

**The Experiences of Accessing Health Care for Families of Children with
Bronchiectasis in the Counties Manukau District Health Board, Auckland, New
Zealand: A Qualitative Study**

Nicola Jepsen

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School of Public Health and Psychosocial Studies

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Abstract

Background: Bronchiectasis is a chronic respiratory condition and a worsening public health problem in New Zealand, particularly in the Counties Manukau District Health Board area in Auckland. The disease contributes to significant health care costs, as well as presenting a social and economic burden to individuals and the community. Population patterns display significant social disparities, with highest rates amongst Māori, Pacific Island and disadvantaged people. While bronchiectasis can develop at any age, children are particularly susceptible, and it is imperative that bronchiectasis is identified and managed early, or even prevented from developing. Poor access to health care is one factor that may influence the development of bronchiectasis. There is no existing literature exploring access to health care for families of children with bronchiectasis. It is important that the experiences of these families are understood, in order to critique and improve current health care systems. The aim of this study was to explore the experiences of accessing health care for families of children with bronchiectasis in the Counties Manukau District Health Board area.

Methods: Interpretive descriptive methodology was used to guide this study. Semi-structured interviews were carried out with ten participants, who were parents of children with bronchiectasis. Interviews were audio recorded and transcribed verbatim. Thematic analysis was employed for data analysis.

Results: Five key themes were developed: 1) *Searching for answers*, describing parents' search for a diagnosis; 2) *(Dis)empowerment*, describing parents' initial vulnerability, then acquisition of knowledge, which led to greater empowerment in the health care provider-parent relationship; 3) *Health care and relationships*, describing the impact of the relationship between health care provider and parent on the parent's health care experiences; 4) *A juggling act*, describing the challenges of juggling health care with school, work and family life; and 5) *Making it work*, describing how, despite experiencing barriers to accessing health care, parents could find a way to 'make it work'.

Conclusions: The study found that the relationship between health care provider and parent was crucial. Health care providers must appreciate the influence of the relationships they build with patients and parents and emphasise patient-centred care. Communication and trust were important factors for fostering a helpful health care relationship and power dynamics inherent in health care provider-parent relationships must be acknowledged. Parents' empowerment within these relationships was facilitated by their acquisition of knowledge. While parents sometimes experienced practical barriers to accessing health care (like financial or transportation difficulties), parents' perceptions of the quality and potential benefit of health care services motivated them to find ways to overcome these barriers. The findings of this study may help to improve access to health care for parents of children with bronchiectasis if identified issues and implications for practice are addressed by health care providers and health system stakeholders.

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Attestation of Authorship

"I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning."

Signed:

A handwritten signature in black ink, appearing to read "Nicomène", with a stylized flourish at the end.

Date: 20/02/2018

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Ethical Approval

This study was approved by the AUT Ethics Committee on the 26 July 2016, under the Ethics Application number 16/252. The study was approved by the Counties Manukau Health Research Office on 9 August 2016, with the Application Registration Number 129. It was also approved by the Counties Manukau Health Maaori Research Review Committee on 26 July 2016.

Chapter 1: Introduction

1.1 Problem Context

Bronchiectasis is a chronic respiratory disease, characterised by a chronic cough, sputum production and abnormal dilation of airways (Polverino et al., 2017). The cause of bronchiectasis is thought to be a vicious cycle of infection, inflammation, mucociliary dysfunction and lung damage (Maselli, Amalakuhan, Keyt, & Diaz, 2017; Polverino et al., 2017). Bronchiectasis may also develop secondary to other chronic diseases like cystic fibrosis or connective tissue disorders (Maselli et al., 2017). Treatment for bronchiectasis focusses on reducing exacerbations, managing symptoms, improving quality of life and slowing progression of the disease (Pasteur, Bilton, & Hill, 2010; Polverino et al., 2017). While bronchiectasis can develop at any age, it often develops in childhood (Pasteur et al., 2000), as a consequence of repeated respiratory infections (Redding et al., 2014; The Asthma and Respiratory Foundation of New Zealand, 2006) and should be considered in a child who has a persistent cough despite antibiotic use, more than three episodes of a wet cough lasting four weeks or more each time, or an abnormal chest radiograph persisting six weeks after appropriate therapy (Chang et al., 2015).

Bronchiectasis is a worldwide problem. Rates of bronchiectasis declined in the 20th century, due to increasing vaccine use, improvements in living conditions and improved identification and management of respiratory infections (Callahan & Redding, 2002; Eastham, 2004; Karakoc, Yilmaz, Altintas, & Kendirli, 2001; The Asthma and Respiratory Foundation of New Zealand, 2006; Twiss, Metcalfe, Edwards, & Byrnes, 2005). Several decades ago, it was considered an 'orphan disease', thought to be reducing in prevalence in developed countries and not worth investing effort into research or treatment (Barker & Bardana, 1988; Callahan & Redding, 2002). Increasingly, however, bronchiectasis is recognised as an ongoing problem and cause for concern in developing nations and particularly for indigenous communities in developed nations (Chang et al., 2015; Redding et al., 2014; Singleton et al., 2014). Factors associated with development of bronchiectasis in these nations and communities include poverty, overcrowded housing, exposure to pollutants, poor maternal education and access to health care (Singleton et al., 2014). Health disparities between indigenous and non-indigenous populations in developed nations are well documented (I. Anderson et al., 2016; Jackson Pulver et al., 2010); bronchiectasis is an example of a disease that disproportionately affects indigenous communities (Chang, Brown, Toombs, Marsh, & Redding, 2014). Indigenous communities in North America, Australia, Pacific Islands and New Zealand (NZ) are known to have much higher rates of bronchiectasis than the general population rates in those countries (Chang et al., 2014; Singleton et al., 2014).

Bronchiectasis is of particular importance in NZ, where prevalence is high in comparison to other developed countries. New Zealand's population prevalence is 158 per 100,000 people (Telfar-Barnard & Zhang, 2017) which is twice that of the United States (Seitz et al., 2010), and much higher than in Finland, where bronchiectasis is rare (Säynäjäkangas, Keistinen, Tuuponen, & Kivela, 1997). Rates of the disease are worsening in NZ, where the general population hospitalisation rate for bronchiectasis increased by 41% between 2000 and 2015 (Telfar-Barnard & Zhang, 2017). Of particular importance are the high rates of bronchiectasis amongst NZ children. The incidence of bronchiectasis in NZ children is estimated to be at least 3.7 per 100,000 people per year (Twiss et al., 2005), seven times higher than the incidence calculated in Finnish children (Säynäjäkangas, Keistinen, Tuuponen, & Kivelä, 1998). Because bronchiectasis is a chronic condition that presents a health care burden throughout one's lifespan, it is important to focus public health efforts on the impact of bronchiectasis in children, as prevention in childhood will have the greatest impact.

Population patterns of bronchiectasis display a significant social gradient in NZ, with Māori, Pacific Island people and those living in lower socioeconomic communities most affected by the disease (Telfar-Barnard & Zhang, 2017; The Asthma and Respiratory Foundation of New Zealand, 2006). In children under 15 years, Twiss et al. (2005) estimate a population prevalence of bronchiectasis of 1 in 3,000 children. Pacific Island children are most affected within the population, with an estimated prevalence of 1 in 625 children under 15 in this group (Twiss et al., 2005). In indigenous populations internationally, this compares to a prevalence of 14.7 per 100,000 Aboriginal Australian children under 15 years (Chang, Masel, Boyce, Wheaton, & Torzillo, 2003) and 14-20 per 100,000 births in an indigenous Alaskan population (Singleton et al., 2000). The main cause of bronchiectasis in adults and children is repeated respiratory infections (Maselli et al., 2017; Pasteur et al., 2010; The Asthma and Respiratory Foundation of New Zealand, 2006). Like bronchiectasis, rates of some respiratory infections, like pneumonia and bronchiolitis, also have higher population rates in NZ than in other comparable countries and population patterns also display significant disparities between ethnicities (C. Grant et al., 1998, 2001; The Asthma and Respiratory Foundation of New Zealand, 2006).

Bronchiectasis is a significant problem for the population of the Counties Manukau District Health Board (CMDHB) area of Auckland, NZ. Counties Manukau is one of twenty district health boards in the country, which are responsible for the provision and funding of health services in their area (Ministry of Health, 2017a). With a total population of over 500,000 people, CMDHB has a large Māori and Pacific Island population, and a third of the population live in areas of high socioeconomic deprivation (Counties Manukau Health, 2016). The area also has the largest population of children in NZ, many of whom are living

in poverty (Counties Manukau Health, 2016). CMDHB experiences more total hospital admissions for bronchiectasis than any other district health board in the country (Bibby, Milne, & Beasley, 2015). Hospital admissions for children and young people in CMDHB are increasing rapidly, with marked social disparities (Craig, Anderson, & Jackson, 2008). Compared with European children, Pacific Island children are 11 times more likely to be admitted to hospital for bronchiectasis and Māori children are five times more likely (Craig et al., 2008). Additionally, children living in the most deprived decile are 14 times more likely to be admitted for bronchiectasis than those living in the least deprived decile (Craig et al., 2008). With a large Māori, Pacific Island and underprivileged population and a high prevalence of bronchiectasis, CMDHB is an important area to focus on when addressing the problem of bronchiectasis and working to improve health equity amongst this population.

