nepe, 1991, as cited in, Pihama, 2001, p. 77).

Central to Kaupapa Maori are Te Reo (the language) and the principles of:

Tino Rangatiratanga – the principle of self-determination;
Taonga Tuku Iho – the principle of cultural aspiration and identity;
Ako Maori – the principle of culturally preferred pedagogy;
Kia piki ake i nga raruraru o te kianga – the principle of socio-economic mediation;
Whanau - the principle of extended family structure;
Kaupapa – the principle of collective philosophy;
Te Tiriti o Waitangi – the principle of the Treaty of Waitangi; and,

Kaupapa Maori, in a broad way, means “plan of action created by Maori, expressing Maori aspirations and expressing certain Maori values and
principles” and may also represent “values and action plans which express a set of deeper cultural values and worldview” (Royal, n.d.). The Taskforce have utilised the process of kaupapa to develop principles to guide and support Whanau Ora and delivery of whanau-centred services (see Appendix 23 for diagram of underpinning principles).

**Definition of self-management**

Section 6.2.3 of the document outlines the Taskforce understanding of whanau self-management and is reproduced in Table 4-1. This excerpt outlines one of the six major whanau goals identified by the Taskforce and specifically discusses self-management. Evidenced across this text excerpt are what Fairclough (2003) refers to as higher-level semantic relations or the “problem-solution” relation. The initial sentence stating whanau well-being as dependent on capacity to manage affairs and determine own pathways, is followed up in 6.2.4 and 6.2.5 with a list of issues that impact on that capacity (the problem). However, this can be contrasted with other statements within this text that seem to offer the “solution” when stating that whanau have capability inherently within their networks, leadership, knowledge and asset base. It appears the authors are setting out the argument that whanau just need to be allowed to get on with self-management and that Whanau Ora is the vehicle for this.
6.2.3 Whanau wellbeing is largely dependent on the capacity of whanau to determine their own pathways and manage their own affairs. Most whanau are already self-managing insofar as they make their own decisions, care for their own people and supply their own needs. They are knowledgeable about their own communities, can access those goods and services necessary for ongoing development, are active participants in a range of networks and have patterns of leadership that provide continuity between the past and the future. Self-managing whanau are able to draw on the skills of their own members in order to advance their collective interests. The assets they hold in common are well managed in accordance with their own traditions. Importantly also, self-management is underpinned by a set of cultural values and traditions that not only include a link to hapu, iwi and Maori communities but also to values such as generosity, sharing, cooperation and mutuality.

6.2.4 A whanau capacity for self-management may be diminished by illness, lack of information, separation from other whanau households, dysfunctional intra-whanau relationships, financial insecurity, inadequate resources either within the whanau or within wider communities, and an absence of leadership.

6.2.5 Effective Whanau Ora services will support and strengthen the leadership in whanau. Sometimes self-management can be undermined by well-meaning agencies that assume leadership roles but without ensuring that whanau leadership is developed to the point that self-management becomes possible. Often whanau leadership is dismissed – sometimes because it is not visible to helping agencies, or presents a threat to them, or because leadership is frequently matriarchal and not necessarily linked to perceived status or obvious power.

It is also evident that:

1. the authors have made a number of existential assumptions (what exists) (Fairclough, 2003) about whanau self-management
   a. it exists - evidenced through the use of the word “already” but quantified through the use of the adjective “most”.

   *most whanau are already self-managing*

   b. it is a group process - revealed through the use of the third person, plural, subjective pronoun “they” and the use of the
pronoun “their” indicating possession, when discussing how whanau already care for themself

\[
\text{they make their own decisions, care for their own people and supply their own needs}
\]

c. it is achievable, that is whanau have capability, leadership, knowledge, skills and assets

\[
\text{they are knowledgeable about their own communities, can access those goods and services necessary for ongoing development, are active participants in a range of networks and have patterns of leadership that provide continuity between the past and the future. Self-managing whanau are able to draw on the skills of their own members in order to advance their collective interests. The assets they hold in common are well managed in accordance with their own traditions}
\]

d. it links the “past and the future” through cultural traditions and links the wider whanau to hapu, iwi and other Maori communities

\[
\text{self-management is underpinned by a set of cultural values and traditions that not only include a link to hapu, iwi and Maori communities}
\]

2. the authors have also made a value assumption (what is good or desirable) (Fairclough, 2003) about whanau self-management because whanau self-management has a sound basis for relevance to Maori through its roots in Maori cultural values, principles and traditions

\[
\text{self-management is underpinned by a set of cultural values and traditions that not only include a link to hapu, iwi and Maori communities but also to values such as generosity, sharing, cooperation and mutuality.}
\]

From this analysis, self-management could be understood as a collective, inclusive and valuable plan or framework for moving forward, linked to the past and future and embedded in Maori culture, values, principles, traditions and world view reflecting perfectly the underlying discourse of kaupapa Maori.
Conclusion
The critical discourse analysis of the National Health Committee, Meeting the needs of people with chronic conditions, the Flinders Program™ and Whanau Ora documents revealed two underlying discourses, those of NPH and Kaupapa Maori, with NPH the dominant discourse across all documents. NPH was shown to be a discourse that has silently permeated and invaded people’s lives through its broad focus on health promotion and prevention and involvement with and across social and economic function of government. The control of environmental and lifestyle risk was revealed to be central to NPH and resulted in forms of coercion that

1. bring individuals into line with political objectives through the use of “disciplinary technologies” such as surveillance, evaluation and discipline via government programmes and construction of knowledge;
2. view capabilities of individuals as resources that need to be harnessed, utilised, directed or “ruled” in some way, and;
3. engage individuals, as knowing or unknowing consumers, in health practices for managing perceived or real risk leading to change of choices or desires by the individual so they align with current political agendas.

The discourse analysis revealed it was the engagement with health practices or healthism that has led to situating the problem of health and disease at the level of the individual. Solutions to these health problems were then deemed to lie within the realm of individual choice. This reduction of health problems to the level of individual responsibility and choice has resulted in categorisation of individuals into “those at risk” and “those posing a risk”. Ignoring the risk was shown to place the individual in danger of illness, disability and disease, and resulted in costs to themselves and the taxpayer. To not ignore the risk, left the individual with an apparently obligatory choice; one based upon a moral duty to do the “right thing” by and for themselves, their family and the wider society.
The discourse analysis also revealed that NPH was effected by and influences the process of medicalisation, whereby NPH contributes to the expansion of previously non-medical issues becoming defined and treated as medical problems, illnesses or disorders. Consequences of medicalisation were individualisation of issues that are effectively social problems, the muddying of social forces that influence well-being, the development of new medical markets, the rise of the consumer and the resultant need for managers. Analysis of NPH consumerist and medicalisation discourses suggested underfunding of healthcare systems by governments increasingly forced those who can afford it into the “market” to meet their personal healthcare requirements under the guise of “choice” and hidden in notions of “personal responsibility and moral duty”. Those who showed an inability to participate in healthcare were subjected to training courses, assessments, interventions, goal setting and care plans designed to direct them toward self-motivation required for independent self-management.

Within NPH, the managerial discourse was one that appeared to have been taken up by nurses or applied to the nursing role via outside influences. The management role seemed to demand nurses empower individuals they work with through provision of education, training, support and on-going supervision. Analysis indicated that as the individual successfully took on more of the required self-management tasks, the nurse was required to take on a leadership role that encompassed a visioning of the individual’s health and articulation of that to them and their family. The role of the nurse thus became one of leading individuals living with long-term conditions to “self-realisation” through encouraging them to self-manage their long-term condition.

The discourse of Kaupapa Maori evidenced a different picture; that of collective wisdom, derived from past and present experiences of Maori and underpinning principles, beliefs, experiences, understandings and interpretations of the interactions of Maori for their world and people.
Chapter 5: Results

Individual interviews with participants living with long-term conditions

Life is self-management - why should it be any different living with a long term condition – isn’t that what life is anyway? (E-survey, 197).

Introduction
This chapter presents findings from individual interviews exploring views, beliefs, interpretation and experience regarding self-management. A profile of participants is provided and the remainder of the chapter defines, describes and illustrates identified themes arising from these interviews.

Profile of participants living with long-term conditions
A total of nine people agreed to participate in a semi-structured interview, two males and seven females. Two of the women were partners who sat in on the interview and contributed to the discussion. After discussion with both supervisors, one of the transcripts was excluded as it did not appear the participant had Type 1 or 2 diabetes but rather a recollection of gestational diabetes when pregnant with her children. This left six individual interview transcripts for analysis with eight participants (two male and six female).

The age range was 42-91 years of age and long-term conditions represented were ankylosing spondylitis, cardiomyopathy, COPD, chronic renal failure, congestive heart failure, diabetes type 2 diet and medication controlled, gout, hyperlipidaemia, hypertension, long term back pain, osteo-arthritis, pulmonary hypertension and rheumatoid arthritis. Eight participants identified as New
Zealand European. One participant identified as Maori but mostly New Zealand European and then told this researcher to “cross out ‘Maori’”.

**Findings from individual interviews with participants living with long-term conditions**

Two major themes of “supervision” and “loss” became evident as this researcher discussed the data with supervisors, read interview transcripts and categorised relevant quotes. Definitions for major themes, sub-themes and categories have been derived from the Merriam-Webster online dictionary and thesaurus (Merriam-Webster, 2013). The first theme of “supervision” includes the sub-themes of “personal choice”, “direction” and “observation”. The second theme of “loss” incorporates the sub-themes of “resignation”, “restriction”, “isolation” and “regret” (Table 5-1).

**Table 5-1: Themes from individual interviews**

<table>
<thead>
<tr>
<th>Major Themes</th>
<th>Sub-themes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervision</td>
<td>Personal choice</td>
<td>Pragmatic choice</td>
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<tr>
<td></td>
<td></td>
<td>Emotive choice</td>
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<td></td>
<td></td>
<td>Imperceptible choice</td>
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<tr>
<td></td>
<td>Direction</td>
<td>Partner direction</td>
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<td></td>
<td></td>
<td>Healthcare professional direction</td>
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<tr>
<td></td>
<td>Observation</td>
<td>Individual observes</td>
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<tr>
<td></td>
<td></td>
<td>Partner observes</td>
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<tr>
<td>Loss</td>
<td>Resignation</td>
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<td></td>
<td>Restriction</td>
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<td></td>
<td>Isolation</td>
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<tr>
<td></td>
<td>Regret</td>
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</table>

**Supervision**

The theme of “supervision” was defined as the individual maintaining oversight, surveillance and direction. “Supervision” demonstrated how individuals kept an overall critical or close watch, directed activities or the course of action
regarding managing their long-term condition. The sub-themes of “personal choice”, “direction” and “observation” further contribute to the theme of “supervision” and reveal individuals and their partners’ beliefs about their roles in managing the long-term condition.

**Personal choice**

The first sub-theme of “personal choice” was defined as an individual deciding upon options that they may take for management of their long-term condition/s. This sub-theme is divided into “pragmatic choice”, “emotive choice” and “imperceptible choice”.

“Pragmatic choice” revealed that participants made choices about aspects of management of their long-term condition sensibly and realistically based on practical considerations. The first quote illustrates how the participant knowingly ate what she knew she should not eat but still made a decision that went against medical recommendation.

> And if I go out and I go to somebody’s place and they serve up a meal that I shouldn’t have, well I’ll eat it (Participant 2).

The second quote demonstrates how the participant felt she had to choose one activity over another in order to continue to function and maintain balance in her daily life.

> I could go swimming or something, but seriously, I wouldn’t want to train for iron man [laughs] but there is that, you know, there is that, like going for a walk with the dog. It would be nice if we could walk together, you know, like that would be kind of cool, but I just, ah, if I haven’t done anything all day, it would be nice to go for a walk, but if I’ve been at work, there’s no way (Participant 6).

“Pragmatic choice” shows how the participants made choices that fitted with the circumstances of that moment in time or that assisted in maintaining equilibrium in their life.

“Emotive choice” revealed aspects of long-term condition management that aroused some emotion for or against a decision the participants had to make.
Some decisions were shown to be difficult or appeared to be made out of fear of a possible worsening of their condition. This participant quote illustrates the difficulty faced in balancing the knowledge of needing to lose weight with a love of food.

Yeah, and I’m sure that if I can lose some weight, which is very hard work for me, [because] I love food and there’s a hole in my face that I put it in (Participant 2).

This participant discussed how she did not wish to go on insulin and her self-management decisions were driven by the fear of that perceived inevitability.

I would be annoyed, ah, putting it politely if I had to go on to insulin. I’m fighting not to go on to insulin. ... I go on one more metformin apparently. I can go onto five and then I’ve got [to] go on insulin. That’s what Doctor told me anyway. So, um, I’m fighting against it. I don’t really wan[t] [to] go on insulin (Participant 3).

“Emotive choice” illustrates how some decisions the participants made were hard to make or driven by an emotion.

The third category in this section, “imperceptible choice”, was defined as unable to be understood by a sense or the mind and therefore difficult to comprehend as real or existing. This theme was only evident within transcripts of participants with diabetes and for these participants; diabetes was diet or tablet controlled. “Imperceptible choice” is illustrated in the quote through revealing how the participant could not see or feel the effects of diabetes on his body the way he could see and feel a cut or feel the pain of arthritis within his joints.

The fact that you don’t actually feel unwell, like when you cut your finger, there’s the cut, that’s it. Um, with the arthritis, it’s the same, like you know, to an outsider they can’t often see that, you know, your joints are sore, but with this [diabetes], there is nothing, there’s no sign even for yourself. There is nothing and that’s, that’s really, the hard bit to say, but you know, I’ve got diabetes, you know have I got a big D on my forehead? So you know that’s what I find really hard, is to say you’ve something but there’s no, I don’t feel any different and I’ve got nothing to show (Participant 4).
“Imperceptible choice” shows the dichotomy between the diagnosis of diabetes and the individual’s reality of feeling well and not having any problems thus making it difficult to prioritise diabetes management over other more pressing issues. These three categories of “pragmatic choice”, “emotive choice” and “imperceptible choice” reveal in a small way how complicated an individual’s self-management choices can be in regards to the management of a long-term condition.

Direction
The second sub-theme, “direction”, was defined as another person providing guidance or supervision for an action. This sub-theme revealed the participants to be under the direction or guidance of another individual, group or system or wanting to pass the responsibility for aspects of their long-term condition management to another person. This sub-theme was separated into supervision for aspects of long-term condition management undertaken by a partner or by a health professional. This participant quote illustrates how the partner guided her husband’s food choices because he has a sweet tooth, through allowing him some dessert but limiting how much he eats by permitting only a small portion.

But if he wasn’t allowed it [dessert], he would crave it and he would end up going behind everybody’s back and eating a whole lot. So the way I deal with it is I let him have some but not a full serving, just a small amount, so that he knows he’s had it, but he hasn’t overdone it (Participant 4).

This quote illustrates how the partner reads and interprets her husband’s visual and audible cues and suggests appropriate treatment to counteract the pain.

Looking at him, knowing what he looks like, [because] he can lie to me. [laughs] .... He can sit there an[d] go “‘Ah, oh’” and I says [sic], “What’s wrong?” “Nothing. Nothing. Nothing.”’” And I can tell that he’s had sharp pains but he doesn’t want to do anything. I says [sic], “Don’t you think you should take a spray?” “Oh, I will in a minute.”’” In a minute! When he says in a minute, I know he’s had a couple of jolts (Participant 5).

The following quote illustrates how the participant would like to relinquish responsibility for the long-term condition to a healthcare provider because the demands of managing the condition are hard work and on-going.
Um [laughs] well, I started doing extra walking and when I have a sugar craving I go and do something else and that sort of thing and when I read that [newspaper advert for alternative treatment for symptoms of diabetes] I thought, I don’t have to, that’s out of my hands now (Participant 2).

The theme “direction” revealed in a small way how the partner prompts, guides or directs the individual’s self-management choices in order to maintain adherence to diet or for symptom control and how participants would love to acquiesce some of the responsibility for decision making to their healthcare professional.

Observation
The third sub-theme of supervision was “observation”. This has been defined as watching or questioning carefully, especially with attention to detail or behaviour for the purpose of making a decision. “Observation” has two facets, the individual observing others and the partner observing the individual for the purpose of information gathering to assist making self-management decisions. The first participant quote illustrates how the individual has observed self-management behaviours in relatives (who also had diabetes) that she would not choose to do herself as she perceives them as the wrong choice.

See I’ve got a [relative], I don’t know how he’s lived so bloody long, and [sister] used to do it too actually. [Sister] was on insulin and my [relative] taught her some bad habits. You can have a cream cake but just give yourself a little bit more insulin. See I wouldn’t do that. I know I’m not supposed to do it, so why do it? (Participant 3).

The second participant quote illuminates the experience the partner has gleaned from years of observation and how she uses this to inform decisions she has to make on his behalf.

And it’s a combination of over the years of just knowing what he’s taking, what he’s feeling like, do you know what I mean and being very careful (Participant 5).

“Observation” reveals some of the ways individuals or their partners gain the necessary information to inform future self-management choices they may make about the management of their or their partner’s long-term condition.
The theme of “supervision” reveals some underlying self-management beliefs and views of this group of participants and highlights aspects of the complex nature of personal choice related to self-management. “Supervision” shows the convoluted nature of the interaction between the individual, their family and health care professionals for self-management decisions and management of a long-term condition.

**Loss**

The theme of “loss” was defined as being deprived of or being without something that a person has had previously. This theme had four sub-themes of “resignation”, “restriction”, “isolation” and “regret”.

**Resignation**

“Resignation” has been defined as accepting something as inevitable or to be resigned to one’s fate. This theme was evident amongst the diabetic participant’s transcripts and revealed the underlying belief that diabetes was inevitable and that it would get worse. The first quote illustrates how one participant believed diabetes was inevitable because she had gestational diabetes when she was pregnant with her third child.

*I was under a specialist at Christchurch Women’s, and he said I would probably get it [diabetes] back after I finished the change of life, menopause, you know. And sure enough I did* (Participant 3).

The second quote illustrates how one woman knew the symptoms of diabetes would get worse but that she still hoped that it would not be her reality and that she could slow the effect of it on her body.

*I know I’m not going to beat it, but it’s not going to beat me,* [whispers] *I hope* (Participant 2).

Non-diabetic participants discussed a different facet of “resignation”, that of getting on with living and making the most of good days and filling life with things they loved. This participant quote showed how they had balanced the
experience of loss in their life with undertaking things they knew they enjoyed and could do.

*I think it’s really important to find things that you love doing and fill your lives with those, [because], you have to let go of some other things. As long as you follow, keep doing things that you love* (Participant 6).

These facets of “resignation” reveal both the positive and negative nature of the sub-theme but also the on-going daily challenge of living with a long-term condition.

**Restriction**

“Restriction” has been defined as the constraints the individual experiences because of a long-term condition. The sub-theme of “restriction” revealed how the long-term condition exerts some control over what the individual is, or what family members are, able to do in their everyday life. This quote illuminates understanding by the participant of the limitations and disruptions the long-term condition has brought to both her and her family’s life because she can no longer independently fulfil her needs.

*I felt as though I was the biggest nuisance in the world. I still feel a bit like that, having to ask them if I want something or, and I can’t get there and I’ve got [to] say, “Oh can you take me or do this?” And I feel the biggest nuisance in the world, that’s the only feeling I have, just that I feel that if I wasn’t here, they’d be probably glad, I, they hadn’t got to worry about me* (Participant 7).

This sub-theme illuminates the limiting and sometimes disruptive nature of a long-term condition on both the individual and their partner and family.

**Isolation**

“Isolation” has been defined as a feeling of being alone. This theme became evident in two of the non-diabetic participants transcripts. These quotes reveal how these participants feel their long-term condition is a lonely place, not understood by others and is something that can only be dealt with by them.
And you can’t talk to anybody, [because] they don’t actually understand (Participant 5).

[laughs] Do my family help? I think they are, they understand it, um, I don’t think I married the most empathetic person, he’s not so um, so I think I’ve learnt to just deal with it in my way (Participant 6).

One of the participants revealed how at one stage, when in the hospital for an outpatients appointment with her husband, she felt her husband was not quite right and asked a nurse to take his blood pressure for her. The partner felt alone in caring for her husband because of the off-hand way the nurse dealt with her request.

[I felt] that I shouldn’t have taken him there, you know what I mean? Because I’ve got no way of knowing what his blood pressure is and I just needed reassurance (Participant 5).

The sub-theme of “isolation” illuminates the sometimes solitary experience participants or their partners felt when living and dealing with the repercussions of a long-term condition.

Regret
“Regret” has been defined as missing very much or to mourn the loss of something. Participants talked about how they experienced on-going grief over role reversal, loss of health, their past life and lost abilities they had experienced in their lives as a result of the diagnosis of a long-term condition. The first quote illustrates one participant’s grief at the role reversal evident in their relationship because of his long-term condition and his frustration at his inability to undertake physical tasks.

But, I, I, I, oh [sighs] she’s doing all the man’s work and it gets to me. I can’t even bang a bloody nail in. It gets to me (Participant 5).

The second quote illuminates the regret the participant experienced over her loss of freedom and ability pre and post diagnosis of the long-term condition.

Well it’s a huge impact. I think just on how you, um, your freedom, the freedom of what you were pre-health to post is
completely different. So it’s like a whole mental game and that, it’s a consideration for how you live your life (Participant 6).

“Regret” highlights how the participants mourn and grieve changes the long-term condition has wrought in their life and the life of their family.

Overall the theme of “loss”, with sub-themes of “resignation”, “restriction”, “isolation” and “regret”, reveals the impact, changes and on-going nature of loss experienced by the individual and their family after diagnosis of a long-term condition. The two themes of “supervision” and “loss” unite interview transcripts from a small group of participants with diverse long-term conditions and illuminate some of the underlying views and beliefs this group of participants have about self-management of these conditions and their ability to self-care.

**Summary of findings from individual interviews with participants living with long-term conditions**

The theme of “supervision” showed individuals had the final choice about what they would or would not do and retained ultimate responsibility for managing the long-term condition. However a fluid process was also uncovered where individuals appeared to move between making their own decisions, to being under the guidance of a spouse or a healthcare professional while at the same time maintaining overall supervision for self-management choices. Sub-categories of “personal choice”, “direction” and “observation” built on the theme of “supervising” through revealing:

- choices participants made that were:
  - pragmatic and practical to maintain balance in everyday life;
  - challenging to make because the inherent pros and cons of the decision, and;
  - problematic because the disease symptoms were invisible versus the individual’s reality of feeling well and not having any problems thus making it difficult to prioritise diabetes management over other more pressing issues.
• how the partner prompts, guides or directs the individual’s self-management choices in order to maintain adherence to diet or for symptom control and how participants acquiesce some of the responsibility for decision making to their healthcare professional.
• how individuals or their partners gain the necessary information to inform future self-management choices they may make about the management of their or their partner’s long-term condition through observation and questioning of others.

The theme of “loss” revealed the impact, changes and on-going nature of being deprived or without, experienced by the individual and their family after diagnosis of a long-term condition. Sub-categories of “resignation”, “restriction”, “isolation” and “regret” built on the theme of “loss” through revealing:

• acceptance of the course of the disease as inevitable but also just getting on with life and making the most of it;
• how the long-term condition disrupts, controls or limits what the individual or family members can do in their everyday life;
• the feeling that a long-term condition is lonely, not well understood by others and something that can only be dealt with by the individual, and;
• the on-going grief experienced by individuals over role reversal, loss of health and their past life and lost abilities since the diagnosis of a long-term condition.
Chapter 6: Results

E-survey undertaken with participants living with long-term conditions

Self-management is the process of looking after one's self to avoid cluttering up beds at the local DHB (E-survey, 245).

Introduction
The chapter commences with an overview of the e-survey response rate and sample characteristics. The chapter then presents results pertaining to reliability, normality and homoscedasticity and results from non-parametric tests. This is followed by the qualitative findings.

E-survey response rate
A total of 305 responses were received for the e-survey and Figure 3 summarises the response exclusions. Where data appeared to match, the researcher compared each line to ascertain if a duplicate was submitted. When it was established that two attempts by the same respondent had occurred, a decision was made to delete one response. Only four “double-ups” were noted and condensed into two responses. Exclusion criteria for the e-survey were ‘not a New Zealand resident’ (n=2) and ‘cancer’ (n=1) therefore those respondents who indicated they were non-resident or living with cancer were excluded prior to data analysis. After data cleaning and screening, a total of 251 responses remained. All 251 completed the Demographic (S1) and Stanford sections (S2) and 213 respondents contributed to the voluntary Open-ended section (S3).
To ensure quality reporting and complete description of e-surveys, Eysenbach (2004) suggests a checklist similar to CONSORT (randomised controlled trials) or QUORUM (systematic reviews) as a way to allow the reader to judge for themselves bias (from selection bias – non-representativeness of the Internet population and self-selection by participants because the topic interests them) and validity of an Internet survey (Eysenbach & Wyatt, 2002; Schonlau, 2004). Traditional surveys usually report a response rate based on number of people presented with a questionnaire divided by number of people completing allowing an estimation of representativeness and bias, however Eysenbach asserts there is no one way to calculate a response rate for an e-survey because the researcher has multiple figures that could be used as the numerator and denominator. He proposes use of view, participation and completion rates to ascertain validity and bias of the e-survey (Eysenbach, 2004).
Data obtained by the software technician indicated 464 unique site visitors. From this figure it was then possible to calculate view, participation and completion rates for the e-survey. The view rate of 65.7% for this e-survey was considerable given Eysenbach (2004) advises it is not unusual to achieve view rates of less than 0.1% for a voluntary survey. Participation (97.7%) and completion rates (86.2% to end S2 and 70.1% to end S3) were excellent; however these figures do suggest evidence of very high self-selection bias (Eysenbach & Wyatt, 2002). It could be inferred from the view, participation and completion rates that validity for use of an e-survey to collect data was good, bearing in mind that the sample was a convenience sample and self-selected. A summary of response rate, prevention of multiple entries and analysis decisions are provided in Appendix 24.

**E-survey demographics**

A total of 251 participant’s responses were included in the analysis. Nearly two thirds were female \((n=161; 64.1\%)\) and one third male \((n=90; 35.9\%)\). Respondents ranged in age from eighteen to eighty-two years old and the mean age was forty-eight years and a statistically significant difference was noted between female (44.79 years) and male (55.03 years) means. The majority of respondents identified as New Zealand/European \((n=217; 86.5\%)\) and 8.4% \((n=21)\) identified as Maori. Respondents were able to choose all ethnic categories that applied. Half the respondents were married \((n=130; 51.8\%)\) and 28.7\% \((n=72)\) indicated they had never married.

Respondents were able to select all categories that applied for the question “Who lives in the same household as you?” and forty (15.9%) respondents identified they lived alone. The majority \((n=211; 84.1\%)\) lived with someone else (Husband/wife, civil union partner, partner/boy/girlfriend, parents, children, brothers/sisters, grandchild/ren, flatting or others). Over half the respondents \((n=151; 60.2\%)\) identified a religious affiliation.
Income for respondents was sourced mainly from wages and salary \( (n=169; 67.3\%) \), interest and dividends \( (n=59; 23.5\%) \), pensions \( (n=48; 19.1\%) \) or self-employment \( (n=34; 13.5\%) \). Respondents were able to choose all income sources that applied to them. One hundred and five \( (41.8\%) \) respondents had an undergraduate or postgraduate degree, sixty respondents \( (23.9\%) \) indicated some sort of certificate, trade, diploma or association membership and 22.7% \( (n=57) \) had five years or less of high school. Twenty-nine \( (11.6\%) \) respondents did not indicate their highest educational level.

Response by region was variable and no respondents were gained from Gisborne, West Coast of South Island and Tasman. These responses reflect where the e-survey was promoted by third parties. The majority of respondents reported that they lived in an urban area \( (n=197, 78.5\%) \), where this was defined as a population of >30,000 people.

The average number of long-term conditions was 1.63, \( (Md 1.00) \) (Female: \( M = 1.49 \); Male: \( M = 1.62 \)) with arthritis and asthma the most common conditions experienced \( (n=76; 30.3\% \) and \( n=71; 28.3\%) \) respectively. Table 6-1 sets out a summary of sample characteristics.
Table 6-1: Sample Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>( n=251 )</th>
<th>( SD )</th>
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<tr>
<td>Age (Years)</td>
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<tr>
<td>Range</td>
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<tr>
<td>Mean</td>
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<td>Female Mean</td>
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<tr>
<td>Male Mean</td>
<td>55.03</td>
<td>15.5</td>
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<tr>
<td>Sex</td>
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<td></td>
</tr>
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<td>64.1</td>
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<tr>
<td>Male</td>
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<td>35.9</td>
</tr>
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<td></td>
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<td>NZEuro</td>
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<td>Other</td>
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</tr>
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</tr>
<tr>
<td>Indian</td>
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</tr>
<tr>
<td>Pacific Island</td>
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<tr>
<td>Separated</td>
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<tr>
<td>Living arrangements</td>
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<td>With someone else</td>
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<td>Alone</td>
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</tr>
<tr>
<td>Religious affiliation</td>
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<tr>
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<td>151</td>
<td>60.2</td>
</tr>
<tr>
<td>No</td>
<td>100</td>
<td>39.8</td>
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Table 6-1: Sample Characteristics - continued

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<td>Income</td>
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<td>Wages/salary</td>
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<td>NZSuper/pension</td>
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<td>19.1</td>
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<td>13.5</td>
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<tr>
<td>Invalids benefit</td>
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<td>7.2</td>
</tr>
<tr>
<td>Other income</td>
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<td>7.2</td>
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<tr>
<td>Sickness benefit</td>
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<td>ACC/Insurance</td>
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<td>4.0</td>
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<td>Student allowance</td>
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<td>2.8</td>
</tr>
<tr>
<td>Unemployment benefit</td>
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</tr>
<tr>
<td>No Income</td>
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<td>0.8</td>
</tr>
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<td>High school (3-5yrs)</td>
<td>57</td>
<td>22.7</td>
</tr>
<tr>
<td>Certs/Dips/Trades/Assns</td>
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<td>23.9</td>
</tr>
<tr>
<td>University (undergrad – PhD)</td>
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<td>41.8</td>
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<tr>
<td>No answer</td>
<td>29</td>
<td>11.6</td>
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<td>Responses by Region</td>
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<tr>
<td>Waikato</td>
<td>87</td>
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<td>Wellington</td>
<td>61</td>
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<td>Auckland</td>
<td>49</td>
<td>19.5</td>
</tr>
<tr>
<td>Otago</td>
<td>19</td>
<td>7.6</td>
</tr>
<tr>
<td>Canterbury</td>
<td>9</td>
<td>3.6</td>
</tr>
<tr>
<td>Nelson</td>
<td>9</td>
<td>3.6</td>
</tr>
<tr>
<td>Bay of Plenty</td>
<td>5</td>
<td>2.0</td>
</tr>
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<td>Northland</td>
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<td>1.2</td>
</tr>
<tr>
<td>Southland</td>
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<td>1.2</td>
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<tr>
<td>Marlborough</td>
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<td>0.8</td>
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<td>Hawkes Bay</td>
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<td>0.4</td>
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<td>Manuwaatu-Wanganui</td>
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<td>0.4</td>
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<tr>
<td>Gisborne</td>
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<td>0.0</td>
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<tr>
<td>Tasman</td>
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<td>0.0</td>
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<tr>
<td>West Coast</td>
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<td>0.0</td>
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<tr>
<td>Urban/rural split</td>
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<td></td>
</tr>
<tr>
<td>Main urban (pop 30,000+)</td>
<td>197</td>
<td>78.5</td>
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<tr>
<td>Minor urban (pop 1,000-9,999)</td>
<td>26</td>
<td>10.4</td>
</tr>
<tr>
<td>Secondary urban (pop 10,000-29,999)</td>
<td>20</td>
<td>8.0</td>
</tr>
<tr>
<td>Other rural (not population specific)</td>
<td>5</td>
<td>2.0</td>
</tr>
<tr>
<td>Rural centre (300-999)</td>
<td>3</td>
<td>1.2</td>
</tr>
<tr>
<td>Long-term Conditions (LTC)</td>
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<td></td>
</tr>
<tr>
<td>One LTC</td>
<td>151</td>
<td>60.2</td>
</tr>
<tr>
<td>Two LTC</td>
<td>66</td>
<td>26.3</td>
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<tr>
<td>Three or more LTC</td>
<td>34</td>
<td>13.5</td>
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<tr>
<td>Arthritis</td>
<td>76</td>
<td>30.3</td>
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<tr>
<td>Asthma</td>
<td>71</td>
<td>28.3</td>
</tr>
<tr>
<td>Heart</td>
<td>51</td>
<td>20.3</td>
</tr>
<tr>
<td>Diabetes</td>
<td>41</td>
<td>16.3</td>
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<tr>
<td>COPD</td>
<td>21</td>
<td>8.4</td>
</tr>
<tr>
<td>Other lung disease</td>
<td>7</td>
<td>2.8</td>
</tr>
<tr>
<td>Cancer</td>
<td>7</td>
<td>2.8</td>
</tr>
</tbody>
</table>
Reliability

Reliability of the scales and subscales in the present study were examined and reported in Table 6-2 along with the reliability co-efficient for all subscales. All Cronbach alpha values were above .70 indicating good reliability in the present study.

Table 6-2: Reliability of scales: Comparison with Stanford scales

<table>
<thead>
<tr>
<th>Scales</th>
<th>Study sample α</th>
<th>Stanford α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms – Health Distress (SHD)</td>
<td>0.91</td>
<td>0.87</td>
</tr>
<tr>
<td>Daily Activities – Social/Role Activities Limitations (DASRA)</td>
<td>0.91</td>
<td>0.91</td>
</tr>
<tr>
<td>Medical Care – Communication with Physicians (MCCPHY)</td>
<td>0.73</td>
<td>0.73</td>
</tr>
<tr>
<td>Self-Efficacy for Managing Chronic Disease 6-Item Scale (SEMCD)</td>
<td>0.92</td>
<td>0.91</td>
</tr>
<tr>
<td>Chronic Disease Self-Efficacy Scales</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obtain Help from Community, Family, Friends Scale (SEOHCFF)</td>
<td>0.82</td>
<td>0.77</td>
</tr>
<tr>
<td>Communicate with Physician Scale (SECPHY)</td>
<td>0.91</td>
<td>0.90</td>
</tr>
<tr>
<td>Manage Disease in General Scale (SEMDG)</td>
<td>0.89</td>
<td>0.87</td>
</tr>
<tr>
<td>Do Chores Scale (SEDC)</td>
<td>0.94</td>
<td>0.91</td>
</tr>
<tr>
<td>Social/Recreational Activities Scale (SESRA)</td>
<td>0.91</td>
<td>0.82</td>
</tr>
</tbody>
</table>

Normality

The distribution of data on each of the Stanford scales was explored. Normal distribution was violated on all scales (Appendix 25). Significant results on the Kolmogorov-Smirnov and Shapiro-Wilk tests of $p = .001$ were demonstrated on nine scales. The result for the Self-efficacy – Managing Chronic Disease (SEMCD) and Self-efficacy – Obtain Help from Community, Family, Friends (SEOHCFF) Kolmogorov-Smirnov test, $p = .004$, suggest violation of the assumption of normality. Three scales evidenced positive Kurtosis distribution (peaked or clustered in the centre) (Medical Care – Communication with Physicians (MCCPHY), Self-efficacy – Get Information About Disease (SEGIAD) and Self-efficacy – Manage Disease in General (SEMDG)). All other

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42 Does not include Self-rated Health or Self-efficacy – Get Information About Disease as these consist of only one item.
scales had Kurtosis values below zero indicating flat distribution (too many cases in the extremes) (D. Flynn, n.d.; Pallant, 2011).