Reports of delayed diagnosis of childhood bronchiectasis suggest that there is a limitation in health care access and early identification of signs of infection for people who develop bronchiectasis (Edwards, Asher, & Byrnes, 2003; Twiss et al., 2005). By the time children are diagnosed with bronchiectasis they have often had a productive cough (a common initial symptom) for some time (Eastham, 2004). In one NZ study, Twiss et al. (2005) found that 40% of children in their cohort had experienced a productive cough for over two years preceding diagnosis of bronchiectasis. The median age of onset of a productive cough was 2.3 years, while the median age of diagnosis of bronchiectasis was nearly three years later, at 5.2 years. An earlier NZ study reported that children had a median of four (and a maximum of 18) hospitalisations prior to being diagnosed with bronchiectasis (Edwards et al., 2003). The NZ Health Survey (Ministry of Health, 2017b) shows that those who are most at risk of chronic diseases like bronchiectasis (for example Māori, Pacific Island people and those in lower socioeconomic groups) are also more likely to report an unmet need for health care, which is an unmet need for primary health care due to cost or transport. Children with bronchiectasis will need to access a range of different health care services, including their general practitioner (GP), specialist clinics and after-hours care (Chang et al., 2015). Access to efficient, effective, culturally appropriate health care is crucial for identifying respiratory infections early and potentially preventing the development of bronchiectasis. It is important that research strives to better understand the experiences of people who are most at risk of chronic disease and who experience significant barriers to accessing health care, in order that health care services can be better tailored to those people. This would allow for improved access to health care for all, especially people who would otherwise experience barriers to health care, with the aim of improving health equity in the population.

1.2 Rationale for the Study

Bronchiectasis is a chronic, disabling respiratory disease that presents a huge social and economic cost to the health system (Bibby et al., 2015; Telfar-Barnard & Zhang, 2017; The Asthma and Respiratory Foundation of New Zealand, 2006). Its prevalence in NZ is considered to be too high for a developed nation (Twiss et al., 2005). Cases of bronchiectasis are mostly concentrated in Māori, Pacific Island and lower socioeconomic groups (Telfar-Barnard & Zhang, 2017) and its prevalence has also been increasing in indigenous groups within other developed nations (Chang et al., 2014; Singleton et al., 2014). Considering these significant and inequitable social disparities that influence the distribution of bronchiectasis in the NZ population, this is a problem that must be addressed.

In NZ, a robust public-private health care system should provide health care to cater to the needs of the whole population, however portions of the population experience significant barriers to accessing basic health care (Jatrana & Crampton, 2009; Ministry of Health, 2017b). Literature has identified some of the practical barriers to accessing health care, like transportation and cost (Ballantyne, Benzies, Rosenbaum, & Lodha, 2015; Bolitho & Huntington, 2006; Jatrana, Crampton, & Norris, 2011). Other literature has identified that health care access is inequitable, with some groups of people experiencing more barriers to health care access than others (Gibson et al., 2015; Jansen & Smith, 2006; Jatrana et al., 2011; Pullon et al., 2015). Local literature has explored the experiences of accessing health care in Māori populations in NZ (Bolitho & Huntington, 2006; Jansen & Smith, 2006; Slater et al., 2013). No literature has yet explored the experiences of accessing care from the perspective of NZ families of children with bronchiectasis. For the purposes of this study, children were defined as being aged 0-17 years, as is further justified in the methods section (chapter 3). This study provided a unique perspective that is particular to a group of high-needs health consumers in the context of NZ and, specifically, CMDHB. The study used qualitative methodology to explore the experiences of accessing health care for families of children with bronchiectasis, to identify enablers of, and barriers to, accessing health care from the perspectives of families themselves. It is intended that understanding these perspectives will help health care and service providers to better understand some of the barriers and enablers to accessing health care for this group, in order to better align health care services with those who need them the most.

1.3 Research Question and Objectives

This study addressed the following research question: What are the experiences of accessing health care in Counties Manukau District Health Board for families of children with Bronchiectasis?

The research question was addressed through the following research objectives:

- To understand families' experiences of accessing different health care services, for example general practitioner, specialist clinics and hospital care.
- To identify barriers and enablers to accessing health care services for families of children with Bronchiectasis.
- To identify areas for improvement within the health care system, to enable families to access health care services more easily.

1.4 Theoretical Foundation

Factors that may lead to the development of bronchiectasis and affect health care access are complex and multi-factorial and include economic, social, environmental and cultural elements. A socio-ecological model, such as that described by McLeroy, Bibeau, Steckler and Glanz (1988), can be used to make sense of this complex interplay of factors affecting health care access. This model, adapted from Bronfenbrenner's earlier model (1979), appreciates the interweaving of personal factors, institutional factors, the community and the wider social environment. Figure 1 shows an adaptation of the model described by McLeroy et al. (1988).

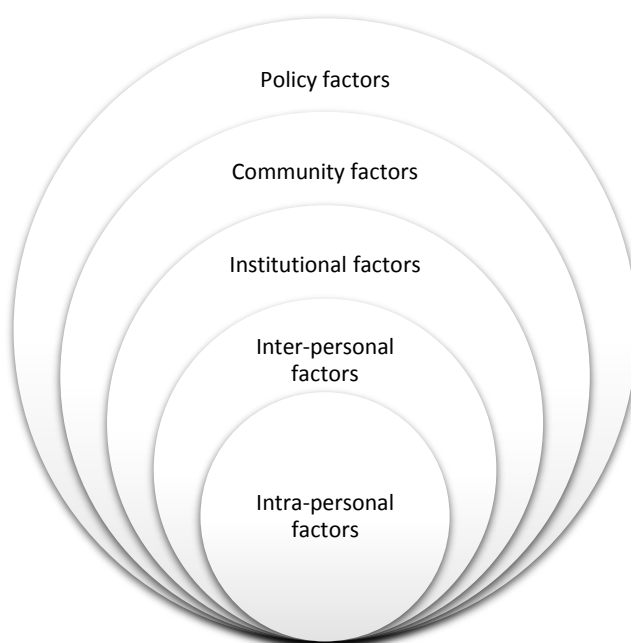


Figure 1. The socioecological model, adapted from “An Ecological Perspective on Health Promotion Programs” by McLeroy et al., 1988, *Health Education and Behaviour*, 15, 8, p.355.

The socio-ecological model was used in this study to structure the consideration of the factors that influence how families may access health care services. Another similar model, a behavioural model developed by Andersen (1995), was considered for use in this study, but it was felt that the model had a greater focus on individuals and did not allow for careful consideration of families, culture and wider policy implications. The socio-ecological model, in contrast, is broad and allows a topic to be examined with numerous levels of influence, including families, communities, culture and policy. These aspects of the model were particularly important for the present study, because the population under study comprises a diverse range of cultures. As will be discussed in the literature review (chapter 2), Māori and Pacific Island cultures, in particular, place significant importance on the influence of families and the community on health and wellbeing. The socio-ecological model was used in this study to provide structure to the literature review and will be further considered in the discussion section.

McLeroy et al. (1988) argue that the long-standing ideology emphasising personal responsibility for health does not appreciate the more complex social and environmental forces at play in public health, producing an unrealistic model of behaviour. The emphasis on personal responsibility for health was propelled by the neoliberal political agenda and has driven a health model that puts individuals and their health behaviours at the centre of public health strategy (Ayo, 2012), ignoring the wider determinants of health that influence behaviour (Minkler, 1999). This has led to a dramatic increase in health inequity, as poorer individuals are generally less able to make healthy choices than wealthier individuals (Labonté & Stuckler, 2016). This neoliberal, individualistic view has many limitations; it does not consider the role of an individual's community, cultural or environmental circumstances; nor does it appreciate that people are shaped by the world they live in, the people they interact with and the worldviews they hold (Ayo, 2012). In contrast, the socio-ecological model appreciates that there are many diverse contextual forces acting upon an individual, many of which are beyond an individual's direct control. Ecological models draw attention to the social and environmental context within which an individual is situated, identifying the role that different determinants, like relationships, the environment and public policy, may have on an individual's health (McLeroy et al., 1988). While the individual must not be ignored and must still be at the centre of health interventions, Minkler (1999) argues that greater thought must be given to the social and environmental influences that act upon that individual, in order to appreciate the wider context of health care and health systems. The socio-ecological model can illustrate this complex interplay of determinants of health and can help to unpack and structure thinking around the factors that may influence a certain phenomenon.

The socio-ecological model has undergone various adaptations and iterations since it was first developed. The model that is referred to in this study is described by McLeroy et

al. (1988) using five levels. The first level includes intra-personal factors, describing characteristics of an individual, such as knowledge and behaviour. The second level, inter-personal factors, involves relationships and support systems, including family, friendships and health care relationships. The third level, institutional factors, considers organisations and their rules and structures. The fourth level, community factors, encompasses factors relating to groups of people or institutions, including cultural communities. Finally, policy factors relate to wider policies of local and national laws and regulations.

1.5 Thesis Structure

The introduction to this study has explained the problem context and outlined the research question and objectives. Chapter two, the literature review, first describes the health care system in NZ and elements of the health system that children with bronchiectasis will need to access. The literature review then uses the socio-ecological model to structure a discussion of existing literature exploring factors that influence access to health care. In the following chapter (chapter 3), the study's qualitative methodology and methods are outlined. The results chapter (chapter 4) describes the main themes that arose from thematic data analysis. A discussion of these results (chapter 5), embedded in pertinent literature, draws relevance to the study's findings and identifies the strengths and limitations of the study. Finally, in chapter 6, the study concludes with implications for practice and further research.