Lorig et al. (1996) report most of their data from the self-management behaviour measures were “slightly skewed” in that the majority of their respondents scored at the lower end (i.e., were not performing the behaviour). The developers did not report this as an issue, as the intervention of the Chronic Disease Self-management Program was designed to increase the behaviours. Data from this sample, which used only one self-management behaviour scale, Medical Care – Communication with Physicians (MCCPHY), showed the distribution was similarly skewed with respondent scores clustered toward the lower scores indicating they did not perform the behaviours being tested (preparing a question list, asking questions about things they want to know and do not understand about treatment and discussing personal problems related to their long-term condition).

Lorig et al. (1996) report mean scores for the self-efficacy measures were one to two points above the mid-point (10-point scales) resulting in “slightly skewed” scales. They note respondents had a tendency to report high self-efficacy. Data from this sample for Self-efficacy - Managing Chronic Disease (SEMCD), Self-efficacy - Get Information About Disease (SEGIAD), Self-efficacy – Obtain Help from Community, Family, Friends (SEOHCFF), Self-efficacy – Communicate with Physician (SECPHY), Self-efficacy – Manage Disease in General (SEMDG), Self-efficacy – Do Chores (SEDC) and Self-efficacy Social/Recreational Activities (SESRA) were similarly skewed with respondent scores clustered toward high self-efficacy.

Health status outcome scale distribution as reported by Lorig et al. (1996) varied across scales. Data from this sample for the Daily Activities – Social/Role Activities Limitation scale was slightly skewed with most respondents having fewer limitations and is similar to that reported by Lorig et al. (1996). Lorig et
al. report the General Health - Self-Rated Health and Symptoms – Health Distress measures were normally distributed “with mean scores lying roughly midway between the endpoints” (1996, p. 23). Distribution data for this sample does not follow the Stanford pattern with the mean score (1.93) sitting below mid-point (2.5) and scores clustered toward to the lower values meaning respondents had a tendency to report less distress about their health for the Symptoms – Health Distress (SHD) scale. Distribution data from this sample for General Health – Self-Rated Health (SRH) shows a similar pattern. The mean score (2.89) sits just below the mid-point (3) with scores clustered toward the lower values showing respondents had a tendency to report better health.

Table 6-3 presents a direct comparison of mean and standard deviation for the sample scores with available Stanford scores (Lorig, et al., 1996; Stanford School of Medicine, 2007). Based on the mean score, the current sample reported:

- better self-rated health;
- less health distress and perceived social, role activity limitations;
- higher self-efficacy for managing a long-term condition;
- comparable self-efficacy for getting information about their long-term condition;
- slightly higher self-efficacy for obtaining help from community, family and friends, and;
- greater perceived self-efficacy for asking their doctor things about their illness that concerned them, discussing personal problems related to their illness, working out differences with their doctor, managing their long-term condition/s, undertaking chores and social/recreational activities than the Stanford sample.

However, based on the mean score the current sample reported poorer perceived ability to communicate with doctors through preparing a question list, asking questions about things they want to know and do not understand about treatment
and discussing personal problems related to their long-term condition than the Stanford sample (Lorig, et al., 1996).

Also evidenced in Table 6-3 is median, mode, and observed range of scores for the current sample. Comparison of mean, median and mode reveals evidence of both floor and ceiling effects for a number of the scales. A ceiling effect suggests that a high proportion of the participants in this study reported maximum scores for the self-efficacy scales. A floor effect is evident for both Symptoms Health Distress and Daily Activities – Social/Role Activities Limitations. This indicates a high proportion of participants in this study reported minimum scores on these scales. For these scales, it is possible that because participants reported high self-efficacy, minimal health distress and activity limitations, that the scales did not adequately measure these constructs for this group of participants or these respondents are coping well with the implications of living with their long-term condition/s. SPSS reported two scales (Communicate with Physician (MCCPHY) and Self-efficacy – Manage Disease in General) with multiple modes evidencing two common values appearing with the same frequency. A graph setting these out is shown in Appendix 26. Further comparison was undertaken between e-survey and Stanford mean scores through calculation of $z$-scores. This shows the standard deviation, above or below the Stanford mean scores for the e-survey means, with all $z$-scores for the e-survey falling within the acceptable range of -2 to +2.
Table 6-3: E-survey and Stanford Scales descriptive statistics comparison

<table>
<thead>
<tr>
<th>Scale</th>
<th>Study sample</th>
<th>Stanford</th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
<td>(SD)</td>
<td>Median</td>
<td>Mode</td>
<td>Range</td>
<td>Observed</td>
<td>n</td>
<td>Mean</td>
<td>(SD)</td>
<td>z-score</td>
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<tr>
<td>Self-rated health (SRH)</td>
<td>251</td>
<td>2.89</td>
<td>1.03</td>
<td>3.00</td>
<td>3.00</td>
<td>1-5 ↓</td>
<td>1-5</td>
<td>1129</td>
<td>3.29</td>
<td>0.91</td>
<td>-0.44</td>
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<tr>
<td>Health distress (SHD)</td>
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<td>1.93</td>
<td>1.32</td>
<td>1.75</td>
<td>2.00</td>
<td>0-5 ↓</td>
<td>0-5</td>
<td>1130</td>
<td>2.04</td>
<td>1.16</td>
<td>-0.09</td>
<td></td>
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<tr>
<td>Social/Role activity/limits (DASRA)</td>
<td>248</td>
<td>1.17</td>
<td>0.91</td>
<td>1.00</td>
<td>0.00</td>
<td>0-4 ↓</td>
<td>0-3</td>
<td>1130</td>
<td>1.70</td>
<td>1.11</td>
<td>-0.48</td>
<td></td>
</tr>
<tr>
<td>Communicate physician (MCCPHY)</td>
<td>248</td>
<td>2.42</td>
<td>1.15</td>
<td>2.33</td>
<td>2.00</td>
<td>0-5 ↑</td>
<td>0-5</td>
<td>1130</td>
<td>3.08</td>
<td>1.20</td>
<td>-0.55</td>
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<td>SE 6 item scale (SEMCD)</td>
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<td>2.17</td>
<td>6.83</td>
<td>9.00</td>
<td>1-10 ↑</td>
<td>1-10</td>
<td>605</td>
<td>5.17</td>
<td>2.22</td>
<td>0.70</td>
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<td>10.00</td>
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<td>0.00</td>
<td></td>
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<tr>
<td>SE-obtain help (SEOHCF)</td>
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<td>10.00</td>
<td>1-10 ↑</td>
<td>1-10</td>
<td>478</td>
<td>6.18</td>
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<td>0.07</td>
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<tr>
<td>SE-communicate physician (SECPHY)</td>
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<td>2.18</td>
<td>8.67</td>
<td>10.00</td>
<td>1-10 ↑</td>
<td>1-10</td>
<td>477</td>
<td>7.30</td>
<td>2.71</td>
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<td>SE-manage disease (SEMDG)</td>
<td>234</td>
<td>7.46</td>
<td>1.88</td>
<td>7.75</td>
<td>8.00</td>
<td>1-10 ↑</td>
<td>1-10</td>
<td>478</td>
<td>6.92</td>
<td>2.15</td>
<td>0.25</td>
<td></td>
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<tr>
<td>SE-do chores (SEDC)</td>
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<td>2.41</td>
<td>8.00</td>
<td>10.00</td>
<td>1-10 ↑</td>
<td>1-10</td>
<td>478</td>
<td>6.29</td>
<td>2.70</td>
<td>0.48</td>
<td></td>
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<tr>
<td>SE-social/rec activities (SESRA)</td>
<td>233</td>
<td>6.99</td>
<td>2.62</td>
<td>7.00</td>
<td>10.00</td>
<td>1-10 ↑</td>
<td>1-10</td>
<td>478</td>
<td>6.50</td>
<td>2.65</td>
<td>0.18</td>
<td></td>
</tr>
</tbody>
</table>

↓ lower score indicates better self-rated health, less health distress and less activity limitations
↑ higher score indicates better communication with physicians and higher self-efficacy

Multiple modes exist – smallest value is shown
A one third cut off (or near to as possible with figures provided by SPSS) was established on each of the scales in order to interpret the data\textsuperscript{43}. This allowed the researcher to compare the top one-third of a percent of respondents who reported high health status, self-management behaviour and self-efficacy with those who reported moderate to low health status, self-management behaviour and self-efficacy (Table 6-4). These figures show that many of the respondents believe they are coping well. Of particular note are those who are not coping as well. 64\% of respondents rated their health as only poor to good and 87\% reported they did not often prepare a list of questions, ask questions and seek clarification about treatment and discuss personal problems related to their illness with their doctor. On scales measuring self-efficacy, just over 60\% reported less confidence for managing their symptoms, issues and emotional distress arising because of the chronic disease and 65\% were not as confident about getting support and help from family, friends or community resources that they needed.

<table>
<thead>
<tr>
<th>Comparison</th>
<th>Top 1/3</th>
<th>Other 2/3</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Health Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SRH</td>
<td>251</td>
<td>35.9</td>
</tr>
<tr>
<td>SHD</td>
<td>248</td>
<td>45.2</td>
</tr>
<tr>
<td>DASRA</td>
<td>248</td>
<td>60.5</td>
</tr>
<tr>
<td>Self-management behaviour</td>
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<td></td>
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<tr>
<td>MCCPHY</td>
<td>248</td>
<td>12.9</td>
</tr>
<tr>
<td>Self-efficacy</td>
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<td></td>
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<tr>
<td>SEMCD</td>
<td>214</td>
<td>38.8</td>
</tr>
<tr>
<td>SEGIAD</td>
<td>238</td>
<td>42.0</td>
</tr>
<tr>
<td>SEOHCF</td>
<td>238</td>
<td>34.5</td>
</tr>
<tr>
<td>SEPHY</td>
<td>237</td>
<td>66.7</td>
</tr>
<tr>
<td>SEMDG</td>
<td>234</td>
<td>47.0</td>
</tr>
<tr>
<td>SEDC</td>
<td>233</td>
<td>57.1</td>
</tr>
<tr>
<td>SESRA</td>
<td>233</td>
<td>45.1</td>
</tr>
</tbody>
</table>

\textsuperscript{43} Refer to Methods, Data analysis: Sections 1 & 2, page 102 for explanation
A comparison of mean scores was undertaken with published data from other studies that have used the Stanford scales (Table 6-7 – page 173). The majority of studies were undertaken in America (eight); of these three were Internet or email based and one of the studies collected data in both Texas and Mexico. Three studies were conducted in Hong Kong, two in the United Kingdom (one of which was Internet mediated) and one each in Australia, China, Netherlands and Hawaii. Subject numbers varied \( n = 46 \text{ - } 1216 \), age range was 18 - 95; long-term conditions represented were cardiovascular, respiratory, endocrine, renal, mental health, autoimmune, pain and cancer. The most frequently used Stanford Scales were Self-rated Health, Symptoms Health Distress, Daily Activities – Social/Role Activities Limitations and Self-efficacy for Managing Chronic Disease. A variety of statistical tests were run by the authors of these studies. A table summarising these studies and their references are provided in Appendices 27-28.

All studies reported improvement in some or all outcomes measured other than Elzen, Slaets, Snijders and Steverink (2007, p. 1838) who “did not find any significant effects”. They suggest a number of explanations for this: cultural differences; their subjects already had high baseline self-efficacy and health status resulting in ceiling effects; they did not use all the questionnaires usually associated with CDSMP, and the alternate measure chosen did not adequately measure self-efficacy (they tested this and found their measure did not necessarily cause lack of effects); the control group improved on some variables, and; some of their subjects were personally invited rather than recruited from general population (Elzen, et al., 2007). The range of mean scores for the most commonly occurring scales from compared studies is demonstrated in Table 6-5 suggesting various normality distribution patterns are possible across different populations.
Table 6-5: Range of mean scores evidenced across different studies

<table>
<thead>
<tr>
<th>Stanford Scale</th>
<th>Range of mean scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-rated Health</td>
<td>2.80 - 3.93</td>
</tr>
<tr>
<td>Symptoms Health Distress</td>
<td>0.90 – 2.87</td>
</tr>
<tr>
<td>Daily Activities – Social/Role Activities Limitations</td>
<td>0.75 – 1.80</td>
</tr>
<tr>
<td>Medical Care – Communication with Physicians</td>
<td>1.48 – 3.08</td>
</tr>
<tr>
<td>Self-efficacy for Managing a Chronic Disease</td>
<td>1.15 - 7.20</td>
</tr>
</tbody>
</table>

**Homoscedasticity**

Assessment of demographic variables of sex, age (grouped), living arrangements, highest educational qualification (grouped), number of long-term conditions (grouped) and religious affiliation with the Stanford scales was undertaken to check the homogeneity of variance of the data. Examination of the output results for Test of Homogeneity of Variance (Levene’s) using the most conservative figure of the median statistic showed the majority did not violate the test (D. Flynn, n.d.). Those that violated the test, along with their significance value are reported in Table 6-6.

Table 6-6: E-survey: Homogeneity of variance violations

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Dependent variable</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (grouped)</td>
<td>Self-efficacy – Get Information About Disease</td>
<td>.017</td>
</tr>
<tr>
<td>Highest education qualification</td>
<td>Self-efficacy - Communication with Physician</td>
<td>.030</td>
</tr>
<tr>
<td>Religious affiliation</td>
<td>Self-Rated Health</td>
<td>.009</td>
</tr>
<tr>
<td></td>
<td>Symptoms Health Distress</td>
<td>.001</td>
</tr>
<tr>
<td></td>
<td>Communication with Physician</td>
<td>.043</td>
</tr>
<tr>
<td></td>
<td>Self-efficacy – Manage Chronic Disease in General</td>
<td>.048</td>
</tr>
</tbody>
</table>

Consideration was given to ‘transforming variables’ (to correct for negative and positive skew) in order to run further statistical tests (Pallant, 2011). After careful examination of the distribution of the data and discussion with a biostatistician, it was deemed appropriate to continue with descriptive statistics and to run non-parametric tests (Mann Whitney-U, on selected data and Spearman rho correlations) (C. Frampton, personal communication, October 19, 2012).
Table 6-7: Comparison of mean and standard deviation scores for e-survey, Stanford and other international studies

<table>
<thead>
<tr>
<th>Scales</th>
<th>SRH</th>
<th>SHD</th>
<th>DASRA</th>
<th>MCPHY</th>
<th>SEMCD</th>
<th>SEGIAD</th>
<th>SEOHCF</th>
<th>SEPHY</th>
<th>SEMDG</th>
<th>SEDC</th>
<th>SESRA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Studies</strong></td>
<td>Mean</td>
<td>(SD)</td>
<td>Mean</td>
<td>(SD)</td>
<td>Mean</td>
<td>(SD)</td>
<td>Mean</td>
<td>(SD)</td>
<td>Mean</td>
<td>(SD)</td>
<td>Mean</td>
</tr>
<tr>
<td>E-survey</td>
<td>2.89</td>
<td>1.03</td>
<td>1.93</td>
<td>1.32</td>
<td>1.17</td>
<td>0.91</td>
<td>2.42</td>
<td>1.15</td>
<td>6.72</td>
<td>2.17</td>
<td>7.37</td>
</tr>
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<td>Stanford</td>
<td>3.29</td>
<td>0.91</td>
<td>2.04</td>
<td>1.16</td>
<td>1.70</td>
<td>1.11</td>
<td>3.08</td>
<td>1.20</td>
<td>6.92</td>
<td>2.15</td>
<td>7.37</td>
</tr>
<tr>
<td>A</td>
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<td>0.87</td>
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<td>1.20</td>
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<td>1.1</td>
<td>2.1</td>
<td>1.1</td>
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<td>1.1</td>
<td>2.1</td>
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<td>2.32</td>
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<td></td>
</tr>
</tbody>
</table>

**Notes:** All reported scores are baseline scores. *Only reported Native American scores: ** Only reported Spanish scores; *** Only reported Caucasian scores. *Figures as reported in article. Very difficult to ascertain between SEMCD and SEMDG from article description.

Key for studies is available in Appendix 28
Mann Whitney-U Tests
Mann Whitney-U Tests were run comparing groups (male and female, urban and rural, arthritis, asthma and heart (yes or no)) with each of the Stanford scales. Table 6-8 presents e-survey median and effect sizes for each of the groups. A number of statistical differences were noted however most had small effect size $r = .12 – r = .27$. One test revealed a significant difference in health distress levels between those with heart disease ($Md = 1.00, n = 51$) and those without heart disease ($Md = 2.00, n = 197$) of $p = .000$ with a moderate effect size of $r = .32$ ($U = 2762.5, z = -4.962$). This was a somewhat unusual result; however individuals with heart disease often do not associate symptoms with heart disease because of the insidious and non-specific presentation and older individuals may have more difficulty detecting and interpreting symptoms (Lam & Smeltzer, 2012; Riegel et al., 2010). In fact, a recent representative study of over 10,000 respondents undertaken across nine European countries revealed the majority of respondents recognised very few of the initial heart attack and stroke symptoms (Mata, Frank, & Gigerenzer, 2012).
Table 6-8: E-survey median scores and effect size by sex, main/non-main centres and selected long-term conditions and Stanford Scales

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Median</th>
<th>n</th>
<th>Median</th>
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<td>Males</td>
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<tr>
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<td>Non-Main Centre</td>
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<tr>
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<td>.24</td>
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<tr>
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<td>7.25</td>
<td>166</td>
<td>8.00</td>
<td>.14</td>
</tr>
<tr>
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<td>165</td>
<td>8.67</td>
<td>.25</td>
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<tr>
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<td>150</td>
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<td>7.50</td>
<td>.18</td>
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<td>197</td>
<td>2.00</td>
<td>.32</td>
</tr>
<tr>
<td>DASRA</td>
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<td>197</td>
<td>1.25</td>
<td>.19</td>
</tr>
<tr>
<td>SEMCD</td>
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<td>6.58</td>
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<tr>
<td>SEOHCFF</td>
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<td>.13</td>
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<tr>
<td>SECPHY</td>
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<td>SEMDG</td>
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<td>.16</td>
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<tr>
<td>SERSA</td>
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<td>9.00</td>
<td>184</td>
<td>7.00</td>
<td>.19</td>
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</tbody>
</table>

**Correlations**

The relationships between the Stanford scales, age and number of long-term conditions were explored using Spearman rho and Table 6-9 presents the correlation coefficient associations. Data with medium ($r = .30$ to $.49$) and large ($r = .50$ to $1.0$) correlation coefficients are discussed.
**Symptoms Health Distress and Stanford Scales**

There was a strong association between Symptoms Health Distress (SHD) and Daily Activities – Social/Role Activities Limitations (DASRA), \((r = .684, n = 248, p < .000,)\) indicating high levels of distress were associated with greater social and role activity limitations. There was a strong, negative correlation between Symptoms Health Distress (SHD) and Self-efficacy – Managing Chronic Disease (SEMCD), \((r = -.735, n = 214, p < .000),\) suggesting high levels of distress were associated with less self-efficacy for managing a chronic disease. A moderate, negative association was observed between Symptoms Health Distress (SHD) and Self-efficacy – Obtain Help From Community, Family, Friends (SEOHCFF), \((r = -.389, n = 238, p < .000),\) indicating that higher levels of distress were associated with lower levels of self-efficacy for obtaining help. There was a moderate, negative correlation between Symptoms Health Distress (SHD) and Self-efficacy – Communicate with Physician (SECPHY), \((r = -.332, n = 237, p < .000),\) suggesting high levels of distress were associated with less self-efficacy for communicating with a doctor. There was a strong, negative correlation between Symptoms Health Distress (SHD) and Self-efficacy – Manage Disease in General (SEMDG), \((r = -.612, n = 234, p < .000),\) indicating high levels of distress were associated with less self-efficacy for managing a disease in general. A strong, negative correlation was observed between Symptoms Health Distress (SHD) and Self-efficacy – Do Chores (SEDC), \((r = -.601, n = 233, p < .000),\) indicating higher levels of distress were associated with lower self-efficacy for completing household chores, errands and shopping. There was a strong, negative correlation between Symptoms Health Distress (SHD) and Self-efficacy – Social/Recreational Activities (SESRA), \((r = -.687, n = 233, p < .000),\) suggesting high levels of distress were associated with less self-efficacy for continuing with hobbies, recreation and social visits with friends and family.
**Daily Activities - Social/Role Activities Limitations and Stanford Scales**

A strong, negative correlation was observed between Daily Activities - Social/Role Activities Limitations (DASRA) and Self-efficacy – Managing Chronic Disease (SEMCD), \( r = -.724, n = 214, p < .000 \), indicating high social/role activity limitations were associated with lower self-efficacy for managing a chronic disease. There was a moderate, negative association observed between Daily Activities - Social/Role Activities Limitations (DASRA) and Self-efficacy – Obtain Help From Community, Family, Friends (SEOHCFF), \( r = -.400, n = 238, p < .000 \), indicating high social/role activity limitations were associated with lower self-efficacy for obtaining help. A moderate, negative correlation was observed between Daily Activities - Social/Role Activities Limitations (DASRA) and Self-efficacy – Communicate with Physician (SECPHY), \( r = -.317, n = 237, p < .000 \), suggesting high social/role activity limitations were associated with lower self-efficacy for communicating with a doctor. A strong, negative association was observed between Daily Activities - Social/Role Activities Limitations (DASRA) and Self-efficacy – Manage Disease in General (SEMDG), \( r = -.555, n = 234, p < .000 \), indicating high social/role activity limitations were associated with lower self-efficacy for managing a disease in general. A strong, negative correlation was observed between Daily Activities - Social/Role Activities Limitations (DASRA) and Self-efficacy – Do Chores (SEDC), \( r = -.774, n = 233, p < .000 \), indicating high levels of social/role activity limitations were associated with lower self-efficacy for completing household chores, errands and shopping. There was a strong, negative association between Daily Activities - Social/Role Activities Limitations (DASRA) and Self-efficacy – Social/Recreational Activities (SESRA), \( r = -.808, n = 233, p < .000 \), suggesting high levels of social/role activity limitations were associated with lower self-efficacy for continuing with hobbies, recreation and social visits with friends and family.
Self-efficacy - Managing Chronic Disease and Stanford Scales

There was a strong, positive correlation between Self-efficacy – Managing Chronic Disease (SEMCD) and Self-efficacy – Obtain Help From Community, Family, Friends (SEOHCFF), \( r = .559, n = 213, p < .000 \), suggesting high levels of self-efficacy for managing a chronic disease was associated with higher self-efficacy for obtaining help. A moderate, positive correlation was observed between Self-efficacy – Managing Chronic Disease (SEMCD) and Self-efficacy – Communicate with Physician (SECPHY), \( r = .456, n = 212, p < .000 \), indicating high levels of self-efficacy for managing a chronic disease was associated with higher self-efficacy levels for communicating with a doctor. There was a strong, positive association between Self-efficacy – Managing Chronic Disease (SEMCD) and Self-efficacy – Manage Disease in General (SEMDG), \( r = .775, n = 209, p < .000 \), suggesting high levels of self-efficacy for managing a chronic disease was associated with higher self-efficacy for managing a disease in general. A strong, positive correlation was observed between Self-efficacy – Managing Chronic Disease (SEMCD) and Self-efficacy – Do Chores (SEDC), \( r = .710, n = 208, p < .000 \), indicating that high levels of self-efficacy for managing a chronic disease was associated with higher self-efficacy for completing household chores, errands and shopping. There was a strong, positive association between Self-efficacy – Managing Chronic Disease (SEMCD) and Self-efficacy – Social/Recreational Activities (SESRA), \( r = .802, n = 208, p < .000 \), suggesting high levels of self-efficacy for managing a chronic disease was associated with higher self-efficacy for continuing with hobbies, recreation and social visits with friends and family.

Self-efficacy – Obtain Help from Community, Family, Friends and Stanford Scales

A moderate, positive association between Self-efficacy – Obtain Help from Community, Family, Friends (SEOHCFF) and Self-efficacy – Communicate with Physician (SECPHY), \( r = .423, n = 237, p < .000 \), suggesting that high levels of self-efficacy for obtaining help was associated with higher self-efficacy for communicating with a doctor. There was a strong, positive correlation
observed between Self-efficacy – Obtain Help from Community, Family, Friends (SEOHCFF) and Self-efficacy – Manage Disease in General (SEMDG), \((r = .611, n = 234, p < .000)\), indicating high self-efficacy for obtaining help was associated with higher self-efficacy for managing a disease in general. A moderate, positive correlation was observed between Self-efficacy – Obtain Help from Community, Family, Friends (SEOHCFF) and Self-efficacy – Do Chores (SEDC), \((r = .467, n = 208, p < .000)\), suggesting high self-efficacy for obtaining help was associated with higher self-efficacy for completing household chores, errands and shopping. There was a strong, positive association between Self-efficacy – Obtain Help from Community, Family, Friends (SEOHCFF) and Self-efficacy – Social/Recreational Activities (SESRA), \((r = .541, n = 233, p < .000)\), indicating that high levels of self-efficacy for obtaining help was associated with higher self-efficacy for continuing with hobbies, recreation and social visits with friends and family.

**Self-efficacy – Communicate with Physician and Stanford Scales**
There was a strong, positive association between Self-efficacy – Communicate with Physician (SECPHY) and Self-efficacy – Manage Disease in General (SEMDG), \((r = .513, n = 234, p < .000)\), suggesting that high self-efficacy for communicating with a physician was associated with higher self-efficacy for managing a disease in general. A moderate, positive correlation was observed between Self-efficacy – Communicate with Physician (SECPHY) and Self-efficacy – Do Chores (SEDC), \((r = .384, n = 233, p < .000)\), indicating that high self-efficacy for communicating with a physician was associated with higher self-efficacy for completing household chores, errands and shopping. There was a moderate, positive correlation observed between Self-efficacy – Communicate with Physician (SECPHY) and Self-efficacy – Social/Recreational Activities (SESRA), \((r = .417, n = 233, p < .000)\), suggesting high levels of self-efficacy for communicating with a physician was associated with higher self-efficacy for continuing with hobbies, recreation and social visits with friends and family.
Self-efficacy – Manage Disease in General and Stanford Scales
A strong, positive correlation was observed between Self-efficacy – Manage Disease in General (SEMDG) and Self-efficacy – Do Chores (SEDC), $r = .587$, $n = 233$, $p < .000$, indicating high self-efficacy for managing a disease in general was associated with higher self-efficacy for completing household chores, errands and shopping. There was a strong, positive association between Self-efficacy – Manage Disease in General (SEMDG) and Self-efficacy – Social/Recreational Activities (SESRA), ($r = .691$, $n = 233$, $p < .000$), suggesting high levels of self-efficacy for managing a disease in general was associated with higher self-efficacy for continuing with hobbies, recreation and social visits with friends and family.

Self-efficacy – Do Chores in General and Self-efficacy - Social/Recreational Activities
There was a strong, positive association between Self-efficacy – Do Chores (SEDC) and Self-efficacy – Social/Recreational Activities (SESRA), ($r = .819$, $n = 233$, $p < .000$), indicating that high levels of self-efficacy for completing household chores, errands and shopping was associated with higher self-efficacy for continuing with hobbies, recreation and social visits with friends and family.
Table 6-9: E-survey Spearman’s rho correlations between Stanford Scales, age and number of long-term conditions

<table>
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<tr>
<th>Variable</th>
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<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>214-251</td>
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<td>.289**</td>
<td>-.256**</td>
<td>-.053</td>
<td>0.17</td>
<td>.222**</td>
<td>.088</td>
<td>.234**</td>
<td>.217**</td>
<td>.017</td>
<td>.102</td>
</tr>
<tr>
<td># LTC</td>
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<td>.110</td>
<td>.143*</td>
<td>-.031</td>
<td>-.018</td>
<td>.138*</td>
<td>.007</td>
<td>-.106</td>
<td>-.090</td>
<td></td>
</tr>
<tr>
<td>SHD</td>
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<td>1</td>
<td>.684**</td>
<td>.221**</td>
<td>-.735**</td>
<td>-.389**</td>
<td>-.332**</td>
<td>-.612**</td>
<td>-.601**</td>
<td>-.687**</td>
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<tr>
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<td>.260**</td>
<td>-.724**</td>
<td>-.400”</td>
<td>-.317**</td>
<td>-.555”</td>
<td>-.774”</td>
<td>-.808”</td>
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<td></td>
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<td>-.038</td>
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<td>-.131”</td>
<td>-.205”</td>
<td>-.180”</td>
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<td>.802”</td>
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<td>.611”</td>
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<td>.691”</td>
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<tr>
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<td></td>
<td></td>
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</table>

*Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.01 level (2-tailed)
Summary of correlation findings
Results from the correlation table reveal Medical Care – Communication with Physician (MCCPHY) had slight relationship with Stanford Scales. Other results suggest high levels of discouragement, fear, worry and frustration as measured by Symptoms Health Distress (SHD) and limitations to social and role activities as measured by Daily Activities – Social/Role Activities Limitations (DASRA) impact on many domains of the lives of individuals living with a long-term condition. Results also suggest self-efficacy is negatively impacted for:

- managing physical symptoms;
- obtaining physical and emotional support;
- confidence in discussing issues pertaining to a long-term condition with a doctor;
- the daily self-management of a long-term condition;
- reduction of emotional distress caused by the long-term condition;
- completing household cleaning tasks, errands and shopping; and,
- confidence for continuing hobbies, recreational and other social activities when high health distress and greater social role activity limitations are experienced. However, correlations also suggest high efficacy (in SEMCD, SEOHCFF, SECPHY, SEMDG, SEDC and SESRA) results in a belief that:

- obtaining physical and emotional support;
- confidence in discussing issues pertaining to a long-term condition with a doctor;
- the daily self-management of a long-term condition;
- reduction of emotional distress caused by the long-term condition;
- completing household cleaning tasks, errands and shopping; and,
- confidence for continuing hobbies, recreational and other social activities can be undertaken with success.
Key results

Overall there was a good response to the e-survey with comparable demographic ratio of female to male respondents for internet based surveys utilising Stanford scales in America and the United Kingdom (Lorig, et al., 2008; Lorig, et al., 2006). A comparison with published Stanford reliability coefficients showed this study had good reliability with Cronbach’s alpha values above .70. Although this study violated normality assumptions for distribution, comparison with Stanford’s published results and other studies using Stanford scales suggests this may be a common issue.

Comparison of mean and standard deviation scores with available Stanford scores indicated respondents for this study reported better self-rated health, less health distress and perceived social, role activity limitations. The mean scores show that the study sample reported higher self-efficacy for managing a long-term condition, talking with a doctor, undertaking chores and social/recreational activities with slightly higher mean scores for self-efficacy for obtaining help from community, family and friends than the comparative Stanford sample. Comparable self-efficacy for getting information about a long-term condition was evident between the two scores. However, the mean scores for the current sample showed respondents reported poorer perceived ability to communicate with doctors through preparing a question list, asking questions about things they want to know and do not understand about treatment and discussing personal problems related to their long-term condition than the Stanford sample (Lorig, et al., 1996; Stanford School of Medicine, 2007).

Using a one third cut off to compare health status, self-management behaviour and self-efficacy between the top one third and the other two thirds of respondents indicated that although most respondents reported coping well the reality for many is that they are not. 64% of respondents rated their health as only poor to good, just over 60% have less confidence for managing their symptoms, issues and emotional distress arising because of the chronic disease
and 65% were not as confident about getting support and help from family, friends or community resources that they felt they needed. Also of interest was the high proportion of respondents (87%) indicating they did not often prepare a list of questions, ask questions and seek clarification about treatment and discuss personal problems related to their illness with their doctor suggesting communication with their doctor about their long-term condition could be improved.

Results from correlations suggest health distress and social/role activity limitations impact significantly on respondent’s self-efficacy to manage symptoms and continue with activities of daily life while living with a long-term condition/s. Also evidenced was the suggestion that high efficacy leads to a belief that daily living with a long-term condition is possible.
Profile of respondents from  
Section 3: Open-ended e-survey questions
The sample consisted of seventy five males and 139 females who responded to some or all the voluntary open-ended questions. Other demographic characteristics are reported earlier in this chapter. Table 6-10 lists the questions and the number of responses to each of the eight main questions.

Table 6-10: Number of responses to eight open-ended questions

<table>
<thead>
<tr>
<th>E-survey questions</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do you think of the statement “a long-term condition is a lonely journey?”</td>
<td>213</td>
</tr>
<tr>
<td>Please explain.</td>
<td></td>
</tr>
<tr>
<td>What has helped you to accept that you have a long-term condition? Please explain.</td>
<td>212</td>
</tr>
<tr>
<td>How has the impact of your long-term condition affected your partner and/or family relationships?</td>
<td>214</td>
</tr>
<tr>
<td>Sometimes people with long-term conditions feel a sense of loss or limitations, what has been your experience of this?</td>
<td>210</td>
</tr>
<tr>
<td>What are the main issues for you when managing your long-term condition?</td>
<td>211</td>
</tr>
<tr>
<td>Someone has expressed the opinion that looking after your long-term condition is a “moral duty”. How would you respond to this statement?</td>
<td>208</td>
</tr>
<tr>
<td>How would you explain self-care to someone else?</td>
<td>196</td>
</tr>
<tr>
<td>Please share in your own words what you understand by the term “self-management”.</td>
<td>195</td>
</tr>
<tr>
<td>Total responses</td>
<td>1659</td>
</tr>
</tbody>
</table>

Findings from e-survey open-ended questions
Thematic analysis for the eight open-ended questions within the e-survey revealed two major themes of “regulation” and “loss”. The major theme of “regulation” includes the sub-themes of “self-responsibility”, “necessary choice”, “personal duty” and “reciprocity”. The major theme of “loss” includes “restriction”, “regret”, “coping” and “attitude”. The major themes, their subthemes and categories are outlined in Table 6-11. Definitions for major themes, sub-themes and categories have been derived from the Merriam-Webster online dictionary and thesaurus (Merriam-Webster, 2013).
Table 6-11: Themes from e-survey open-ended questions

<table>
<thead>
<tr>
<th>Major Themes</th>
<th>Sub-themes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regulation</td>
<td>Self-responsibility</td>
<td>Taking charge</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Isolation</td>
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<tr>
<td></td>
<td></td>
<td>Vigilance</td>
</tr>
<tr>
<td></td>
<td>Necessary choice</td>
<td>Essential choice</td>
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<td></td>
<td></td>
<td>Planning</td>
</tr>
<tr>
<td></td>
<td>Personal duty</td>
<td>Role of self</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Role of self to significant others</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Role of self to society</td>
</tr>
<tr>
<td></td>
<td>Reciprocity</td>
<td>Reciprocity between self and others</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reciprocity between self and health system/government</td>
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**Regulation**

“Regulation” has been defined as the adjustment an individual makes to return equilibrium and bring order and control back into one’s life when coping with a long-term condition. The theme of “regulation” reveals the underlying struggle for respondents of wanting to have control of the long-term condition and situation they find themselves in (through the sub-categories of “self-responsibility”, “necessary choice” and “personal duty”) and of being aware that there are times where they are unable to successfully regulate so must cede some control to others (“reciprocity”) in order regain order and equilibrium for themselves and their family. The control relinquished to others is based on trust that family, doctor or health system will support and suggest the right thing to try or do, thus enabling the individual recommence self-regulation of the
condition for themselves. This theme has four sub-themes of “self-responsibility”, “necessary choice”, “personal duty” and “reciprocity”.