Chapter 2: Literature Review

2.1 Structure and Literature Search Methods

This literature review explores current national and international literature around bronchiectasis and its risk factors, the NZ health care system and factors that influence access to health care. Articles were sought that had a particular focus on NZ, indigenous populations, minority populations, children, deprivation and health equity. The type of review is a literature review, described by M. Grant and Booth (2009) as a summary of current or recent literature, using inclusion criteria determined by the author, identifying quality literature and critique of that literature within a structured analysis. The socio-ecological model, as described in the previous chapter, has been used to structure and interpret factors that may limit or enable health care access. Each level of the model will guide the examination of issues influencing health care access in NZ to build a picture of the barriers and enablers of health care access.

Literature searches were conducted between July 2016 and January 2018. Journal articles were accessed using EBSCOhost research databases, which included health databases CINAHL, Medline and SPORTDiscus. Search terms with Boolean operators were used. Search terms included, but were not limited to, bronchiectasis, chronic suppurative lung disease, respiratory; health care, health service, diagnosis, treatment; access, availability, use; paediatric, pediatric, child*; barriers, limit*, enabl*, facilitat*. Articles were limited to papers published in English. Articles were screened by title and abstract to determine if the topic of the article was within the focus of the review. Grey literature was accessed online from Government websites, such as the Ministry of Health and Statistics NZ, the CMDHB website and respiratory societies or foundations, such as the European Respiratory Society and the Asthma and Respiratory Foundation NZ.

2.2 Bronchiectasis, its Risk Factors and Population Patterns

Bronchiectasis is a chronic suppurative lung disease that is characterised by abnormally dilated airways, excessive sputum production and recurrent respiratory infections (Maselli et al., 2017; Pasteur et al., 2010; Polverino et al., 2017). The pathogenesis of bronchiectasis is thought to be related to a vicious cycle of infection and inflammation – a theory proposed by Cole (1997) and still widely accepted. Most of the time, bronchiectasis is caused by repeated respiratory infections, though some non-infectious causes may include congenital abnormalities with impaired mucociliary clearance, auto-immune disorders and post-radiation treatment (Maselli et al., 2017). While bronchiectasis may

develop at any stage in the life span, it is commonly diagnosed in childhood, as children are particularly susceptible to repeated infections. Adults diagnosed with bronchiectasis have frequently had a persistent cough for several decades (Eastham, 2004; Maselli et al., 2017), while children in NZ have often reported a productive cough for over two years (Twiss et al., 2005).

Early signs of bronchiectasis include persistent infections, usually with a chronic, productive cough. Diagnosis of bronchiectasis is confirmed using high-resolution computed tomography (HRCT) (Pasteur et al., 2010). While bronchiectasis was once a rare disease, incidence and prevalence in adults and children are increasing both internationally (Callahan & Redding, 2002; Maselli et al., 2017) and in NZ (Telfar-Barnard & Zhang, 2017). One reason for this may be the improved ability to diagnose bronchiectasis using HRCT scanning, which is readily available nowadays in most urban areas (Hill, Pasteur, Cornford, Sally, & Bilton, 2011; Maselli et al., 2017). Difficulties with recognising the early signs of bronchiectasis in children and low access to sophisticated scanning technology in remote communities means that bronchiectasis is probably under-diagnosed in many populations (Singleton et al., 2014), including the population under investigation in this study.

The disease trajectory of bronchiectasis is dependent on the age of the patient and severity of the disease, though it is generally considered to be a progressive disease, punctuated by episodes of acute exacerbation (Maselli et al., 2017; Redding, 2009). Treatment of bronchiectasis should include airway clearance and exercise and may also include antibiotic therapy, among other medical interventions (Chang et al., 2015). With improving medical treatment, life expectancy is improving (Pasteur et al., 2010). There is some evidence that in children, improvement of symptoms, or even reversal of pathological processes, may be possible (Al Subie & Fitzgerald, 2012; Redding, 2009). In order for therapy to be commenced early, emphasis must be on early detection of respiratory infections and early suspicion of bronchiectasis in susceptible children (Al Subie & Fitzgerald, 2012).

Despite these improvements in the diagnosis and treatment of bronchiectasis, the disease remains a significant burden on health care systems both internationally and locally. Hospitalisations for bronchiectasis have been noted to be increasing in Germany (Ringshausen et al., 2013), Australia (Chang et al., 2014) and in the United States of America (Joish, Spilsbury-Cantalupo, Operschall, Luong, & Boklage, 2013). In NZ, a report on the national impact of respiratory disease (Telfar-Barnard & Zhang, 2017) showed that in the general population (adults and children), both hospitalisation rates and mortality rates have been increasing over time, with hospitalisations having increased by 41% between 2000 and 2015. The cost of hospitalisations across NZ was estimated to be over \$25 million in one fiscal year (Bibby et al., 2015). Of all the District Health Boards in NZ, CMDHB has

the highest age-adjusted rate of hospitalisations for bronchiectasis (Telfar-Barnard & Zhang, 2017). Bibby et al. (2015) calculated the cost of bronchiectasis hospitalisations in CMDHB to be almost \$5.5 million in one year. These figures only represent a portion of the true burden of the disease on health care systems. While hospitalisation and mortality rates are relatively easy to quantify and cost, it is important to recognise that the true impact must also take into account the costs of primary care and the impact of the disease on individuals, communities and families (Thacker et al., 2006).

Hospitalisation rates have also been shown to display social and economic disparities in the population. Hospitalisations for bronchiectasis in NZ have been shown to be highest in the elderly population, followed by children under 15 years, compared to adults (Bibby et al., 2015; Telfar-Barnard & Zhang, 2017). Children show greater socioeconomic disparity than other age groups; a 2015 report showed that Pacific Island children showed the greatest disparity, with a hospitalisation rate 7.4 times higher than non-Māori, non-Pacific children (Telfar-Barnard, Baker, Pierse, & Zhang, 2015). An update of this report (Telfar-Barnard & Zhang, 2017) has shown that Māori young people aged 15-29 are 14.5 times more likely to be hospitalised for bronchiectasis than non-Māori. These two populations clearly face inequity in the health system, resulting in poorer health outcomes, as displayed by these hospitalisation figures.

Economic deprivation is noted to be one of the main risk factors for bronchiectasis in NZ. The hospitalisation rate for bronchiectasis (for the total population) is 3.4 times higher in the most deprived decile, compared to the least deprived (Telfar-Barnard & Zhang, 2017). This effect is most marked in the Māori population (Telfar-Barnard & Zhang, 2017). The reasons that economic deprivation increases the risk of development of bronchiectasis are complex. Associations have been made in literature between respiratory disease and poor living standards, household crowding, low vaccination rates and poor nutrition (Baker & Howden-Chapman, 2012; C. Grant et al., 2001; Mudarri & Fisk, 2007). Low vaccination rates in NZ, especially amongst Māori, with 78% coverage, and low-income populations, where having a low household income reduced the odds of being fully immunised by half (Ministry of Health, 2007b), have been identified as a significant risk factor for respiratory disease (The Asthma and Respiratory Foundation of New Zealand, 2006). Other factors that commonly link vulnerable populations to poor health outcomes in NZ are poor knowledge, low health literacy levels and limited access to health care (Ministry of Health, 2007a, 2017b), as will be further explored in the following sections.

Bronchiectasis is known to disproportionately affect indigenous and disadvantaged communities within developed countries (Chang et al., 2014; Edwards et al., 2003; Singleton et al., 2014; Twiss et al., 2005). In NZ, Māori children, Pacific Island children and children living in deprived areas are known to have more respiratory infections, more hospitalisations

for respiratory illness (Telfar-Barnard et al., 2015; Trenholme et al., 2012) and are diagnosed with bronchiectasis more frequently (Twiss et al., 2005) than non-Māori, non-Pacific children and those living in more affluent areas. In fact, these groups are over-represented in most statistics detailing poor health for adults and children in NZ (Ministry of Health, 2017b). Māori, the indigenous people of NZ, have experienced poor health largely as a consequence of colonisation. Dispossession of land, language and culture has led to Māori disempowerment and marginalisation (Zambas & Wright, 2016). Pacific people have experienced similar consequences in their home countries, and, upon migration to NZ, have experienced low socioeconomic status as manual labour workers (Arlidge et al., 2009). Both Māori and Pacific Island people still experience marginalisation in many areas of society, including health care (Zambas & Wright, 2016). With many Māori and Pacific Island people living with low incomes in NZ (Marriott & Sim, 2014), living in over-crowded conditions (Marriott & Sim, 2014; Statistics New Zealand, 2012) and having limited access to culturally and linguistically appropriate health care (Buetow et al., 2002; Zambas & Wright, 2016), these groups are heavily affected by bronchiectasis. In order to improve health equity among these populations, emphasis must be placed on improving health care access and ensuring health systems cater for these populations.

2.3 Health Care Access

Access to efficient, effective health care is crucial to the early identification and management of respiratory infections, to prevent the development and progression of bronchiectasis. This section describes the NZ health care system, the health system in CMDHB and the health care services that children with bronchiectasis and their families need access to.

2.3.1 Defining health care and access to health care

The World Health Organisation (WHO), through their Constitution (1948), declared health to be a basic human right, stressing the importance of equity in health care and the necessity for states to promote and protect the health of their people, without discrimination. Further to this, the Alma-Ata Declaration of 1978 urged countries to implement primary health care services as a way to organise health care, with a focus on reducing inequality and providing health for all people by 2000 (World Health Organisation, 1978). Health equity must be distinguished from health equality; the terms are most easily compared using their antonyms. Health inequality is any difference in health outcomes between groupings of people in a population (Arcaya, Arcaya, & Subramanian, 2015). The definition of health inequality is free from moral judgement about what is right, just or fair (Arcaya et al., 2015). In contrast, health inequity describes any health inequality that is avoidable or unjust, such

as inequalities associated with nationality, ethnicity or social factors (Arcaya et al., 2015; World Health Organisation, 2018).