**Self-responsibility**

The first sub-theme of “self-responsibility” has been defined as the individual imposing a specific duty, responsibility, obligation and/or trust on themselves. The categories of “taking charge”, “isolation” and “vigilance” contribute to the sub-theme of “self-responsibility”.

“Taking charge” has been defined as a position of leadership or supervision. Respondents wrote how they felt they were personally in charge of looking after their long-term condition/s. Some suggested quite strongly that looking after a long-term condition was not other people’s responsibility – it was up to the individual. This respondent quote illustrates the belief that ultimately how to live successfully with a long-term condition rests with the person with the long-term condition. Only they can work it out.

*In the end it will always be YOUR [emphasis in original quote] condition, no one else’s. You have to cope and live with it (Q1, 232).*

The following quote illuminates another respondent’s belief that looking after a long-term condition is most definitely not another’s duty.

*I think they need a reality check, and they need some kind of mental health help, no one should feel it is a duty to look after me (Q5, 173).*

The third quote reveals quite nicely how this respondent believed they were in charge of their life and any support received from others was with their consent and in partnership with them.

*Doing what I can for myself and ensuring that any support from anyone/anywhere is done in partnership with me and with my full consent and choice around issues that concern me. I lead and am responsible for my life (Q7, 165).*
“Taking charge” highlights how respondents believe looking after their long-term condition is up to them, they are in charge, have overall supervision and it is their responsibility to look after themselves.

The second category contributing to “self-responsibility” is “isolation” which has been defined as a feeling of being on one’s own. “Isolation” reveals facets of aloneness, of others never truly understanding and of a road only travelled by one. This respondent’s quote illustrates how their long-term condition has isolated them through the visible effects of the condition and their resulting decreased self-confidence.

I don't have a partner but I would say that my eczema in particular has had a big impact on my relationships with family - it affects my confidence and general outlook on life and has stopped me participating in a lot of activities. I don't feel confident about meeting a potential partner, either as I feel very self-conscious about my condition (and not very attractive!) (Q3, 408).

“Isolation” is revealed within this respondent’s quote through the belief that other people are not able to really know what another person experiences.

No one can essentially know what someone else is going through. Our understanding of each other is only ever partial (Q1, 197).

“Isolation” demonstrates how respondents feel they remain alone even though they may have relationship with others, but remain solely responsible for dealing with the day to day minutiae of living with a long-term condition.

The final category contributing to “self-responsibility” is “vigilance”. “Vigilance” has been defined as careful watch for possible danger or difficulties. “Vigilance” is revealed within this respondent’s quote through highlighting the belief that only the individual person can know their body and therefore only they can act on cues their body gives them.

You know your body best, so act on your own instinct if you think things are not right (Q7, 164).
“Vigilance” is also evidenced within this respondent quote and shows that the surveillance required is constant, on-going and all consuming.

"Constant vigilance". ;) Seriously, I would explain it as having to prioritise a lot more carefully than most people, having to be aware of my own shortcomings and the pitfalls around me, and having to commit to a life-long plan of medication, diet, rest, and exercise regardless of whatever else it is I would rather be doing (Q7, 193).

Respondents described monitoring the situation, being aware of shortcomings and pitfalls, of listening to and knowing their own body thus maintaining self-responsibility for looking after their long-term condition. The categories of “taking charge”, “isolation” and “vigilance” further contribute to the theme of “self-responsibility” and reveal respondents’ beliefs about their role in managing their long-term condition/s.

_necessary choice_

The second sub-theme of “necessary choice” has been defined as a required choice made to achieve certain personal result or effect and has two categories, “essential choice” and “planning”.

“Essential choice” has been defined as a choice that is unavoidable or of utmost importance. “Essential choice” revealed respondents believed if they did not look after their long-term condition/s, no one else would and they would be the one to suffer the ill effect of choosing not to do so. This respondent quote reveals the feeling of the unavoidable nature of the choice. If they do not choose wisely – they and only they suffer the consequences.

_I don't have much choice. It's me that suffers if I don't (Q5, 154)._

“Essential choice” illuminates how respondents just get on with looking after their long-term condition because the consequences of not doing so are unpleasant, be it physically, or because the symptoms of the long-term condition impact on their ability to function in their day to day life.
“Planning” has been defined as a detailed, orderly arrangement of life in order to meet an overall objective, goal or aim. Respondent quotes described taking precautions, being self-disciplined, goal setting and developing a programme of “self-management”. This respondent’s quote reveals planning through being organised with a bag ready and having documented current medications and recent hospital visits for the emergency hospital admission.

*If you know hospital admission is a likely outcome - have a bag ready - make sure the family have documented the medication you are on and how often, your hospital admissions and any other info they need. Help them to help you (Q7, 181).*

The next quote evidences how the respondent plans management of their long-term condition through finding appropriate information and then maintaining independence through self-discipline.

*Start off with arming yourself with the right information and be self-disciplined enough to maintain a regime for self-betterment and independence (Q8, 226).*

This following quote likens self-management to servicing a car – self-management tasks must be planned. There are regular tasks and those that only need to be undertaken every now and then.

*I describe as being like servicing your car. There are things that need to be done regularly and other things that are intermittent (Q7, 216).*

“Planning” revealed a number of different ways respondents negotiated the extra “jobs” arising from having a long-term condition and the choices they needed to make in order to achieve their personal goal, result or effect. The categories of “essential choice” and “planning” further contribute to the theme of “necessary choice” and reveal respondent’s beliefs about their role and how they undertake to manage their long-term condition/s.

**Personal duty**  
The third sub-theme of “personal duty” revealed how respondents felt they were obliged to look after their long-term condition for personal, family and societal reasons. “Personal duty” has been defined as an act required by an individual...
because of social custom or their position in society. The categories of “role of self”, “role of self to significant others” and “role of self to society” further contribute to the theme of “personal duty” and reveal respondents’ beliefs about their role in managing their long-term condition/s for themselves, their family and society.

“Role of self” has been defined simply as the role of the individual in looking after their long-term condition. Respondents explained how they looked after their long-term condition for themselves in order to have good quality of life. This respondent quote illustrates how the respondent links compliance with how to look after their long-term condition with maintenance of a good quality of life.

“If I don't look after it then I wouldn't expect others to have to do that for me. Compliance with treatment instructions and directions is important if I am to maintain a good quality of life (Q5, 174).

“Role of self” revealed the personal duty respondents felt toward themselves. A “doing what they needed to do” in order maintain an acceptable quality of life thus facilitating a capacity to enjoy life to its fullest despite living with a long-term condition.

“Role of self to significant others” has been defined as the obligation an individual feels toward family and or friends in looking after their long-term condition. Respondents wrote how they looked after their long-term condition for their family because they believed they were responsible and it was a personal duty to do so. The first quote illuminates how the respondent does not wish to be a burden on their family so believes it is their duty to look after themselves.

“A personal duty, so as not to be a burden on your family (Q5, 142).
The second quote reveals a slightly different facet of “role of self to others” in that it highlights the parental responsibilities of the respondent and how these drive her to be responsible when looking after herself.

*I am a mother and I have to be responsible* (Q5, 208).

“Role of self toward significant others” showed how the individual felt they were obliged to look after themselves because they had others to care for.

“Role of self to society” has been defined as the obligation the individual feels they owe other people. “Role of self to society” reveals how respondents show their personal obligation for looking after a long-term condition extends beyond themselves and their family to the wider society. This respondent’s quote illustrates the awareness of the respondent of the economic cost to the tax payer if they do not look after their long-term condition appropriately.

*If you don’t look after your long term condition, it not only affects you but sucks thousands of taxpayer dollars into looking after you* (Q5, 147).

“Personal duty” exposes respondents’ beliefs about their perceived obligation to themselves, significant others and society when diagnosed with a long-term condition. It reveals individuals feel obligated to look after their long-term condition in order to avoid hurting themselves or becoming a burden to their families and friends or society in general.

*Reciprocity*

The fourth sub-theme, “reciprocity”, has been defined as a mutual give and take, shown by both sides, a supportive, cooperative relationship. The categories of “reciprocity between self and others” and “reciprocity between self and health system” contribute to the theme of “reciprocity”.

“Reciprocity between self and others” has been simply defined as the cooperative and supportive relationship existing between an individual and those living and interacting with them – i.e. family and friends or doctors. “Reciprocity between self and others” highlights the reciprocity of support the
individual understands to exist between themselves and others. As this quote reveals, the respondent was aware of the two way nature of the relationship. Receiving support for a long-term condition from health professionals, family and friends means the respondent has a responsibility to look after themselves as well as they can.

*But if you are expecting health professionals and friends and families to be supporting you, then I do think you have a responsibility to do your part too and take care of yourself as best you can (Q5, 172).*

“Reciprocity between self and others” reveals the relationship that must exist between the individual and others in order to cope with and effectively look after a long-term condition.

“Reciprocity between self and health system/government” has been defined as the individual, the combination of resources that contribute to delivery of health services to people and the governing body of a country working together to assist the individual to look after themselves. This category reveals how individuals understand that the relationship extends beyond themselves to health system/government level and that the individual cannot look after their long-term condition by themselves. This respondent’s quote reveals the understanding that the health system is paid for by working individuals through the taxation system for the benefit of all.

*It is a moral duty for the health system because they are there for that reason, to look after the health and well-being of the population. It's paid for by all of us, for the benefit of all of us (Q5, 375).*

One respondent described their expectation of support from the health system/government or others coupled with a responsibility to do the best they could to look after their long term condition. However, their quote reveals they believe the health system/government is not necessarily living up to the respondent’s expectation about the relationship.

*We all have a responsibility to look after our health, yet cigarettes and alcohol are still being sold and consumed, healthy*
food is expensive to access, gyms are not accessible to those most in need of one, large funds are spent managing illness instead of promoting and funding early healthy behaviour modifications to prevent disease (Q5,195).

“Reciprocity” reveals the underlying belief that looking after a long-term condition in the New Zealand context is a two way relationship between an individual and their family, friends, health professionals and the health system/government. It shows the underlying belief that looking after a long-term condition cannot be undertaken alone. The four sub-themes of “self-responsibility”, “necessary choice”, “personal duty” and “reciprocity” illuminate the struggle respondents face daily in regulating their lives and in controlling the changes the long-term condition brings to their and their families’ lives.

**Loss**
The theme of “loss” revealed aspects of being deprived of or being without something that the person has had previously. The theme of “loss” has four sub-themes – “restriction”, “regret”, “coping” and “attitude”. These four sub-themes present two sides of the experience of “loss” through the negative experiences of “restriction” and “regret” and the more positive aspects of respondents’ attitude and how they cope with and move on from diagnosis of a long-term condition.

**Restriction**
The sub-theme of “restriction” revealed how the long-term condition exerts some control over what the individual is, or what family members are, able to do in their everyday life. “Restriction” has been defined as limitations imposed by the long-term condition and has been split into “restriction for self” and “restriction for others”.

“Restriction for self” illuminates the physical symptoms of fatigue, pain, breathlessness, memory loss, decreased sexual function, continence issues, decreased mobility and low mood experienced by some of the respondents and the impact these have on their lives. This quote reveals the many physical,
emotional and relationship changes experienced as a result of living with a long-term condition.

Multiple medications induced erectile dysfunction, snappy, crabby, frustrated, not the sports coaching Granddad I used to be, physically incompetent, silly old twerp who has to sit down after walking in from the car until he gets his breath back. Loss of memory possibly due to medication is embarrassing in that I have to write everything down or else I forget (Q3, 267).

“Restriction for others” shows how the impact of the long-term condition affects the family and limits the activities of the family. This respondent’s quote illustrates how the family has given up many activities because of their parent’s illness and treatment requirements.

They [the children] have had to give up team sports for Saturday play as I am unable to get them, there let alone support them and the team. Our family life revolves around my dialysis times which are never consistent or reliable due to machine failure or some other issue which can arise (Q6, 388).

The sub-theme of “restriction” through “restriction for self “and “restriction for others” illuminates the limiting and sometimes disruptive nature of a long-term condition on past and present activities for both the individual and their partner and family.

Regret

The sub-theme of “regret” has been defined as missing very much or to mourn the loss of something and illuminates the personal cost to the individual and the regret the individual feels. Respondents wrote how they experienced identity crisis, loss of control, loss of their future, dreams and careers, of the financial impact, the frustration around the loss of health, their past life and abilities as a result of the diagnosis of a long-term condition. This respondent’s quote illustrates how their employment opportunities have been limited because of the impact of their long-term condition on their life.

I have turned down an employment position, because I couldn't commit to the two years and know wholeheartedly or with any certainty that I would be capable of holding the position for the two years, and not get half way through and feel that I have let
them down, or taken the opportunity away from someone else (Q4, 155).

This respondent’s quote reveals just how much of an impact diagnosis of a long-term condition has had on their life and the lives of their children. They outline how not being able to work and only receiving a sickness benefit has meant the loss of their home, bankruptcy and an uncertain future for them and their children.

I had to stop work immediately for safety reasons - I was self-employed. I got a sickness benefit, however I lost my house as it did not cover my mortgage. I am now bankrupt and living in a tiny rental with 5 dependent children. I have no idea how I will recover what I have lost financially and I doubt I ever can (Q3, 223).

Respondents also wrote about the regret they felt about the extra stress, worry, and workload the effect of the long-term condition has on their family and the changes their family have had to make to accommodate the effect of the long-term condition. This respondent’s quote reveals the regret they feel that family have had to witness the extreme symptoms of their illness.

They have had to see me gasp for breath and be in life threatening situations and this is very scary for them (Q3, 181).

This quote further highlights how the children’s lifestyle with sport, music lessons and pets has been altered through loss of finance because of a long-term condition.

My children have lost pretty much everything, including being able to play sports and take music lessons. I could not afford to feed our cats and dog, so they had to be put to sleep. Basically our lives have been completely and utterly devastated by this illness. But we will survive and we will make it as a family, one way or another (Q3, 223).

“Regret” highlights how the respondents miss their past lives and grieve changes the long-term condition has wrought in their life and the life of their family.

Coping

“Coping” illuminates some of the ways respondents adjust to having a long-term condition. “Coping” has been defined as the strategies an individual uses to face and deal with problems or difficulties. As this respondent’s quote highlights,
adjustment takes time, knowledge, support and encouragement from family and ownership by the individual for the consequences of their actions.

Time, knowledge, support and encouragement from loved ones, family and friends. Ownership of what I have to do and understanding the why it’s important for me to continue with the choices I make, and consequences (Q2, 257).

Respondents revealed they used knowledge and education, hobbies, sports, their personal belief, support from family and friends and other strategies to come to terms with diagnosis of a long-term condition and the daily difficulties the condition presented.

Attitude
“Attitude” has been defined as a mental state, feeling, emotion or outlook on life and can be negative or positive. “Attitude” contributes the theme of “loss” through revealing how respondents maintained a positive attitude (most of the time), were flexible, disciplined, and saw the long-term condition as a challenge or opportunity. As this respondent’s quote illustrates, the focus is on the positives in their life and they make life happen for themselves.

I live by the philosophy of being thankful for what I have, rather than wanting what I do not have. Maximising opportunities to do the things I am able to do (which is most things), and adapting environments or behaviours to make activities accessible (Q2, 172).

This quote reveals gratitude for life and medical advancements but also minimising of their experience through the statement “there are always others worse off than me”.

There is always someone worse off than me and I am lucky to be alive. 100 years ago - I would have been dead by now (Q2, 238)

Other respondents were grateful for a second chance at life and were driven to use their time wisely as they felt they were given the second chance for a particular purpose, as this respondent quote illustrates.

When I was told that I had died and come back, I felt the Lord must have saved me for a reason so I now have a moral obligation to acknowledge His Saving Grace and use my time as best as I can, in His service by helping others (Q5, 267).
“Attitude” revealed a number of different ways respondents came to terms with and moved on from diagnosis of a long-term condition perhaps facilitating acceptance of the loss experienced. Overall the theme of “loss”, with sub-themes of “resignation”, “regret”, “coping” and “attitude” reveals both the loss experienced and strategies utilised by respondents after diagnosis of a long-term condition. The two themes of “regulate” and “loss” unite views of respondents with diverse long-term conditions and illuminate some of the underlying views and beliefs this group have about management of these conditions and their ability to self-care.

Summary of findings from e-survey open-ended questions with participants living with long-term conditions

The theme of “regulation” revealed the underlying struggle and adjustments respondents experienced and made in order to control the long-term condition and situation (through the sub-categories of “self-responsibility”, “necessary choice” and “personal duty”) and of being aware that there were times where they were unable to self-regulate, so must cede some control to others (reciprocity) in order to return to equilibrium, order and control in one’s life. Sub-categories of “self-responsibility”, “necessary choice”, “personal duty” and “reciprocity” contributed to the theme of “regulation” through revealing:

- how respondents have imposed on themselves the specific duty and obligation for management of a long-term condition and thus believe they are solely responsible because:
  looking after a long-term condition was not other people’s responsibility – it was up to the individual;
  the individual does not feel others ever truly understand what it is like to live with a long-term condition, and;
only the individual can listen to and know their own body, monitor the situation and be aware of potential shortcomings and pitfalls.

- choices respondents made that were:
  - unavoidable or of utmost importance because the consequences of not doing so were unpleasant, be it physically, or because the symptoms of the long-term condition impacted on their ability to function in their day to day life;
  - planned and detailed, in order to meet goals or aims and maintain a semblance of order in life;
- the sense of obligation felt by the individual to themselves, in order to enjoy life to its fullest; to their family as a responsible partner or parent; and to avoid becoming a burden to society;
- the underlying beliefs that looking after a long-term condition in the New Zealand context:
  - cannot be undertaken alone;
  - was a two way relationship between an individual and their family, friends, health professionals and the health system/government. However, some respondents believed the health system/government was not always living up to its part of the two way relationship.