In her report on ten years in public health, the former director of the WHO, Dr Margaret Chan (2017), reflected on changes in public health systems since then. She described how at the time, the Alma Ata declaration was revolutionary. The idea of health for all, or Universal Health Coverage, has been one of the tenets of public health work since. Chan (2017) highlighted that while many countries have implemented some form of primary health care system, inequity between and within countries still exists. Disorganisation of global health systems, lack of health funding and challenges faced by developing nations has meant that the goal of the Alma Ata Declaration has not been met (World Health Organisation, 2017). As a result, access to health care is not as equitable as it had been hoped to be by now. In 2008, recognising the disarray of global health systems, the WHO again called for a return to primary health care as the most affordable, efficient way to provide health for all people (World Health Organisation, 2017).

Access to health care is more than a simple equation of supply and demand. According to Gulliford et al. (2002), access to health care is a multi-faceted concept incorporating availability, utilisation, effectiveness and equity of those services. Accessing health care services may include visiting the doctor, filling medication prescriptions, recognising the need to take medication or seeking further help if required. Mooney (1983) argued that equity in health care primarily concerns equal availability of services; whether or not the service is utilised is up to the potential consumer. In contrast, Aday and Andersen (1981) highlighted the importance of a just approach to health care service allocation, emphasising the right to health care; they started to appreciate the complex array of political, health system and personal factors that affect access and utilisation of health care services. As communities become more diverse and modern lifestyles change, public health has seen growing health inequities in many communities. More recent public health literature, as will be discussed in section 2.4 of this review, has emphasised that equity is much more complex and that there are numerous factors that may influence one's ability to access health care.

In NZ, while an established public health system provides free, or subsidised, health care for many, the NZ Health Strategy (2016b) acknowledges that equitable access to health care has not yet been achieved in NZ. Many people in NZ still report an unmet need for primary health care, including 20% of all children involved in the NZ Health Survey (Ministry of Health, 2017b). Adolescents are known to be under-users of primary care services – in a nation-wide survey, 19% of school-aged students indicated that they were unable to access health care when needed (Clark et al., 2013). This was more common among students from the most deprived areas, compared to students from less deprived areas (Clark et al., 2013). The NZ Health Survey, similarly, reports that people most likely to report an unmet need for

health care are people living in the most deprived areas, as well as Māori and Pacific Island people (Ministry of Health, 2017b). These are the same people who are most affected by poor health, especially chronic health conditions (including bronchiectasis) and they must be the focus of efforts to improve access to health care in NZ.

2.3.2 The health care system in New Zealand

New Zealand's health care system is a public-private mixed system. Public health services are funded by the Government's Ministry of Health and distributed amongst NZ's twenty district health boards (DHB), such as CMDHB. The Ministry of Health delivers and funds health services in compliance with key legislation, for example the Health and Disability Act 2000. The Ministry of Health developed key strategies to structure the provision of health services in NZ, including the NZ Health Strategy, He Korowai Oranga (Māori Health Strategy), the NZ Disability Strategy and the Primary Health Care Strategy. These strategies emphasise health care access and equity to improve the health status for all New Zealanders.

2.3.3 The hierarchy of health care services

Health care services in NZ are provided under the oversight of DHBs. Health services have previously been referred to as primary, secondary and tertiary services, each service level indicating increasing specialisation. With the exception of primary care, these terms are no longer commonly used. Health services may be classified as primary care or more specialist services, all of which may be public, private or mixed-funded services.

Primary care services are provided in the community, usually by GP doctors, nurses and other health professionals in general practice. Services offered are diverse and may include screening, health promotion and treatment. Primary health care has an emphasis on improving the overall health of the population and striving for health equity (Ministry of Health, 2001). Primary care services may be fully or partially funded by the Government, or may not be subsidised at all. Before 2015, children under six years received free GP care; as of 2015, this has been extended to include all children up to the age of 13 years (Ministry of Health, 2016c). The cost of GP visits varies, as GP practices are privately owned and can set their own fees. People who are enrolled in a GP practice will have their fees subsidised by the Government. Further, people who are eligible for a Community Services card or are high users of health care services may be eligible for reduced cost GP visits (Ministry of Health, 2017c). Some GPs may join a low cost access programme, run by their Primary

Health Organisation, which means they receive extra funding from the Government to reduce costs for the consumer (Ministry of Health, 2017d).

While primary care provided at the GP is now free for children up to age 13 years, primary care provided after hours is not. Fancourt, Turner, Asher and Dowell (2010) point out that 75% of the week lies outside of the working week, and further, evenings are typically a time of deterioration for many childhood illnesses, particularly respiratory illnesses. Access to after-hours care may be more challenging for families living in poverty, who may be unable to pay for multiple trips to the after-hours clinic and may be constrained by work commitments and hourly-paid jobs (Fancourt et al., 2010). The authors make a case for a review of the funding systems constraining this aspect of primary health care, in order to improve access and equity throughout the population.

Other private or non-Government Organisation services may include private hospitals, community trusts or voluntary providers (Ministry of Health, 2017c). Consumers of private services may pay for these services themselves or may be covered by insurance. While having private health insurance is not a necessity for access to health care services in NZ, people with private health insurance may receive more timely access to non-urgent health services (Ministry of Health, 2016a). A Ministry of Health report on private health insurance coverage (2016a) indicates that Māori, Pacific Island people and low income groups are less likely to have private health insurance. As well as this, people with self-reported 'good health' are more likely to have private health insurance than those with poorer health. All of these indicators continue to drive health disparities in high-needs groups within the population.

Specialist services, which have previously been referred to as secondary or tertiary services, may be provided in the hospital setting, in which case they are usually free to the consumer, or they may be provided in a private facility at the cost of the consumer. The largest providers of these types of services are public hospitals in NZ (Ministry of Health, 2017c). Appendix A illustrates the structure of the NZ health and disability sector, as outlined by the Ministry of Health (2017c).

2.3.4 The health care system in Counties Manukau District Health Board

The CMDHB serves a region in the southern part of Auckland, NZ. The population living in the area exceeds half a million people, or 11% of the total NZ population, and this population is growing (Counties Manukau Health, 2016). The population has a diverse ethnic makeup, with large proportions of Māori, Pacific Island and Asian people. Counties Manukau

Health (2016) state that over 30% of people in the area live in areas classed as the most socioeconomically deprived, based on the NZ Deprivation Index (Atkinson, Salmond, & Crampton, 2014). The DHB has a higher proportion of children than the overall NZ population, with 23% of the population being aged 14 years or under (Counties Manukau Health, 2016).

The CMDHB provides primary care and specialist services, with the aim of achieving health equity in the community (Counties Manukau Health, 2017). Members of the community are encouraged to see their family doctor (GP) for all non-urgent health concerns, phone the free Healthline service if advice is needed, attend the after-hours Accident and Medical centre if their doctor is not available, or, in an emergency, to present to the hospital emergency department. Middlemore Hospital is the DHB's main hospital, which includes a paediatric department, Kidz First.

2.3.5 What components of the health care system will children with Bronchiectasis in Counties Manukau District Health Board need to access?

Children with bronchiectasis may access health care services in many different ways. They will have a local GP and may also access after-hours clinics when required. Following diagnosis, they are likely to be referred to a specialist paediatric respiratory clinic for regular follow-ups. While Middlemore Hospital (in CMDHB) has a paediatrics department (Kidz First), the care of children with bronchiectasis has historically been shared with Starship Hospital, Auckland's specialist paediatric hospital (located in the Auckland DHB). Some children in the CMDHB may see clinicians at Starship Hospital only, some may be under the sole care of CMDHB clinicians and some may be under shared care of both clinical teams. Anecdotally, there is no consensus as to which children may be under the care of one clinical team over the other and this may cause confusion and discontinuity of care for children, families and clinicians. For hospital care, many children will access Kidz First, at Middlemore Hospital, while others will only access Starship Hospital. The decision to access one hospital over the other may be made by the ambulance crew, who will take the child to the closest hospital in an emergency; hospital staff, who may recommend Starship Hospital in more acute situations (if more specialised paediatric facilities are required); or by the family, who may drive their child to their preferred emergency department themselves.

The process of diagnosis and treatment of bronchiectasis may require many visits to health care professionals. Typically, a child may present to their GP with a productive cough in the first instance. One study investigating the burden of chronic cough found that over 80% of children had presented for medical treatment over five times before their cough resolved or a cause was found (Marchant et al., 2008). This is likely to be the case for most,

if not all, children diagnosed with bronchiectasis. In fact, a NZ study found that by the time children were diagnosed with bronchiectasis, they had already had a median of four hospital admissions for respiratory symptoms (Edwards et al., 2003). Misdiagnosis of asthma is common and has been suggested as a possible reason for delayed diagnosis of bronchiectasis in the primary care setting (Eastham, 2004; Stafler & Carr, 2010). Another reason may be that because bronchiectasis has, in the past, been thought to be a disease in decline (Edwards et al., 2003; Twiss et al., 2005), it may not be immediately recognisable to many GPs (Maselli et al., 2017). Once bronchiectasis is suspected, a referral may be made for the child to attend a specialist respiratory service and a HRCT scan will be performed (Pasteur et al., 2010). If bronchiectasis is confirmed, it is recommended that children with bronchiectasis should have treatment plans linked to both primary and specialist services (Chang et al., 2015; Pasteur et al., 2010). Children in CMDHB will continue under the care of a paediatric respiratory service (either through CMDHB, Starship, or both) and will continue to see their GP as their primary care option. The process from diagnosis to long-term management may be lengthy and involve many health professionals, which is frequently confusing for families, who may be unsure which service to access and when (Buetow et al., 2002). This confusion may lead to challenges with accessing health care, as will be discussed in the next section.