The theme of “loss” revealed the negative aspect of being deprived or without experienced by respondents, and some positive strategies utilised to move on from diagnosis of a long-term condition. Sub-categories of “restriction”, “regret”, “coping” and “attitude” built on the theme of “loss” through illuminating:

- how the physical symptoms impact on the individual and how the long-term condition affects family and limits the activities of the family;
- the grief the individual feels over the financial impact, the loss of their future, dreams, career, health, past life and abilities and regret
over the extra stress, worry and workload, the effect of the long-term condition has on their family and the changes their family have had to make to accommodate the long-term condition.

- ways respondents adapt to having a long-term condition, and;
- how respondents were flexible, disciplined, and saw the long-term condition as a challenge or opportunity. Some respondents also shared how they felt even though they had a long-term condition; there were always others worse off than themselves.
Chapter 7: Results

Nurse focus group and interviews

Self-management is when you take control
and manage yourself and what you are doing.
Self-management is taking responsibility (E-survey, 421).

Introduction
This chapter presents findings from the nurse focus group and interviews exploring views and beliefs regarding their role in the management of long-term conditions. A profile of participants is provided and the remainder of the chapter defines, describes and illustrates identified themes arising from these interviews.

Profile of nurse focus group participants
The focus group consisted of twelve participants from the Centre for Postgraduate Nursing Studies - Long-term condition management course, a moderator (supervisor LW) and this researcher. The participants work in a variety of settings (tertiary and secondary hospitals, GP practices, Maori Health organisations and specialist clinics), locations (Wellington through to Dunedin), roles (general practice, ward and various specialties) and are undertaking postgraduate study.

Profile of nurse interviewees
The two nurse interviewees work in primary health with a non-government organisation and a tertiary hospital and outpatient clinic. One works with individuals who live with diabetes, asthma, COPD, emphysema, cardiovascular disease and cancer and the other predominantly works with individuals with cardiovascular disease. Both nurses were undertaking postgraduate study.
Findings from nurse focus group and interviews

One major theme of “responsibility” became evident as this researcher read nurse focus group and interview transcripts and categorised relevant quotes. The theme “responsibility” incorporates the sub-themes of “advocating”, “collaborating”, “enabling”, “managing” and “supervising” as shown in Table 7-1. “Responsibility” brings together the nurse interview and focus group transcripts and reveals some of the underlying views and beliefs this group of nurse participants have about their role in the management of long-term conditions. Definitions for major themes, sub-themes and categories have been derived from the Merriam-Webster online dictionary and thesaurus (Merriam-Webster, 2013).

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Responsibility

The theme of “responsibility” has been defined as liable to be called on to answer; holding a specific duty and/or trust. The theme of “responsibility” suggests a nurse belief of a moral or legal obligation for their conduct to themselves, the patient, the health system and governing bodies. Because of this, the nurse undertakes to advocate, collaborate, enable, manage and supervise in order to assist the individual with a long-term condition to self-manage. One
particular story, communicated by a nurse participant, encapsulates this overall theme of responsibility through the story of a man who had been discharged from hospital just prior to the September 2010 earthquake. This nurse noted that he had commenced on a powerful antidiuretic which required close monitoring via blood work. The appropriate people were followed up with telephone calls, facsimile of blood forms and instructions and requested a copy of the results. The man was relocated to another rest home because of earthquake damage and not long after readmitted to hospital with severe renal failure. He died a few days after readmission.

The nurse’s quote illustrates advocacy, collaboration and coordination for the patient through follow up phone calls to the GP and rest home staff in order to coordinate the blood test request. “Managing” is evidenced through the nurse instigating having the rest home staff request GP follow up for the required blood tests. Supervising is apparent in the initial read of the discharge letter and the ensuing follow-up, despite the patient having technically left the care of the hospital.

Yeah, Monday was a wee bit, everyone was still a bit jittery, people were at work, not at work. Tuesday, I re-read the discharge letter, and said, “Oh, oh, this guy’s been started on metolazone every second day,” I think it was. So, I, um, rang the GP, I rang the, ah, um, [name of rest home] and said, “Look, I understand you are really busy.” He’d been moved out of his room because it was damaged, he was just sort of in the lounge. And [I] said, “This man’s been started on metolazone, it’s incredibly potent. You need to have a blood test,” you know, “today or tomorrow. Can you get your GP to follow that up?” And, um, “If he ends up moving from [rest home], to wherever else,” you know, “can you just pass on?” So I said, “I’ll fax through the req [requisition] for the blood.” And so I did that, put a copy to come to us, um, a copy of his results, and um, what blood test we wanted and further explanation again about being a potent drug and needing follow up blah, blah, blah, faxed it through and then didn’t hear.

But I’d heard that he’d been shipped out to, went to another rest home, but I didn’t hear that till Monday. I thought well, that’s good, well, they’ll be following that up. The next minute he’s
admitted to [name of ward] with severe renal failure. [Whispers] He died in about three days [normal voice] and I felt really bad because you know, I had, we, the copy of the results never came back to us. Of course, I got distracted and hadn’t written it down to go and check, [because] as far as I was concerned the GP was checking it. I’d worked this plan for the, and you know, the poor [rest home] staff. they were stressed, you know, having to move, you know, at you know, it really fell through the cracks. And um, of course, then a [specialty] physician said to me, “Thought you were following him up in the community.” I said, “Well hang on; there’s been this big earthquake” (Participant 2).

The following discussion and illustration with participant quotes highlights how the sub-themes of “advocating”, “collaborating”, “enabling”, “managing” and “supervising” are facets of the theme of “responsibility” and reveals nurse participants’ beliefs about their role in long-term condition management.

Advocating
The first sub-theme of “advocating” has been defined as someone who supports or promotes the interests of another. Nurses’ comments revealed that being an advocate was sometimes confrontational and was about encouraging other health professionals to think outside the square for treatment options for their patient. This participant’s quote illustrates how the nurse advocated for the patient choice to die through challenging the consultant’s stance on the issue.

You know, there have been huge arguments between a patient and a consultant. I had a consultant come out and say “Well you’re [going to] die.” You know, straight up. “They’ll be dead.” You know. And I said, “Isn’t that their choice?” You know. “Can’t they choose to?” Can’t you choose to say no to something? Aren’t we told that we’re allowed to choose to take something or not, but some doctors struggle to let that go (Participant 1).

“Advocating” highlights how the nurse participants endeavoured to support and promote the interests of the individual living with a long-term condition.

Collaborating
“Collaborating” has been defined as participating or assisting in a joint effort in order to accomplish something and the theme was only evident within the two
nurse interviews. Nurse participants discussed the importance of working alongside other team members and how collaboration was an important part of their practice and took time and resources to develop. The following participant’s comment highlights the importance of teamwork and the foundation it provided for her to assist individuals living with long-term conditions.

*Absolute paramount to my whole practice, that [collaboration] oversees it, underpins it and provides the huge foundation for it to work. I must work very collaboratively, um, and I have to network. So that takes years of accumulating, it never ends. It’s a living document (Participant 1).*

The nurse participants’ comments showed they sought to work with other members of the health team in order to improve long-term condition management for the individuals they worked with.

**Enabling**

The third sub-theme of “enabling” has been defined as making able or possible or to provide with means or opportunity. The facets of “coordinating”, “facilitating”, “acting as a portal”, “acting as a conduit”, “perceptibility”, “establishing a therapeutic relationship” and “frustrating” contribute to this sub-theme. “Enabling” revealed the different ways nurse participants attempted to assist individuals to manage their long-term condition/s.

The first category, “coordinating”, has been defined as bringing about common action, movement or condition and was only evident within the two nurse interviews. “Coordinating” revealed how the nurse participants arranged for assessments, communicated with and chased the rest of the team on behalf of the individual in their care. This participant’s quote illustrates how the nurse worked with both the patient and the various wards and doctors to coordinate care for an un-well patient.

*If they’ve [a patient] rung up to say that they’re not so well, and um, their weight’s up, they’re more breathless, and all that, we’ll arrange for them to come into clinic to be assessed. And then, often we will just, or then they can arrange it for them, on what*
would be a good day and they can have intravenous fluids. So that’s a matter of sort of coordinating the [unit], the patient, with the team and getting the prescription and all those sorts of things. And then um, sort of chasing up blood results and things like that. We do that and we chase up whichever doctor about that, um, the [specialist] team or the GP and things (Participant 2).

Through their discussion, nurse participants revealed how they felt they were a lynch pin between the patient, the rest of the healthcare team and other services enabling the individual to self-manage their long-term condition/s.

The second facet of “enabling”, “facilitating” has been defined as bringing about an outcome through on-going indirect, unobtrusive assistance, guidance or supervision. “Facilitating” highlights how nurse participants use different strategies for different individuals, break down self-management tasks into small learnable and achievable steps and approach long-term condition management as a gradual, on-going and long process. The first participant’s quote illustrates facilitation through the description of breaking down a task to assist the individual they are working with, to see it is possible to achieve positive change in their life.

*Taking something very simple, that they can quite easily manage and just doing it in little, little, little steps until they can actually see that they can have some, um, some effect on their own life* (Participant 10).

The second quote highlights a participant’s view of the constant, sometimes time consuming nature of working with individuals with long-term conditions in order to assist the individual to independently undertake a self-management task or goal.

*You might be chipping away and those sorts of people do come back and come back and you don’t sort [of] get rid of them. Is that an awful way to say it? They do keep on accessing the service, so it might be the penny drops after [a while]* (Participant 13).
The third participant’s quote highlights a different approach to facilitation that of fostering a latent potential within a person and encouraging that person’s ability to achieve.

*It is all about empowerment and if you’re going to get self-care in an individual, you have to let them. But even I struggle with that term ‘letting them’. Like who gives me the power to let them do something? They always had it. So I look at me tapping their potential and I do talk to them about “you always had it in you. It was there, you just needed me to identify it and then you recognised it, and now you’ve run with it” (Participant 1).*

Comments reveal how nurses endeavour to facilitate self-management of a long-term condition together with the individual and thus enable more independent self-care.

“The acting as a portal” has been defined as a person serving as a guide or entry point to the health system and can include links to other relevant resources as appropriate. “Acting as a portal” shows how nurse participants planned for self-management failure, for on-going support and saw themselves as a link into the healthcare system for the individual. This participant’s quote illustrates the nurse making sure the individual they have been working with understands they can see the nurse if they find they are not coping.

*But making sure that they know that, if that’s, if they can’t manage that, then they know where to come and they know how to access you (Participant 6).*

This quote highlights how this participant uses their position in the healthcare team to ensure their patients understand they have access to specialist services should they require them.

*So we try and push the point with our patients, we’re an indirect line to their [specialists] (Participant 2).*

The facet of “acting as a portal” reveals the belief that nurse participants feel the need to provide a back door to the health system for individuals in their care to enable individuals to continue to successfully manage their long-term condition/s.
“Acting as a conduit”, the fourth category of “enabling”, has been defined as a means of transmitting or distributing something. “Acting as a conduit” revealed how nurse participants teach and educate, sometimes repetitively, the individuals and family they work with in order to enable self-management of a long-term condition as this participant’s quote illustrates.

I guess it’s just reiterating it. If you think they’re not, they haven’t got it, then you, it is just a matter of, kind of, always reiterating it, being happy to go back and reiterate to them what those basic things are and trying to make it as basic as possible. Um, you know you can try and explain it to the family and things as well (Participant 2).

Nurses also seemed to believe that they required education and knowledge themselves in order to pass this knowledge along to the individuals they work with and this is evidenced in the following participant’s quote.

And making sure that you have the knowledge to put out there to the people who you want to self-care (Participant 6).

From these two quotes, it also seems to be possible that nurses determine the level and rate of information passed on to individuals. The facet of “acting as a conduit” contributes to the sub-theme of “enabling” through highlighting how nurse participants transmit and distribute knowledge to enable the individual to self-manage their long-term condition/s.

The fifth category of “perceptibility” has been defined as capable of being perceived by the senses or the mind. It reveals how nurse participants utilise test results to provide visual feedback and recall of the individual’s past symptom experience to aid understanding of the long-term condition. This quote illustrates how the participant utilised test results to prove to the individual the existence of a long-term condition.

Until they get that, those results, and they can see them, they don’t believe that they’ve got a drinking problem (Participant 8).
This participant’s quote illustrates the process used to assist patients to understand how the body system works, related symptoms and results to educate and enhance understanding of an invisible process.

So usually we spend a good hour with education with the book, with the heart model relating it to their echo and their clinical notes (Participant 2).

And this quote evidences the linking of past symptomatology to the present situation the participant undertakes in order to enhance a patients understanding of their long-term condition.

So if you can say, “Well remember that time you came to [hospital] and you felt like this?” I think, you know, you can give an example of how you really felt; they often remember and learn from it (Participant 6).

The category of “perceptibility” reveals how nurses attempt to make visible the invisibility of symptoms and side-effects in order to enable the individual to understand and better self-manage their long-term condition.

“Developing a therapeutic relationship” has been defined as a relationship between a nurse and the individual that develops over time and exists to meet the needs of that individual. Nurse participants talked about how important it was to make connections, to be honest with people, to challenge, to establish trust and to check out what they could and could not get away with. This is illustrated in the participant’s quote through the imagery of a journey and the nurse walking alongside the other person.

He was saying to have somebody to walk along side you (Participant 1).

The nurse participants’ comments showed they understood the importance of establishing and maintaining a therapeutic relationship and wherever possible, used it to enable the individual to self-manage their long-term condition/s.

The final category of “enabling” is “frustrating”. “Frustrating” has been defined as the emotion felt when one’s expectations are not met. A feeling of frustration
became apparent within the nurse participant’s comments and appears as a negative consequence of their effort to enable individual’s to self-manage. This quote illustrates the underlying frustration experienced by the participant because the patient would not listen to their advice regarding use of diuretics and potential damage to the kidneys.

_We had a guy who really ruined his kidneys ... and was going to need dialysis and everything, but you couldn’t tell him. He was just going to do what he was going to do, because he wanted to be lighter_ (Participant 2).

This second quote illustrates the frustrating nature of needing to allow people to make their own choices, even when it goes against the participant’s knowledge of treatment options.

_He was really sick and he’d stopped his insulin. He died and I was up here, actually, and I found out he died, so I couldn’t attend the tangi. But I went to visit him after I went back, after my study, and he was lying at home in his coffin with the lid off, you know. And in the Maori world you go in and you get to say what you need to, and I did. And I said to him, “You bloody, little pain,” I said. “Jeez, you know, if you’d followed what I knew, but I respect your decision to choose. And I’m glad that you did it your way”_ (Participant 1).

Nurse participants discussed how individuals, despite their best effort to enable self-management, will ultimately do what they want to and of needing to respect that person’s right to choose.

Categories of “coordinating”, “facilitating”, “acting as a portal”, “acting as a conduit”, “perceptibility” and “establishing a therapeutic relationship” highlight the many ways utilised by these nurse participants to enable individuals to self-manage their long term condition. The category of “frustrating” revealed the resignation and exasperation nurse participants felt when their best efforts to enable self-management of a long-term condition were ignored. The theme of “enabling” reveals some underlying beliefs of this group of nurse participants and shows aspects of the complex role nurses perceive they have in the management of long-term conditions.
The fourth and fifth sub-themes of “managing” and “supervising” are very similar. However, the nurse participants’ quotes revealed slightly different facets of their views and beliefs about self-management and their role in assisting the individual living with a long-term condition. The way this researcher has differentiated these two very similar themes is to broadly think of “managing” as nurses make the plan that is to be followed and “supervising” as nurses ensuring the plan is followed.

**Managing**

In addition to the previous explanation, “managing” also incorporates the exercising of executive and administrative direction of someone. “Managing” also speaks of leadership and control. Nurse participants revealed how they looked at the “big picture” and identified potential barriers to self-management, as illustrated in this participant’s quote.

> We have to look at their social circumstances and be practical. Let’s make their, when is their benefit day? Wednesday. I’ll see you on Thursday. You know, so, because that’s, then they’ve actually got the money to get a bus or ... So it’s not just about health and their self-care and their self-management, it is looking at the big picture stuff (Participant 9).

Other participants discussed creating a plan of care from their assessment of the individual as shown in this participant quote.

> We talk about it a lot. And because we share the whole case load, rather than you just have yours and me just have mine and just making individual decisions, we think about them. We both know the patients then quite well. So we talk about our experiences with them, what we’re thinking, what our gut feeling is and all that sort of thing. What do you think we should do? And we often make a plan together and just confirm a plan. And um, often that will involve, we’ll talk about what we think should happen (Participant 2).

This quote illustrates how the participant identified what the individual particularly needed to know and then only imparted the required knowledge.

> It is guided by what they need to know. If you give somebody something in terms of knowledge before they’re ready to get it,
they’re not going to do anything with it or possibly not going to embrace the topic (Participant 1).

The sub-theme of “managing” reveals how nurse participants attempt to exercise overall control of self-management planning and often create the plan separate from the individual leading to nurse management of a long-term condition.

Supervising
“Supervising” has been defined as critical watching and directing. Nurse participants discussed undertaking close monitoring, evaluating and being a safety net to ensure the individual maintained appropriate self-management of their long-term condition. This participant’s quote illustrates the underlying belief that nurses need to ensure self-management is being undertaken appropriately through follow up with the individual.

You’re still going to need someone to evaluate their self-care and support them if they need. … Figure out how they’re going, you know (Participant 14).

This second quote reveals the close monitoring and evaluation this nurse participant undertakes to assist individuals to remain well in the community.

You need to bring them into clinic about every week, at least, or see them twice a week. And go like, “Okay, what are we doing here? What are we doing here?” And, um, and just be really vigilant with making them come in and be assessed, because they’re just not reading. They’ll let their weight, like where her weight was 114 she was getting again up to 118 and not ringing us or telling us. It would go up quickly and she’d end up back in hospital again (Participant 2).

The final sub-theme of “supervising” revealed how nurse participants believe they need to keep a critical watch over and direct individuals with long-term conditions to ensure “the plan” is adhered to.

Overall the theme of “responsibility”, with sub-themes of “advocating”, “collaborating”, “enabling”, “managing” and “supervising”, revealed the underlying beliefs and views about the nurse participant’s role in long-term condition management and the extent to which nurse participants endeavour to
assist the individual to self-manage their long-term condition. “Responsibility” illuminates the nurse’s belief of a moral or legal obligation to the individuals they work with and begins to expose the complicated nature of the nurse patient relationship with management of long-term condition/s.

Summary of findings from nurse focus group and interviews
The theme of “responsibility” suggested a nurse belief of a moral or legal obligation for their conduct to themselves, the patient, the health system and governing bodies. Sub-categories of “advocating”, “collaborating”, “enabling”, “managing” and “supervising” built on the theme of “responsibility” through revealing how nurses:

- supported and promoted the interests of their patient;
- worked alongside team members for the benefit of patients;
- provided the means or opportunity by:
  - arranging assessments, communicating with and chasing the rest of the team on behalf of the individual in their care;
  - using different strategies for different individuals, breaking down self-management tasks into small learnable and achievable steps and approaching long-term condition management as a gradual, on-going and long process;
  - planning for self-management failure and on-going support and seeing themselves as a link into the hospital for the individual;
  - teaching and educating, sometimes repetitively, the individuals and family;
  - utilising test results to provide visual feedback and recalling verbally the individual’s past symptom experience to aid understanding for the individual;
  - making connections, being honest with people, challenging, establishing trust and checking out what they could and could not get away with; however,
- a feeling of *frustration* appeared as a negative consequence of nurse efforts to enable individuals to self-manage.

- looked at the “big picture”, identified potential barriers to self-management, identified people who they thought could or would engage and discussed creating a plan of care from their assessment of the individual.

- undertook close monitoring, evaluated and were a safety net to ensure the individual maintained appropriate self-management of their long-term condition.
Chapter 8:
Discussion and conclusion

Self-management is ... DIY [do it yourself] but needs assistance (E-survey, 390).

Introduction
Self-management was argued to be an integral component of how an individual managed a long-term condition. The idea of self-management appeared to have been appropriated by policy as a tool for assisting individuals to better manage a long-term condition. Self-management was understood by individuals as a reality and a necessity for living life well, and by nurses as part of their role. It is perhaps these differing perspectives that contribute to impacting on an individual’s ability to self-manage. This study aimed, through interviews, an e-survey and a critical discourse analysis to reveal the different perspectives of self-management in the New Zealand context, and how these impacted on an individual’s ability to develop their self-management skills. This discussion begins with a summary of key findings. Findings and results are then interpreted within the context of the rhetoric and reality of self-management. Suggestions follow, drawn from the literature, on how nurses might successfully negotiate the tension that appears to exist between their reality of self-management and the individual’s reality of self-management. The strengths and limitations of the research are outlined, followed by suggestions for future research and an overall conclusion.

The findings identified the discourse of NPH as the dominant influence on both lay and professional understanding of long-term condition management. This approach, which has become prevalent over the past two decades, can be described as the rhetoric of self-management. The basis of this rhetoric stems from two major foci. Firstly, it regards health status as a direct consequence of
individual choice and health management as the responsibility of the individual. The rhetoric incorporates the imperatives of self-responsibility, self-control and self-discipline, and positions healthy lifestyle choices as achievable by all but also the individual’s moral responsibility. As such, individuals are obligated to maintain beneficial physical and mental health as evidence of “good” citizenship. However, should an individual living with a long-term condition become unwell; the self-management rhetoric positioned this as a consequence of that individual’s lifestyle choices. Secondly, the rhetoric of self-management viewed the self-management capability of individuals as a resource that can be utilised to control health risk. As such, health professionals and other sources reinforce the notion of individual accountability for lifestyle choices.

When considering findings and results from this study, a synthesis of “keeping order” became evident across all three qualitative sources. This synthesis revealed the planning, regulating and arranging undertaken by participants and respondents to maintain balance or control in life. Additionally, a disconnection between individuals living with a long-term condition and others was evidenced across findings from individual interviews and the quantitative data. This disconnect suggested there was an underlying sense of isolation experienced by the individual in their self-management role.

The reality of self-managing a long-term condition was characterised by the individual “keeping order” in their lives. Individuals described balancing loss and an altered health reality with continued engagement with the “new” and “different” everyday life/realality. The reality for these people was an experience that was not static, linear or with an achievable end goal, but rather an active and constantly changing daily process. There was an expectation held by the individuals that they would independently manage their health and make healthy lifestyle choices, yet this was not always a simple matter of choice. The reality suggested that while the individual felt responsible for and obligated to maintain their health and manage their long-term condition, they did not always have the
capability or the resources available to them to undertake or achieve the balance they sought for themselves and their family. The capacity to undertake this role was not only dependent on available resources, but also on the individual’s belief in their ability to self-manage a long-term condition. Most participants in this study identified that they did not feel able to communicate their needs to their doctor and did not feel confident about getting the help they required. This suggested a sense of isolation was experienced by individuals in their self-management role and revealed the underlying struggle these individuals experienced in maintaining health status that at times required support from sources outside of themselves.

Additionally, at face value the findings suggested both the rhetoric and reality appeared to agree the individual was responsible for managing their long-term condition. However, expectations arising from these two perspectives were dissimilar. The rhetoric, as a discourse embedded in policy, reflected expectations about what an individual was expected to do. Yet the individual experience evidenced obligation to self-manage their condition, which was stressful and not always helpful. It is these differing expectations that may create potential conflict between the healthcare professional and the individual. Furthermore, these expectations position the healthcare professional as a mediator of the dilemma that arises between an individual’s ability to engage with long-term condition management and what was expected from the individual in relation to resources available as determined by the rhetoric. As introduced, the following discussion outlines the findings within the context of the rhetoric and reality of self-management, commencing with the reality of self-management for individuals who live with long-term conditions. This is followed by the effect of the rhetoric on the reality and then by discussion on how the rhetoric affects clinical practice and thus self-management reality.

The reality of self-management was described by participants and respondents as an activity to facilitate maintenance of order in their lives. This was experienced
by individuals as a balancing of the loss of their health, of adapting to altered health status, and of the necessity for ongoing engagement with everyday life. This process was a dynamic, fluctuating and challenging daily experience that often altered previous priorities and requirements. Much of the literature about living with a long-term condition has often been disease specific or focused on generic symptoms similar to a group of long-term conditions (Thorne & Paterson, 2000), and/or focused on the disruption a long-term condition has brought to an individual’s life story (Bury, 1982) or their self-identity (Charmaz, 1983, 1987). More recent literature appeared to focus on the transformational process undertaken by individuals in order to come to terms with their changed identity (Aujoulat, et al., 2008; Cooper, et al., 2010; Dubouloz et al., 2010; Whitehead, 2006; G. Williams, 1984). Yet there was only a limited amount of literature discussing the daily experience of balancing self and other priorities with the altered health, socioeconomic and personal reality.

The self-management reality for participants and respondents showed they utilised the idea of self-management to facilitate and keep order in their lives. The idea that an individual would make every effort to maintain some semblance of order in their life after diagnosis with a long-term condition was congruent with a study by Kralik, Koch, Price and Howard (2004). Their study identified that individuals who lived with arthritis initiated a process of self-management “to create order from the disorder imposed by illness” (p. 262). Inherent within the idea of “keeping order” after diagnosis of a long-term condition was the ongoing necessity of balancing a changed life with engagement in the same but somehow different life. Participants in the current study kept order through balancing the personal, financial and health impacts they experienced after diagnosis of a long-term condition with as much of their previous life as they could. Order was kept through making decisions that fitted with the ongoing and changing reality of their life. These ideas were similar to other literature depicting the theme of “balance” as maintaining equilibrium between identity management and symptom control (Bury, 1991; Kneck, Klang,
& Fagerberg, 2012; Townsend, et al., 2006; S. Williams, 2000), a self-management process (Schulman-Green et al., 2012), or a dynamic and organic process (Jacelon, 2010) requiring successful cognitive, emotional and existential processing (Jutterstrom, Isaksson, Sandstrom, & Hornsten, 2012) with continuous adjustment between activity, attitude, autonomy, health and relationships (Jacelon, 2010).

The idea of having to balance aspects of one’s life was represented by the Shifting Perspectives Model of Chronic Illness (Paterson, 2001; Thorne & Paterson, 1998) and was reflective of ideas of order and balance found within the current study. Paterson’s model suggested that living with a long-term condition was an on-going and shifting process whereby individuals constantly dialogued with different aspects of their life and moved between “illness in the foreground and wellness in the foreground” (Paterson, 2001). This process has been described as living in the orange.

If red is illness and yellow represents wellness, then I like to be a blend of both things. In the orange. It is not a good idea for me to be completely in the yellow because then I forget that I have MS and I do stupid things that I pay for later. And if I am totally in the red, I am too depressed to do anything. I never stay completely in the orange but it’s where I like to be and where I try to be. Other people might like to be a little pinker or more yellow (Paterson, 2003, p. 990).

It was this idea of living in the orange or perhaps constantly moving through the colours (sometimes daily), that most reflected the idea of keeping order and the necessity of balancing life that was evident within the current study. However, these studies seemed to infer that individuals engaged in a process of conscious decision making with regard to self-management of the long-term condition. Yet Kendal et al., (2011) suggested individuals focused on the whole of their life and often did not distinguish health-related behaviours from other aspects of their lives. This was certainly evidenced in the current study as individuals frequently described their understanding of self-management as “just looking after myself” or “what I do every day”.

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Recent research has identified that attaining balance in life was a process of integration of a long-term condition into daily life that included modifying lifestyle but additionally sought “normalcy in life through balancing the pursuit of meaningful activities with appropriate attention to illness needs” (Schulman-Green, et al., 2012, p. 141). Other studies identified that the key to balancing a meaningful life, the impact of the disease and its management involved successful cognitive, emotional and existential processing (Jutterstrom, et al., 2012). Jacelon (2010), in her study with older individuals living with a variety of long-term conditions, found that these individuals maintained a balanced life through a dynamic, organic, continuous process of adjusting the relationships between activities, their attitude, autonomy, health and external relationships. However, this research reflected an individual process, whereas the current study revealed that although the individual undertook these processes to “keep order” and balance, there were times when others, outside of the individual, assisted with maintaining order and balance. The current study evidenced a fluid process that shifted between the individual and another (usually a spouse or partner). Participants described fluctuating between making their own decisions to facilitate balance, to being under the direction of a spouse or healthcare professional and back to making their own decisions to keep order and balance in their lives.

Although the current study found that balancing was at times undertaken by others, the reality of self-management also suggested that individuals expected they would independently manage their health. This apparent contradiction does not appear to have been investigated in the wider literature. However, a recent study, illuminating the family experience of living with a loved one with a long-term condition, suggested an underlying expectation that those living in the same home “should help each other” before others were approached to assist (Arestedt, Persson, & Benzein, 2013). Additionally, what does not appear to have been drawn out in the wider literature was that participants in the current
study sometimes made self-management decisions that were contrary to advice and education provided by health practitioners, to maintain balance and keep order.

Individuals in the current study felt responsible for, and obligated to maintain their health and manage their long-term condition, yet they did not always have the capability or the resources available to them to undertake or achieve this. The capacity to undertake a self-management role was argued to be dependent on the individual’s belief in their ability to self-manage a long-term condition, and belief in ability was drawn from prior personal accomplishments, vicarious experiences, verbal persuasion and the individual’s emotional state (Bandura, 1977). Experiential and vicarious learning are the major ways an adult living with diabetes learns about their disease, and these ways eclipse structured educational input (or as Bandura calls it, verbal persuasion) from healthcare professionals (Wilkinson, Whitehead, & Ritchie, 2013). Generation of experiential knowledge for individuals with diabetes was argued to be a process whereby the individual reflected, and entered into “an inner dialogue between the self, the body and life” (Kneck, Klang, & Fagerberg, 2011, p. 564). It could be argued that this “inner dialogue” and the resultant acquisition of experiential knowledge, was what facilitated the process of maintaining balance and keeping order for an individual living with a long-term condition. The current study certainly revealed evidence of these learning strategies and the dialogue between the self, the body and life that existed to maintain balance and keep order.

The majority of participants in this study identified that they did not feel able to communicate their needs to their doctor and did not feel confident about getting the help they required. This suggested a sense of isolation was experienced by individuals in their self-management role because they could not approach others to ask for assistance. This sense of being separated from others because of the long-term condition was reflective of the contradictions highlighted within Paterson’s (2001) Shifting Perspectives Model of Chronic Illness.
contradiction arose from wellness in the foreground perspective. Living this way necessitated paying attention to the management of the long-term condition “in order to not have to pay attention to it” (Paterson, 2001, p. 24). However, management of a long-term condition required (at times) consultation with healthcare practitioners in order to maintain this perspective. Yet doctors sometimes avoid discussions about self-management or aspects of a long-term condition (Blakeman, et al., 2010). Doctors described not wishing to upset the individual, create an extra burden or increase anxiety through constantly bringing the long-term condition and its implications to the centre of conversations (Blakeman, et al., 2010). This avoidance of issues pertaining to self-management may contribute to the isolation experienced by the individual.

The second contradiction occurred if an individual adopted an illness in the foreground perspective. This perspective was argued to be “self-absorbing” and alienated a person from others (Paterson, 2001, p. 25). Because they were regarded as a hypochondriac, the individual may experience additional isolation. Also others may mediate the hypochondriasis through avoiding discussion about the long-term condition or aspects of it (Paterson, 2001).

However, another way to view this may be that individuals felt isolated because their experiential knowledge did not appear to be valued by healthcare professionals (Kendall, et al., 2011). Learning to live with a long-term condition was argued to be a complex process “involving fluctuations and movement back and forth, as the individual grapples with strong reactions to the loss of life as it was” and this process can be affected by the reactions of others (Telford, Kralik, & Koch, 2006, p. 458). If an individual “feels dismissed during contact with a healthcare professional they may feel diminished and unsupported” (Telford, et al., 2006, p. 458), reducing the likelihood of the individual approaching the healthcare professional with questions or for help at a later date. Therefore, it could be argued if this occurs, what has been termed “the therapeutic relationship” cannot develop because the individual has not been accepted as a partner in care “with the right to make decisions which are not necessarily those
which the professional would choose” (Coates & Boore, 1995, p. 638) potentially isolating the individual from a source of support.

Expectations embedded within the discourse of policy (the rhetoric of self-management) suggested that an individual’s health status arises as a direct consequence of choices they have made which suggested they had failed in their moral obligation. The rhetoric holds that an individual will be responsible, controlled and disciplined and thus make healthy lifestyle choices to achieve optimal health. Good health was linked with being an upright, moral citizen and the rhetoric expected beneficial health to be achievable by all. However, these obligations were not always achievable and created additional stress for individuals in their daily quest to keep order in their lives. Analysis suggested the discourse of NPH has permeated all aspects of people’s lives and has subtly coerced individuals into believing that they, personally, are morally responsible for long-term condition self-management. Yet, people have been “self-managing” one way or another, for a long time, and long before the advent of NPH. Kendall et al (2011) suggested that, from an individual’s perspective, the reality of self-management contains an inherent contradiction, that of an individual’s experiential life knowledge about living with their condition versus the so called “more legitimate knowledge” provided by healthcare professionals (Kendall, et al., 2011, p. 94). Because of this, individuals take advice from healthcare professionals, but continued “to manage their health and their lives as they see fit” since often the “more legitimate knowledge” was deemed irrelevant to their current life situation (Kendall, et al., 2011, p. 93).

Individuals make choices based on the context of their lives, and thus self-management beliefs and therefore, choices are influenced by a number of factors. Factors that influence self-management reality were the physiological, sociocultural (Berman & Iris, 1998; Gately, Rogers, & Sanders, 2007; Thorne & Paterson, 2000), and socioeconomic (Lindsay & Vrijhoef, 2009) personal life situation of the individual. Additional factors incorporated the future the
individual envisioned for themselves (Coates & Boore, 1995; Thorne, Paterson, & Russell, 2003), the curability or controllability of the condition (Harvey & Lawson, 2009), and their perception of “how challenging … the social, personal, environmental and economic obstacles” were “to achieving or maintaining a specific behaviour or a set goal for that behaviour” (Bauman & Dang, 2012, p. 34). Thus, if an individual’s choices do not line up with recommended guidelines about their long-term condition, or their biological markers do not fall within recommended parameters, an individual may be deemed to have “failed” in self-management, or they may be “labelled irresponsible or, worse as a burden” (Kendall, et al., 2011, p. 93).

The rhetoric also potentially affected the reality through isolating individuals from their both social and cultural support systems. Evidence from the quantitative statistics suggested possible underlying issues in communication and relationships between the individual, their family and health professionals that may impede development of self-management. Medicalisation of self-management has resulted in the reduction of self-management to a set of tasks. This task orientated view of self-management placed self-management within “the domain of health professional experts” (Kendall, et al., 2011, p. 91). As such, this view of self-management assumed the “application of a predetermined set of self-management strategies” would result “in improved quality of life, greater satisfaction with health services and better health status”; rendering the individual “passive and dependent” and needing “to be educated about what is ‘good for them’” (Kendall, et al., 2011, p. 91). Yet, positioning the healthcare professional as the expert in self-management and thus devaluing an individual’s experiential knowledge (Kendall, et al., 2011), isolated the individual from a source of support. Additionally, the rhetoric, because of its individualistic approach isolated individuals from their cultural roots, increasing health inequalities and isolation. The individualistic approach of the rhetoric of self-management privileged “professional ways of knowing” (Kendall, et al., 2011, p. 97) over cultural ways of knowing, thus limiting opportunity for choice in
how to manage long-term conditions and the ability of cultural communities to respond to social inequities (Kendall, et al., 2011).