2.4 Barriers to, and Enablers of, Accessing Health Care

There are many factors that may present as barriers or enablers to accessing health care. This section addresses some of these factors, drawing on literature examining the topic in a variety of populations. Due to the paucity of literature relating specifically to paediatric bronchiectasis, literature was sourced that relates to respiratory conditions and other chronic conditions, with a particular focus on children, indigenous groups or marginalised communities. These groups were chosen to reflect the likely characteristics of people who are disproportionately impacted by bronchiectasis in NZ.

The socio-ecological model (McLeroy et al., 1988) has been used to provide structure to the following section of this literature review and to unpack the complex web of factors that affect access to health care. First, intra-personal (individual) factors will be explored, such as health literacy, health beliefs and employment. Secondly, inter-personal (relationship) factors will be considered, such as relationships and communication with health care providers. Thirdly, institutional factors will be reviewed, such as navigating the health system. Community factors will be examined next, such as culture and social support. Lastly, policy factors will be analysed, such as health equity. A summary of the findings of the literature review are presented at the end of this section.

2.4.1 Intra-personal factors that affect health care access

Intra-personal factors are those that are specific to an individual that may determine how easy, or difficult, it may be for them to access health care services (McLeroy et al., 1988). Some of these factors include health literacy and personal beliefs and perceptions about health care. Intra-personal factors may also include more pragmatic factors, such as the financial status of the individual and transportation options available.

Health literacy is the ability to understand, process and make appropriate health decisions, including the ability to seek, and act upon, health information and health care (Kickbusch, Wait, & Maag, 2005; Ministry of Health, 2015b). Improving health literacy may be empowering, allowing people to have a sense of responsibility and control over their health (Kickbusch et al., 2005). Lower health literacy levels are associated with poorer health and are also linked to health inequalities (Kickbusch, Pelikan, Apfel, & Tsouros, 2013). Population health literacy levels are limited, both globally and locally. The European Health Literacy Survey showed that nearly half of all Europeans had limited health literacy, with people with lower social status and poor health having worse health literacy than the general population (Kickbusch et al., 2013). New Zealanders, on average, also have poor health literacy, with Māori in all income groups having poorer health literacy skills than non-Māori - over 75% of Māori are considered to have poor health literacy skills (Ministry of Health, 2007a).

Health literacy may influence access to, and engagement with, health care services. Many parents may have a poor understanding of their child's health condition or the treatment needed or being provided for them. Schneiderman and colleagues (2010), in an American study undertaken with English and Spanish-speaking parents, found that many people did not understand explanations given to them by doctors, regardless of the parent's level of English. Parents in this study were asked about perceptions of health care in a survey with pre-determined questions. While this method of data collection may not produce rich, varied views, it did identify some key areas of interest. Their finding that few people understand doctors' explanations, despite their command of the English language, suggests that poor health literacy may be a problem for many people. Health literacy is particularly a problem in low income and indigenous groups, often limiting communication with, and access to, health care providers (Diette & Rand, 2007). A NZ study (Buetow et al., 2002) reported that many patients did not understand when to seek care for their child with asthma, or how to access that care when needed. The study reported that many Pacific Island patients, in particular, did not understand the need to access their GP in the first instance, or the importance of ongoing GP care, even when well (Buetow et al., 2002). Pullon et al. (2015), in a well-designed qualitative study of barriers to health care in an impoverished community in NZ, call for a greater emphasis on improving health knowledge of Māori,

especially those living in impoverished or rural areas, many of whom may be poorly educated and parenting alone.

For some parents, alternative personal health beliefs may have a greater influence on health care access. When health beliefs are different to those of the health care professional, parents are less likely to seek conventional health care (Diette & Rand, 2007). An American study by Mansour, Lanphear and DeWitt (2000) showed that while asthma management strategies were often targeted at improving parents' knowledge, it was parents' alternative health beliefs that dictated whether or not they accessed health care services. In this study, focus groups were undertaken with parents of urban, minority children with asthma. While the authors stated that there was widespread belief that barriers to health care include difficulty accessing health care or insurance, in contrast, they found that it was in fact the parents' health beliefs that most influenced patterns of health care utilisation. These parents were often distrustful of medicines or did not view pharmacological therapy as a preventative strategy. Parents were more likely to use non-medicinal strategies, like breathing exercises and dietary alterations, in favour of their doctor's prescribed asthma-management plan. In this study, all participants described themselves as having a black racial background and all were considered underprivileged. This meant the group probably did not provide a range of diverse beliefs and may have had similar cultural beliefs; this may have led to a greater emphasis on the unexpected findings. Indeed, cultural factors may also influence personal beliefs of health care, where some may choose alternative therapies that are more culturally appropriate. Another American study (Seid, 2008) explored parents' beliefs of asthma management using an interview survey, in English or Spanish, with pre-determined questions about barriers to care and perceptions of care. This was a quantitative study, so did not provide information as rich and varied as may have been achieved with more open-ended questioning (French, Reynolds, & Swain, 2001). Nevertheless, the authors identified that health beliefs, expectations of care and marginalisation may all have a significant impact on primary care experiences of vulnerable children and families. They highlighted the experiences of Latin American families in particular, who may rely on folk beliefs and alternative therapies for treatment of asthma, and have a general distrust of prescribed medicines (Seid, 2008). Similarly, a qualitative study exploring perceptions of health care in Scotland from the perspective of Eastern European migrants found that alternative health beliefs significantly influenced families' health care practices (Sime, 2014). As will be discussed later in this review, cultural beliefs are also important for families in NZ, where Bolitho and Huntington (2006) found that for Māori families, their understanding of illness, and whether or not they believed a doctor could help them, influenced their decision to access health care.

Financial barriers also affect families' abilities to access health care. While the cost of seeing a GP in NZ is now free for children under 13 years, families who have limited

financial resources may still find it difficult to pay for medications (Bolitho & Huntington, 2006; Jatrana et al., 2011), transportation to health care providers (Ballantyne et al., 2015) or after-hours care (Lee & North, 2013). Some families report financial enablers to accessing health care, like having a disability allowance for their child, being able to access reduced rates or having an account with their health care provider (Bolitho & Huntington, 2006). Others, who may not have such an arrangement with their health care provider, may be compelled to access the emergency department as a free health care option (Pullon et al., 2015). This not only puts pressure on the public health care system, but may also lead to worse outcomes for children, as the illness may have progressed further by the time they are taken to the emergency department (C. Grant et al., 2001; Pullon et al., 2015). Cost barriers have been found to weigh more heavily on people with chronic conditions, who will have frequent and long-term health care needs (Wendt, Mischke, Pfeifer, & Reibling, 2012). Unfortunately, people in lower-income groups often have poorer health and more chronic and long-term health conditions requiring frequent medical care (Ministry of Health, 2017b), further compounding the problem.

Employment may be an enabler for families who struggle financially (Bolitho & Huntington, 2006), but can also present difficulties when making time for appointments. In most health care systems, including in CMDHB, GPs and specialist clinics operate in traditional weekday working hours. Specialist appointment times are usually set by health care providers and can be difficult to change if they do not suit the patient or family. Ballantyne et al. (2015) interviewed Canadian mothers and health care professionals about the perceived barriers and enablers to attending a neonatal follow-up clinic. This study used a qualitative descriptive methodology, identifying that some mothers who were employed found that they were financially in a better position to access health care for their child, and those who had flexible employers found that employment was an enabler to health care access. Some mothers, conversely, found that their employers were not as flexible, or they found it difficult to find time to access health care for their child if they were juggling multiple jobs (Ballantyne et al., 2015). This may lead to families needing to access the after-hours or accident and emergency clinics, where they are faced with doctors who do not know their child and a cost for the health care service provided there (Bolitho & Huntington, 2006). Māori families interviewed by Bolitho and Huntington (2006) discussed negative experiences of using accident and emergency clinics, identifying that communication between the patient and health care provider was limited, and negatively impacted on their experience. Participants remarked that interactions with health care providers who had no knowledge of their child did not help to build trusting relationships between them and the health care providers. Participants concluded that after these experiences they no longer wanted to access these clinics – this indicates the importance of relationships to parents' engagement with health care services.

The intra-personal factors identified in literature that influence health care access are health literacy, health beliefs, financial barriers and employment. The literature reviewed was predominantly international literature and considered populations different to the population under investigation in the present study. It is important, therefore, that this study includes an exploration of intra-personal factors influencing health care access from the perspective of families of children with bronchiectasis in a NZ context, to compare and contrast the findings of this literature review.

2.4.2 Inter-personal factors that affect health care access

According to McLeroy's (1988) socio-ecological model, inter-personal factors may include formal or informal networks of support, including family, work and friendships. Literature exploring access to health care focusses on the relationship between health care provider and consumer, with a particular emphasis on communication – both within that relationship and between health care providers.

The relationship between a health care provider and the family accessing health care is extremely important. Satisfaction with services and having a good relationship with health care providers are key elements of health care that encourage people to continue engaging with that provider (Alexander, Brijnath, & Mazza, 2015; Barnett, 2000; Bolitho & Huntington, 2006). Papp et al. (2014) describe an important feature of a health care experience as 'patient-centredness', whereby patients expect their doctor to be empathic, sympathetic and prepared to listen and provide explanations to the patient. 'Patient-centredness' focusses on the patient, rather than the illness (Papp et al., 2014). Similarly, Ballantyne et al. (2015) explain that having a comfortable, non-judgemental relationship with a health care provider is important for creating good health care experiences. This is a theme that has been identified in studies exploring health care access in migrant cultures (Alexander et al., 2015), indigenous cultures (Bolitho & Huntington, 2006; Slater et al., 2013) and low-income groups (Alexander et al., 2015; Barnett, 2000), suggesting that a wide range of people consider this to be an important part of a health care experience. Parents commonly report that when they see a different GP at their practice or access after-hours care, the unfamiliar relationship creates tension and a lack of continuity of care (Arlidge et al., 2009; Bolitho & Huntington, 2006; Buetow et al., 2002). The importance of patient-provider relationships was emphasised in a study exploring children and parents' perceptions of paediatricians in a hospital setting (Konstantynowicz, Marcinowicz, Abramowicz, & Abramowicz, 2016). Participants in this study highlighted that doctors who took time to get to know a child and who displayed caring non-verbal behaviour are preferred, while those who used too much medical jargon were not as easy to form a relationship with. The relationship forged between a health care provider and the patient (or

parent) is an essential component of a positive health care experience, leading to improved engagement with, and outcomes from, health services.

Having a good relationship with a health care provider is of particular importance to Māori consumers of health care services. Slater et al. (2013) describe how having a health care provider who understands the individual, their whānau (family) and their worldview increases satisfaction and encourages further engagement with health care services. A Kaupapa Māori study investigating how Māori experience health care (Cram, Smith, & Johnstone, 2003) found that Māori who have had a bad experience with a (usually Pākehā) health care provider in the past may be weary and fearful of the health care system. These participants found that when health care providers took the time to build rapport with them, they had a better experience with the health care system. When whānau do not have a relationship with the health care provider, they may be more likely to feel judged, feel unsure of their decision to access care and may be more likely to delay their visit in the future (Bolitho & Huntington, 2006).

Effective communication with health care providers is the key to a good relationship for many parents. Health care providers who are able to communicate effectively with both the parent and child may be considered to provide a more satisfactory service (Dixon-Woods, Anwar, Young, & Brooke, 2002). Language may act as a barrier to many families, particularly migrant families, who are accessing health care in a new country. This was highlighted by Eastern European parents and children who were interviewed about their experiences of using the Scottish health care system; parents reported that not having a sophisticated understanding of English limited the complexity of information they could receive (Sime, 2014). Negative communication experiences may also present in the absence of a language barrier, for example, when parents are asked the same questions repeatedly, leaving them to feel that they are not being listened to and that different health care professionals are not communicating with each other (Arlidge et al., 2009; Buetow et al., 2002). Families often report feeling frustrated at having to explain things repetitively to different health care providers and across different services (Pullon et al., 2015), suggesting that communication between health care professionals and between services is also important in forming parents' perceptions of health care experiences. Many families stress the importance of health care services having a plan that is communicated between services and with families to improve confidence in the health care system (Pullon et al., 2015). Confidence in health care systems and trust in individual practitioners both influence people's likelihood of accessing health care services (Wendt et al., 2012). Having a greater understanding of how health care experiences foster confidence and trust in health systems and health providers could, therefore, improve engagement in health care services and improve health outcomes.

Literature has shown that the interpersonal factors affecting health care access are relationships with health care providers and communication – between the health care provider and the patient, and between different health care providers or services. Because these factors appear to have a significant influence on health care access for many people, it was important that inter-personal factors were explored from the perspective of families of children with bronchiectasis in CMDHB.

2.4.3 Institutional factors that affect health care access

Institutional factors are those arising out of a social institution or organisation (McLeroy et al., 1988). The health care system can be considered in this way, whereby the consumer's ability to navigate the system and their trust in the system may affect their ability to access health care.

The ability to navigate the complex organisational systems of health care services can be challenging and be a barrier to accessing health care for many. Different countries have different health care system structures, as indicated in a large study by Papp et al. (2014) that looked at perceptions of primary health care quality in seven developed European countries. They found that different populations had varying levels of tolerance for GP waiting times or after-hours availability of their GP. The different populations also had different expectations around the 'gate-keeping' role of their GP as a channel to other specialist services. The route by which families are expected to access health care may also differ from place to place, which may cause confusion - many families have expressed feeling unsure of whether to access primary or hospital care in the first instance (Bolitho & Huntington, 2006; Buetow et al., 2002; Sime, 2014). Others may not be able to afford the cost of GP or after-hours medical services, so use hospital services as their first point of access (Pullon et al., 2015). As well as this, some families have reported being unsure of other services and resources available to them because they did not receive this information from health providers (Arlidge et al., 2009).

As highlighted earlier, inadequate communication is often cited as one of the major problems with navigating the system. Poor communication of hospital systems and procedures leaves parents in the dark about the causes of long waiting times or their child not being seen as a priority (Arlidge et al., 2009; Bolitho & Huntington, 2006; Jacob, Childress, & Nathanson, 2016). A perceived lack of communication between health care providers makes parents feel like they are receiving disjointed, sub-standard care and this creates a barrier to accessing care (Jacob et al., 2016; Pullon et al., 2015). Many parents feel that in order to get the most for their child, they need to be able to 'work' the system

(Jacob et al., 2016; Sobo, Seid, & Gelhard, 2006). This is likely to be most difficult for marginalised populations who are disempowered in the health care system (Zambas & Wright, 2016).

Trust and confidence in health care systems were explored in a large study by Wendt et al. (2012) in countries with different health care funding structures. This study provided a very broad overview, where a large sample (nearly 9,000 participants in seven developed countries) were surveyed, allowing for robust statistical analysis. The study used previously collected data from a telephone survey using multiple-choice questions. The demographics of the population were adjusted to fit country-specific distributions. Because the sample was so large, more detailed questioning, that may have explored perceptions of confidence in more depth, would not have been possible, though it may have been useful. Trust in the health care system is important, because consumers must feel that they will be able to access health care services when they need to. Cost barriers experienced within health care systems were found to have an influence on trust in the health care system. In countries where cost-sharing was widespread, or health insurance was a necessity, consumers had less trust in the system and were more likely to skip appointments because of cost. In this study, NZ was considered to have moderate cost barriers because cost-sharing (between the public system and the consumer) is necessary for many health services, specifically primary care and pharmaceuticals. People in NZ were more likely to miss appointments because of cost than people in all other countries, except the United States of America. Several individual factors also influenced trust in the health system. Individuals with lower education, lower income and poorer health were less likely to have confidence and trust in the health care system. When people felt that they trusted their country's health care system, they were more willing to access health care. Health systems must be robust, reliable, affordable and equitable for this to be achieved.

The institutional factors that literature found to affect health care access were individuals' abilities to navigate complex health care systems, communication between health care providers, and trust in the wider health care system. These broad ideas reflect the influence of the structure and functioning of the wider health care system on individuals' access to health care. Considering the complexity of the health care systems that families of children with bronchiectasis in CMDHB must navigate, it was important that the present study considered the experiences of this group, to compare and contrast institutional factors that may influence health care access from a local perspective.

2.4.4 Community factors that affect health care access

Community factors may include relationships between institutions and organisations, or more informal networks (McLeroy et al., 1988), like communities living in a defined area, who have a common culture. Culture and social support networks are considered here as community factors that may affect access to health care.

Culture has a significant impact on the types of health care services that families access and how they access those services. As previously discussed, individual health beliefs may influence health care access; so, too, may the health beliefs inherent in one's culture (Diette & Rand, 2007). It is widely acknowledged that culture is an important factor influencing how many minority populations experience and access health care services (Gibson et al., 2015; Pullon et al., 2015). In NZ, Māori see health as a more holistic, family- and community-focussed entity than is reflected in the Western health care system (Bolitho & Huntington, 2006; Pullon et al., 2015). Culture also has an impact on the importance that is placed on different aspects of wellbeing. Western medicine places most importance on one's physical wellbeing, but many cultures, including Māori culture, may, at times, prioritise others over their own well-being. This may mean that family commitments, in particular, may take priority over accessing health care (Bolitho & Huntington, 2006). This may weigh more heavily on those who are socioeconomically disadvantaged and may be obliged to meet the needs of the family or community over their own personal needs (Buetow et al., 2002). A qualitative study investigating knowledge of when to access care for children with asthma (Buetow et al., 2002) found that cultural factors significantly limited access to care; many Pacific Island families felt uncertain about using 'white' medicine, while Māori felt that health care professionals did not care for their whole being, only focussing on their physical illness. While this study produced some interesting findings about engagement with health care services, it must be noted that the participants were providers of health care, rather than consumers. The findings relating to why, and how, parents accessed health care must be acknowledged as being the perspectives of health care providers, rather than the true experiences of the families themselves. As recommended by Theunissen (2011), health care services in NZ must work to provide health care services that are receptive to Māori, and other, cultural and health beliefs.