Clinically, the rhetoric of self-management appeared to exert an external pressure on healthcare professionals through two mechanisms. This has been achieved by the medicalisation of self-management and the introduction of legislation regulating and monitoring the practice of healthcare professionals. An outworking of this legislation has been increased personal accountability of the healthcare professional for their practice, and often unknowingly, to the policy rhetoric of the day. Thus, the professional is now required to reinforce patient expectations in relation to available resources as determined by current policy rhetoric.

The discourse of NPH seems to have medicalised the idea of self-management through viewing an individual’s self-management capability as a resource that can be harnessed, utilised and directed to control health risks, and the potential cost to the individual and society arising from these health risks. The rhetoric of utilising self-management as a “cost-cutting mechanism” (Kendall, et al., 2011, p. 90) was evident in international and New Zealand policy regarding self-management. The rhetoric of self-management from this perspective was understood to be “an important strategy for reducing costs, through reduced risk behaviour, improved health, and thus reduced use of costly health services” and implied “a level of personal responsibility for illness” along with “a duty to self-manage for the greater social good” (Kendall, et al., 2011, p. 90). Australia, America, Canada and the UK all appear to reinforce the utilisation of self-management as a resource for cost cutting within their health systems. This was apparent within the American Multiple Chronic Conditions Framework (United States Department of Health and Human Services, 2010), Australian (Flinders Human Behaviour & Health Research Unit, 2011; Kendall, et al., 2011) and Canadian (e.g. Improving health together: A policy framework for chronic disease prevention and management in New Foundland and Labrador.
(Department of Health and Community Services, 2011) long-term condition policy rhetoric, and within UK policy around the Expert Patient (Morden, Jinks, & Ong, 2012; Wilson, 2001).

Findings from the discourse analysis suggested the medicalisation of self-management has led to the rise of consumerist (Crinson, 1998) and managerial discourses (du Gay, et al., 1996) being enforced/adopted within health systems, and consequently the introduction of competencies and audits for healthcare professionals. This has in turn led to professional bodies now not only overseeing the registration of professionals but the introduction of regulatory frameworks to monitor and audit professional practice with the aim of protecting public safety. Australia, Canada, the UK and New Zealand have all introduced various legislation governing healthcare professionals’ practice with the aim of protecting the health and safety of the public, and have regulatory bodies that monitor professional practice. For example, Australia has the Health Practitioner Regulation National Law (2009), enacted by each state in 2010, with one overarching national agency coordinating fourteen professional bodies that regulate health professional practice with the aim of protecting the public (Australian Health Practitioner Regulation Agency, 2010-2013). A similar set up was evidenced within the UK (National Health Service Reform and Health Care Professions Act (2002)) and New Zealand (Health Practitioners Competence Assurance Act (2003)). Canada has legislation regulating health professions for each of its provinces and territories, along with corresponding professional regulatory bodies. Additionally, for nursing in Canada, there is an overarching Council of Registered Nurses coordinating provincial and territorial nursing regulatory bodies (Canadian Council of Registered Nurse Regulators, n.d.). America has professional bodies set up to monitor registration of healthcare professionals but there does not appear to exist overarching legislation specifically aimed at protecting the health and safety of the public, as evidenced in Australia, Canada, the UK or New Zealand.
Within New Zealand health professions (such as chiropractic, dentistry, dietetics, medicine, nursing and midwifery, occupational and physiotherapy, and pharmacy etc.) have legal obligations arising from the Health Practitioners Competence Assurance Act 2003 (Parliamentary Counsel Office - New Zealand Government, 2003) and a number of other Acts. For example, the Code of Health and Disability Services Consumers’ Rights (Parliamentary Counsel Office - New Zealand Government, 1996) and the Health Information Privacy Code 1994 (Privacy Commissioner, 2008). For nurses, obligations arising from such legislation are reinforced by the Nursing Council of New Zealand (NCNZ) through documents such as Competencies for registered nurses (Nursing Council of New Zealand, 2007), the Code of conduct for nurses (Nursing Council of New Zealand, 2012a), and Guidelines: Professional boundaries (Nursing Council of New Zealand, 2012b) which set expectations for behaviour and guide nursing practice. Consequently, nurses’ competency to continue practising is monitored yearly through a compulsory process of the nurse self-reporting on competency to continue to practise to the Council, reinforcing and underscoring the belief of responsibility for the individual. It could be argued that because of the supervised environment in which nurse’s practise, nurses, to keep order for themselves, have come to believe they were morally responsible for their patients. Related research with nurses from the UK supports the link between the nurse feeling responsible for the individuals they work with and avoidance of potential legal ramifications. These studies suggested the belief of responsibility appeared to be connected to hierarchical structures, protocols and fear of litigation (Wilson, et al., 2006), or concern punitive action could be taken by management, nursing or legal professions (Hallett, Austin, Caress, & Luker, 2000).

Analysis from the current study suggested the managerial discourse evident within NPH has pervaded nursing to the extent that regulatory and educational documents reinforce the role of the nurse as manager. Management of care as a nursing competency was underscored within both the Nursing Council
competency documents for registered nurses and nurse practitioners (Nursing Council of New Zealand, 2007, 2008a). Educational documents such as the Flinders Program™ reinforce the NPH managerial ideology through the rhetoric contained within training provided to nurses, and through the set-up of the programme and language used to motivate individuals to identify problems, identify and set goals, and contribute to an agreed care plan for self-management. It appeared that nurses in the current study have incorporated this managerial discourse into their practise, and as such endeavoured to control and manage individuals in their care, and exert pressure on the individual to self-manage responsibly.

Consequently, the nurse inadvertently reinforced the individualistic nature of the self-management rhetoric but at the same time their practice was constrained by the rhetoric via policies, targets and funding constraints. These all impact on a nurse’s ability to tailor an individual programme of care and deliver the kind of care they would like and wish to (Gallagher, 2010). Additionally, because self-management has been reduced to tasks that can be completed to attain certain goals, this may create an issue for both the healthcare professional and the individual. Within the practice setting, viewing self-management as a task may create a self-management dilemma, paradox (Wilson, et al., 2007) or duality (Kendall, et al., 2011), because the health professional’s view of self-management has been privileged over the individual’s. Yet previous discussion has shown the individual will continue to manage their health and life as they saw fit because often the knowledge provided by healthcare professionals was unworkable within their daily life (Kendall, et al., 2011).

The literature positions building and maintaining the therapeutic relationship (Hagerty & Patusky, 2003; Moyle, 2003) and patient education (Kruger, 1991) as two of nursing’s essential roles. It could be argued that these two roles place nurses in a position to be able to mediate the problems arising between the rhetoric and reality of self-management. Additionally, the nurse must be aware
of the discourses affecting their practice and an individual’s self-management reality. The nurse-patient relationship has been shown to be understood by individuals as serving a particular purpose, for a specified time in a certain setting (Halldorsdottir, 2008). Recognition by nurses that their relationship with individuals was short term and for a specific reason could assist nurses to reconfigure their perception of being responsible for the individual. Nurses have been encouraged to “privilege the person’s experience as the basis for developing a sensitive, client-focussed response that takes into account the wider social context of people’s lives as well as the medical aspects” (Telford, et al., 2006, p. 456), and develop a connection that accepted individuals as “full partners in care with the right to make decisions which are not necessarily those which the professional would choose” (Coates & Boore, 1995, p. 638).

However, if the nurse retains their underlying belief of responsibility, they will find it nigh on impossible to accept decisions by an individual that go against recommended guidelines; potentially increasing disconnection and reducing communication between themselves and the individual (Halldorsdottir, 2008). Conversely, a nurse who can shift their perspective to one of feeling responsible to instead of for an individual (R. Anderson & Funnell, 2005), and who is accepting of decisions that may go against recommended guidelines, may increase communication and connectedness between themselves and the individual (Halldorsdottir, 2008).

With regard to a nurses’ educative role, it could be argued that nurses need to come to understand that individuals have accumulated a lifetime of self-management experiences (Berman & Iris, 1998). Individual’s living with a long-term condition want knowledge, yet it requires time to integrate that knowledge into their chosen way of life (Coates & Boore, 1995), and nurses need to allow this to occur. Nurses also need to realise the difference between patient education which defines the problem and provides disease specific information and technical skills, and self-management education which allows the individual to identify the problems through teaching problem solving skills.
(Bodenheimer, et al., 2002). It appeared from the findings of the current study that individuals believed they were responsible for self-management of their long-term condition and the literature suggested that many individuals “believe that they are responsible for the outcome of self-management behaviours and, therefore that they must have a role to play in making decisions about those behaviours” (Coates & Boore, 1995, p. 638). If an individual’s beliefs are recognised by the professional and they are offered the means to build on what they know, it was argued the individual will be more responsive to self-care interventions (Berman & Iris, 1998).

Awareness of underlying discourses that impact on practice and an individual’s self-management reality would facilitate the connection between nurses and individuals living with long-term conditions. The current idea of self-management has grown from “ideals of independence, responsibility for self, individual autonomy and self-determination” (Gallant, Spitze, & Grove, 2010, p. 34), and these ideals may not be congruent with cultural groups beliefs’ about how a long-term condition should be integrated into life. Gallant et al. (2010) argued that that current approaches to self-management have not adequately incorporated cultural values related to health and long-term condition management, and until these are, they suggest health disparities will not change.

The Competencies for Registered Nurses in New Zealand, requires nurses to apply “the Treaty of Waitangi/Te Tiriti o Waitangi to nursing practice” (Nursing Council of New Zealand, 2007, p. 10) and this is reinforced within the Code of conduct for nurses (Nursing Council of New Zealand, 2012a). Yet, a nurse’s ability to meet these requirements may be difficult for the majority of New Zealand nurses for three reasons. Firstly, if nurses are unaware of the competing discourses of NPH and Kaupapa Maori, they may think they were meeting the requirements as set out in the Nursing Council documents; when in fact, as Anderson and Funnell (2005) contend, they quite possibly remain practising from the learned beliefs in which they trained. Secondly, even if aware of the
discourses at play, when conflict is encountered, it was argued that nurses will revert to their learned beliefs which are usually those of the dominant paradigm (R. Anderson & Funnell, 2005). And finally, the current dominance of the discourse of NPH may make integration of “Maori models of health into everyday practice” impossible because of the existing structures of the New Zealand health system and primary healthcare settings. Despite these issues, nurses need to be cognisant of these discourses and “make space for analyses of politics, culture, and history, and how these have variously positioned” and “shaped people’s health and structured our relations with one another”, in order to be able to “work to transform these relations” (Browne & Varcoe, 2006, p. 9).

**Strengths and limitations of the current study**

A number of strengths and limitations were identified in relation to applying the methodology of MMR. A main strength of this MMR study was the combination of approaches which achieved dialogue between multiple realities and allowed development of a “bigger picture” understanding about the rhetoric and reality of self-management in the New Zealand context. However, integration of findings from qualitative and quantitative projects within MMR can be difficult, if the ontological divide and integration of the different perspectives are not considered when the overall structure of the project is designed (Bryman, 2007). For this MMR, the research question necessitated multiple approaches in order to gather data to adequately explore the questions posed. Linked to the research question, was consideration of the organisational structure for the overall research project. The organisational structure guided design and implementation of the study (Collins & O'Cathain, 2009) and allowed this researcher to plan when data was mixed (analysis and interpretation levels). Choice of a dialectic stance enabled situation of the study within a postmodern theoretical perspective, which facilitated addressing the purposes for utilising MMR in the first instance; those of dialogue with multiple realities and a desire to develop a “bigger picture” understanding of the topic of interest (Greene, 2007).
The sample for the individual interviews, and nurse interviews and focus group were small and almost exclusively female and utilised strategies of convenience, snowball and purposive sampling; thus limiting generalisability or transferability to the wider population (Schneider, 2003). However, use of these sampling strategies ensured an appropriate sample was found who could share their experience and perspectives on long-term condition self-management. It could be argued a further limitation was the exclusion of other health professionals’ perspectives on self-management of a long-term condition. However, limiting the health professional perspective to nurses for this research maintained manageability of the project and allows for extension of the research at a later stage. The process of thematic analysis assisted this researcher to gain understanding from the experience of the participants and respondents, identify common threads within and across interviews and across the multiple qualitative data sources, and to draw all the data into a coherent whole; a coherent whole that attempted to present the participant and respondent views and beliefs about self-managing a long-term condition.

Additional limitations for this project relate to the e-survey’s online only presence (i.e. excluding those who did not have internet or computer access) and cross sectional nature; thus limiting generalisability to other populations and ability to infer causal relationships (Schneider, 2003). Data was also self-reported, the respondents were predominantly female, middle aged and highly educated, again limiting generalisability to other populations. One third of respondents reported high self-rated health, nearly half reported low symptom health distress and over one third reported high self-efficacy for managing a long-term condition; suggesting that those who responded to this e-survey may not be representative of the population of individuals living with long-term conditions. However, a total sample size of 250 provided sufficient power >80% for the important comparisons within the data set. This sample size allowed detection of correlation coefficients $r > |0.18|$ as statistically significant (2-tailed $\alpha = 0.05$) with 80% power. Comparisons of subgroups within the data were
undertaken when the smaller subgroups included more than 50 participants. In this scenario effect sizes > 0.45 could be detected as statistically significant ($\alpha = 0.05$) (C. Frampton, personal communication, August 1, 2013). Other limitations, relating specifically to the quantitative data, have been addressed in detail in Chapter 6.

The use of e-survey methodology for this MMR resulted in decreased administration and resources costs, and increased efficiency of data collection and analysis. The e-survey allowed for database connectivity which eliminated the requirement for transcription, and also enabled question diversity and flexibility. Respondent anonymity was also preserved. E-survey methodology also facilitated recruitment of the respondents from around New Zealand expanding the sample size thus enabling a wider diversity of respondents and perspectives on the topic of interest. A further strength of the e-survey was use of previously validated tools which have been used by other researchers, allowing for exposure of another aspect of the reality of self-managing a long-term condition within the NZ context. Overall, use of e-survey methodology was an enjoyable data collection experience for this researcher.

Limitations to CDA were argued to be the interpretative and subjective nature of the analysis, the lack of explicit techniques for undertaking the analysis, limited explanation regarding text selection and whether or not the CDA produces valid, contributing knowledge about the subject under scrutiny. In order to counteract these limitations, this researcher acknowledged her role and influence within the research and the subjective and interpretive nature of the final analysis. Additionally, a senior researcher (MC), skilled in critical discourse analysis was involved in guiding this researcher through the analysis process, and a clear explanation has been provided around how the texts were chosen for analysis and then analysed. CDA enabled this researcher to situate the texts within their social, political, cultural and historical contexts allowing analysis that revealed the unspoken, hidden discourses that underlie and influence the practice and
understanding of long-term condition self-management. As a result, this researcher believes the discourse analysis produced valid knowledge that contributes to a much deeper and wider understanding about self-management of long-term conditions in the New Zealand context, despite its subjective and interpretive nature. The main strength of this MMR study was the combination of approaches to data collection and analysis. These approaches, despite their limitations, have achieved dialogue with multiple realities, and enabled greater understanding about the rhetoric and reality of long-term condition self-management in New Zealand.

Implications for future research
A priority for research, given the health disparities reported for these groups of people, would be exploration of the self-management beliefs of Maori and Pacific Islanders and the impact these have on long-term condition management. This research would need to be undertaken in partnership with these groups. Further avenues for research derive from reflection on the fact that the nurse participants were all female. This has led this researcher to ponder if a male perspective on the nurse role in self-management would contribute a different view to that gained through this study and to that found in the wider literature. The research could also be extended through interviewing different groups of allied health professionals to ascertain their perspectives on long-term condition self-management and how these impact on an individual’s ability to self-manage.

Further potential research possibilities include investigation into the barriers for uptake of self-management programmes by people living with long-term conditions, and the barriers to uptake of postgraduate nursing education regarding self-management by nurses. A further implication for research could include exploring understanding about self-management and utilisation of the Stanford tools with a group of people living with long-term conditions who did not rate their health as highly as the group from the current study.
Conclusion
The focus of this thesis was to explore how the individual, nurse and policy perspectives impact on the individual’s ability to self-manage a long-term condition in the New Zealand context. The use of a dialectical position and mixed methods enabled dialogue with three different perspectives of self-management in the New Zealand context, generated a broader, deeper understanding of self-management, and revealed how these differing views influenced self-management by the individual with a long-term condition. The reality of self-management was shown to be an active and constantly changing, daily process rather than a static, linear or achievable goal. Individuals balanced the loss of their health and altered health status with the necessity for ongoing engagement with everyday life. This balancing process often led to modification of previous priorities and requirements. Individuals held an expectation of independence in self-management but this was not always achievable from within their personal resources. Consequently, the individual was unable to achieve the balance they sought. Additionally, the reality of self-management suggested the individual felt disconnected from others, leading isolation from potential sources of support.

Expectations embedded within the discourse of policy (the rhetoric of self-management) created obligations for individuals that were not always helpful or achievable. Individuals were shown to make self-management decisions based on the context of their lives. However, their experiential knowledge was not privileged by policy or healthcare professionals. The rhetoric of self-management affected professional’s practice through medicalisation of self-management and introduction of legislation regulating and monitoring practice. Thus, the healthcare professional was re-envisioned as manager of resources and mediator of patient expectations as determined by policy rhetoric, while at the same time having their practice constrained.
Constrained practice was shown to limit the nurse’s ability to tailor individual programmes of care and impacted on the kind of care nurses wished to deliver. The therapeutic relationship and patient education were identified as ways the nurse may mediate the dilemma arising between the rhetoric and reality of self-management. However, a shift in understanding about these essential roles was required. Additionally, it was identified that awareness of underlying discourses that impact on practice and the individual’s self-management reality would facilitate increased connection between the two parties. Despite the limitations inherent within the study, this research has contributed to knowledge through exposing the tensions that exist between the rhetoric of self-management and the reality as described by the participants. It is these tensions that have significant implications for healthcare delivery and health outcomes for individuals living with long-term conditions in New Zealand.
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List of Appendices