Social support enables access to health care. Social support may include support from extended family, enabling access to transportation and financial support or providing childcare for other children in the family (Ballantyne et al., 2015; Bolitho & Huntington, 2006). Having social support in an unfamiliar environment, like a hospital, is also beneficial for families of sick children (Ballantyne et al., 2015). A study by Arlidge et al. (2009) explored the hospital experiences of families whose children had unintentional injuries. This study was a well-designed qualitative study with a focus on cultural perspectives. A strength of the study was that the interviewers also had varied cultural backgrounds and could be matched to the culture of the family being interviewed, to allow for a more comfortable and open

relationship between interviewer and participant. They found that the competing demands of work, family and spending time with a child in hospital could be difficult to navigate for many parents. This was exacerbated for single-parent families, who often had little social support. Even for families with both parents present, these demands could be burdensome, with parents working multiple jobs in tandem and juggling childcare. This was particularly the case for Māori and Pacific Island families, many of whom had several children, multiple jobs and fewer resources and social supports than Pākehā families. People with more social support may be better able to meet the demands of navigating complex health systems and managing these demands with the competing demands of family life.

Community factors that literature has found to influence health care access include culture and social support. It was important that these factors were explored for families of children with bronchiectasis in CMDHB, considering the vulnerable cultural and social groups that are most affected by this problem. This study has considered the influence of these factors on health care access, with the aim of identifying areas for improvement that may improve health equity for the population under study.

2.4.5 Policy factors that affect health care access

Policy factors may include local and national laws and policies (McLeroy et al., 1988). Health equity is considered here as the main principle underlying health policy in NZ.

While all factors already mentioned in this literature review have a significant effect on health care access, health equity is the underlying principle that must drive improvements in the health care system in NZ. Health is a human right (World Health Organisation, 1948) and equity must be a priority for governments and society. Improvements in health access must address factors that lead to inequity; poverty is one of these factors (Pullon et al., 2015). National policy must address poverty-related issues like housing and education; this will filter through to improving outcomes and equity in child health (Baker & Howden-Chapman, 2012; Mills, Reid, & Vaithianathan, 2012).

As well as addressing wealth equity, policy must focus on improving health equity for Māori and Pacific Island people, in particular. The NZ health care system is not well set up to cater to the cultural needs of minority groups (Jansen & Smith, 2006; Jatrana et al., 2011). While the system provides equal access to all cultural groups, that access is not always equitable (Robson, 2008). Māori experience more barriers to health care access than non-Māori, including a greater burden from the cost of health care and longer waiting times for treatment (Jansen & Smith, 2006). Additionally, many Māori and Pacific Island families

report discrimination within the health care system and identify that their cultural needs are not well met (Arlidge et al., 2009; Buetow et al., 2002; Theunissen, 2011). The development of health care services that put cultural needs of consumers at their centre may result in more satisfying care for consumers and more equitable access for all (Gibson et al., 2015; Teevale, Denny, Percival, & Fleming, 2013; Thomas, Williams, Ritchie, & Zwi, 2015). The NZ Health Strategy (Ministry of Health, 2016b) emphasises health equity by aiming to target resources towards improving health access and directing care to vulnerable groups in the population, like Māori and Pacific people. Embedded within the health strategy are other strategies that are targeted towards specific groups, like He Korowai Oranga, the Māori Health Strategy (Ministry of Health, 2014b) and 'Ala Mo'ui (Ministry of Health, 2014a), the overarching strategy for improving the health of Pacific Peoples. While broad, overarching strategies like these provide overall strategic direction for health services, they may be criticised for lacking detail that may allow for the translation of theory into practice (Came, McCreanor, Doole, & Rawson, 2016). Came et al. (2016) argued that while the NZ Health Strategy claims to focus on equity in the population, it does not demonstrate a commitment to supporting Māori- and Pacific-led health care solutions, and thus, cannot be considered to be truly committed to addressing health equity. As well as this, under-funding may restrict the successful implementation of equity-promoting strategies, limiting their effectiveness (Sheridan et al., 2011). Policies that are directed more pointedly at Māori and Pacific groups and that involve these groups in their implementation are more likely to be successful in achieving health equity (Came et al., 2016). Whānau Ora (Te Puni Kōkiri, 2017) is an example of a nation-wide policy with Māori needs at its core. This policy was implemented in 2010 (Ministry of Health, 2017e), as a whānau-centred service that works with Māori to improve the wellbeing of the community. A similar policy, Fanau Ola, was established in CMDHB to provide targeted services for Pacific people, supporting Pacific families to guide their health care (Counties Manukau Health, 2015). These targeted, community-focussed approaches to health care delivery demonstrate useful models of effective health care service provision.

The main policy factor that has been found to affect health care access is health equity. The problem of bronchiectasis in NZ disproportionately affects certain groups in the population, displaying an inequitable population health pattern. It is imperative that health care access becomes more equitable within the population. This study has explored the experiences of accessing health care from the perspective of users of health care services, with the aim of hearing families' unique perspectives, that may drive changes in the health care system to improve the experiences of similar families when accessing health care.

The preceding sections of this literature review have used the socio-ecological model (McLeroy et al., 1988) to structure a review of literature exploring the barriers to, and

enablers of, accessing health care. The factors that arose in these sections of the literature review are summarised in Table 1.

Table 1. Summary of factors that influence health care access, using the socio-ecological model (McLeroy et al., 1988).

Level of influence	Factor	Summary
Intra-personal	Health literacy	- Barrier: Poor health literacy
	Alternative health beliefs	- Barrier: Having different health beliefs than the health provider. - Beliefs are often influenced by culture.
	Financial barriers	- Barrier: Difficulty paying for medications, transportation, after-hours care. - Enabler: Having a disability allowance.
	Employment	- Barrier: Employment may make it difficult for some to find time to access health care. After-hours care can be costly and provide little satisfaction. - Enabler: Employment provides income for families to spend on health care.
Inter-personal	Relationships	- Enablers: A non-judgemental relationship, continuity of care. - Māori, in particular, place a lot of emphasis on relationships.
	Communication	- Barriers: Being asked the same questions repeatedly, language. - Enablers: Effective communication between the health care provider, the parent and child; communication between health care providers.
Institutional	Navigating the system	- Barrier: Being unsure of available services and how to access them.
	Trust in the system	- Barrier: Distrust of health systems; cost barriers reduce trust in the system.
Community	Culture	- Barrier: Disconnect between the cultural values of the health system and the health care consumer. Many cultures (e.g. Māori and Pacific Island cultures) have a more holistic view of health care than the Western model recognises.
	Social support	- Enabler: Social support assists with transportation, financial support and managing work and family life.
Policy	Health equity	- Enablers: Policy focussing on poverty-related issues, policies with culture at their core.

2.5 Creating Effective Health Care Services

Policies such as Whānau Ora (Te Puni Kōkiri, 2017) and Fanau Ola (Counties Manukau Health, 2015) have been initiated nationally and locally, respectively, to improve health outcomes for Māori and Pacific Island people in the community. Both programmes consider an indigenous approach to health care, providing health care that is culture-specific. National and international literature has also considered more specific service

provision approaches to reach vulnerable or indigenous groups. Service integration and co-location, prioritising vulnerable groups and focussing on effective relationships have all been considered as potentially effective ways to better structure health care services to reach those in need.

Service integration and co-location may have a significant effect on health care access, particularly for vulnerable groups. Service integration is the co-location of, and collaboration between, primary medical and social service providers, in order to better meet the needs of vulnerable groups (Khanassov et al., 2016). An Australian study by Thomas et al. (2015) emphasised the importance of locating services together to enhance informal communication between health care providers. This study qualitatively investigated the impact of an integrated service for urban Aboriginal children, whereby an outreach clinic incorporating health, social and community services was set up to meet the needs of children and their parents. Clinic attendees appreciated the informal structure, which was more culturally acceptable and allowed for a relaxed communication setting between health providers and patients. Partnerships between care providers also facilitated efficient, patient-centred care. Another study (Pullon et al., 2015), in a remote, largely Māori community in NZ, also pointed to the importance of service integration for the effective provision of health care. This study found that health, education and social services did not communicate or share information well between each other, and this impacted on the health of the community, particularly children. Both of these studies emphasised the need for services to communicate with one another and to work together to achieve the most effective outcomes for the community, particularly remote communities that may have limited access to a range of health services. Khanassov et al. (2016) argue that integrating services in this way may improve the approachability, affordability and availability of health care services, which may, in turn, improve equitable health care access.

Prioritisation of vulnerable children has also been proposed as an effective way to target health services at those who need them the most. Rather than prioritising patients based on their clinical conditions, Zwi, Joshua, Moran and White (2015) proposed a system to characterise a child's vulnerability and use this to prioritise need. This Australian study used a prioritisation tool initially developed for use in refugee populations. The authors

proposed the use of this system to address health equity in the population and improve access to health care services for vulnerable populations. They suggested that placing importance on indigenous groups, refugees, people with disabilities and those on low incomes would help to improve health care access for vulnerable groups and to make health care providers more aware of patients' social statuses and the societal pressures that may make it difficult for some people to access health care. While a prioritisation strategy may help to target health care services at people who are considered to be most in need, this idea presents several moral and ethical considerations. For example, the identification of factors that constitute a 'vulnerable child' may vary from place to place or according to who chooses these factors. The parameters set for these factors may also have the unwanted effect of limiting health care access to some children, who may fall outside of those parameters. It would be imperative that factors that may characterise a vulnerable child be chosen carefully, to limit discrimination. While prioritisation could be an effective and efficient way to target vulnerable groups, it only goes some way to addressing the problem of inequity, by identifying those most in need. Other measures, such as local availability of services and strategies to improve engagement with services would still be required to enable vulnerable groups to take up the health services offered.

A focus on forming effective relationships is important for providing effective health care services. Relationships may be formed between and within health services, including collaboration with stakeholders, other health care providers, schools and the community; relationships must also be formed between health care providers and consumers. Gibson et al. (2015) discuss the importance of collaboration between health services, policy-makers, communities and patients themselves when creating effective public health services. In particular, involvement of indigenous communities is crucial for the planning, implementation and delivery of sustainable, culturally-appropriate health care services (Gibson et al., 2015). This emphasis on the involvement of communities and health care users is also shared by Dixon-Woods et al. (2002), who recognise that the diverse needs of health care consumers must be considered when creating quality, equitable health care services. The authors insist that the views of children, young people and their families must be considered when delivering paediatric health care services (Dixon-Woods et al., 2002). By forming effective relationships between health services and communities, health care providers can engage vulnerable communities and break down barriers to accessing health care (Dixon-Woods et al., 2002; Gibson et al., 2015).

Relationships at the inter-personal level are also crucial. Thomas et al. (2015) contend that effective, equal relationships both between different health care providers and between the health care provider and the patient are crucial to improving access. When health care providers have a trusting relationship with each other, they are able to provide a more effective service and improve their own skills and knowledge (Thomas et al., 2015).

When health care providers take time to forge a trusting relationship with patients, patients have a greater sense of care and commitment from the health care provider. This is particularly important for indigenous communities, where a greater cultural emphasis is placed on relationships as the basis to effective care (Gibson et al., 2015; Thomas et al., 2015). As has been described earlier in this literature review, relationships with health care providers are central to the experience had by health care consumers (Ballantyne et al., 2015; Bolitho & Huntington, 2006; Konstantynowicz et al., 2016). In the interest of improving patient-centred care (Papp et al., 2014), it is important that further research focusses on the perspective of consumers of health care services, in order to identify factors that may influence their experience of accessing health care and implement changes to improve those experiences for all.

2.6 Concluding Comments on Literature Review

This literature review has analysed a range of literature relating to experiences of accessing health care by families, children and minority populations. Barriers and enablers of accessing health care have been identified and their level of influence stratified using the socio-ecological model (McLeroy et al., 1988). Some of the barriers identified included financial barriers, inadequate communication from health care providers and health care services that do not meet the cultural needs of the consumer. Some enablers that were identified included employment, having a trusting relationship with a health care provider and social support. While this literature review has identified some of the most commonly experienced barriers and enablers of accessing health care, further research is required to identify and implement strategies to improve access to health care for vulnerable groups in the community, particularly in NZ. Bolitho and Huntington (2006), following their study looking at the experiences of Māori accessing health care, identified a need for further, more extensive, research into the ways in which Māori interact with health care services. Dixon-Woods et al. (2002) identified a need for research to explore parents' views of accessing health care services, considering the parents are themselves consumers of paediatric health care services too. Little is known about the experiences of parents accessing health care for their children in NZ. Vulnerable groups, such as children with bronchiectasis, must be the focus of such research and interventions that may improve access to health care, allowing early identification of the disease and subsequent access to efficient, effective health care. The study that is outlined in the following sections of this thesis will start to address these gaps in the literature.

Chapter 3: Methods

This chapter outlines the study methods, from planning stages through to data analysis. First, the interpretivist paradigm and interpretive description methodology are discussed, justifying their use as foundations of the study. The methods used for recruitment, data collection and analysis are outlined. Finally, the processes used to ensure trustworthiness of the study are described, as well as a brief outline of ethical approval processes.

3.1 Research Paradigm: Interpretivism

Interpretivism is one of a number of different qualitative research paradigms. The positivist paradigm, which underpins quantitative research, assumes that there is one objective reality that is stable and measurable; interpretivism, in contrast, holds a belief in multiple realities (B. Grant & Giddings, 2002; Merriam & Tisdell, 2015; Nicholls, 2009). That is, phenomena may be experienced in different ways by different people, and each experience is truthful and worthy of investigation (B. Grant & Giddings, 2002). Interpretivist research can be helpful for uncovering personal, social and cultural aspects of phenomena (Nicholls, 2009). The present study is situated within the interpretivist paradigm because it aims to understand families' experiences of accessing health care. The researcher believes that each participant has a different story to tell and that rich meaning can be found in each of those experiences. Each individual's experience is important to understand and to express within a broader story of the experiences of accessing health care for families of children with bronchiectasis. Within the interpretivist paradigm, a number of different methodologies are located; interpretive description was chosen for this study, as is discussed in the following section.

3.2 Methodology: Interpretive Description

Interpretive description sits within the interpretive paradigm of methodologies (B. Grant & Giddings, 2002) and aims to explore and understand the human experience. While other interpretive methodologies, like phenomenology or grounded theory, are deeply philosophical, the aims of interpretive description occupy a space between philosophical theorising and objective description (Thorne, 2008). By providing a framework with which to explore people's experiences of phenomena and develop a practical application of the findings (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004), interpretive description assists researchers to answer complex clinical questions and understand real-life phenomena (Thorne, 1991, 2008).

This research utilises the interpretive descriptive methodology because firstly, it aims to explore families' experiences of accessing health care, and secondly, it aims to develop recommendations around practical solutions to improving health care access for the population under study. As described by Thorne (2008), interpretive descriptive studies originate from a question that has arisen from gaps in discipline-specific evidence and clinical practice. Having an understanding of discipline-specific theory and existing literature in the field is essential to formulating relevant, insightful research, allowing the researcher to ask informed questions and find perceptive links between theirs and others' research (Mitchell & Cody, 1993; Morse, 1994; Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). In the present study, the researcher's reading around the growing public health problem of bronchiectasis, particularly in certain vulnerable groups within NZ and CMDHB, led to questions about why children are not gaining access to existing health care services promptly, or why these services were not suiting their needs. These questions had also been raised by relevant literature (Byrnes & Trenholme, 2010; Edwards et al., 2003; Twiss et al., 2005), further justifying the need for this research. The interpretive description methodology was identified as the most appropriate methodology because it allows the researcher to hear stories of those people who are accessing health care services for their child and encourages the researcher to stay true to participants' own words, meanings and understandings. Interpretive description also guides the researcher to develop reflections, suggestions and plans of action to address the identified problems (Thorne, 2008).

3.3 Study Area and Population

This study was conducted in the CMDHB area of Auckland, NZ. This is a large area in the southern part of Auckland, in which bronchiectasis is particularly prevalent (Telfar-Barnard & Zhang, 2017). A map of the area is displayed in Appendix B. The population is comprised of large Māori and Pacific Island populations, and many people living in deprived communities (Counties Manukau Health, 2016); these are the people who are most at risk of developing bronchiectasis (Telfar-Barnard & Zhang, 2017). Access to health care may be challenging for Māori, Pacific Island and deprived populations (Jatrana & Crampton, 2009; Ministry of Health, 2015a; Zambas & Wright, 2016) and, consequently, many people with bronchiectasis (Byrnes & Trenholme, 2010; Callahan & Redding, 2002; The Asthma and Respiratory Foundation of New Zealand, 2006; Twiss et al., 2005). Exploring health care access in CMDHB in the context of bronchiectasis is important for improving the health, social and economic burden of this disease on the community. Because bronchiectasis may be prevented or improved if respiratory infections are identified early (Byrnes & Trenholme, 2010; Maselli et al., 2017; The Asthma and Respiratory Foundation of New Zealand, 2015), children are an important group of the population to focus on. While health care access for children is the focus of this study, the participants of the study are the parents or caregivers of children (aged 0-17 years) with bronchiectasis, as the main people accessing health care for the child.

3.4 Recruitment and Sampling

3.4.1 Recruitment location

Participants were recruited from paediatric and youth clinics at Manukau Super Clinic, CMDHB, and at Starship Hospital, which is part of the Auckland District Health Board. The two district health boards currently share the care of children under 15 years old with bronchiectasis who live in the CMDHB catchment area. Young people over the age of 15 years are then transferred to the youth clinic at CMDHB, which caters to the needs of teenagers and young adults as they transition to adult services. There are no strict guidelines as to which children are under the care of CMDHB and which are under the care of Starship Hospital, though anecdotally, the service running through Starship Hospital is considered to be the main specialist care centre for children who have more severe disease or require more frequent monitoring. All children diagnosed with bronchiectasis are registered under the care of either the paediatric clinic at CMDHB, the paediatric clinic at Starship Hospital or the youth clinic at CMDHB. Hence, participants were recruited from these clinics run by the two district health boards.

3.4.2 Sampling

Purposive sampling was identified as the most appropriate form of sampling for this project in order to identify information-rich sources (Sandelowski, 1995) that would illustrate a wide range of experiences of health care access for children with bronchiectasis. Purposive sampling aims to recruit a group of participants who will represent different features of the population under study (Thorne, 2008). Sampling aimed to achieve maximum variation in the sample across a range of selected demographic characteristics, such as ethnicity, income level, level of experience in the health care system (as measured by years since diagnosis), number of families in the house and main location of care. These variables were selected because literature suggests that these characteristics may impact on the development of bronchiectasis and the family's experience of the health care system. Demographic information was collected for all participants and this information was tabulated by the researcher to ensure that each variable was identified in one or more participants. This information also guided further recruitment. While recruitment difficulties (as described in the discussion section) hindered the researcher's ability to choose from willing participants, it was still important to the researcher that a sample representing variation in these variables was captured. Due to these difficulties with prompt recruitment, the researcher also used snowball sampling later in the study to enable another route of recruiting participants. Snowball sampling is another method of purposive sampling, whereby each participant is asked if they know of any other people who may be interested in taking part in the study (Merriam & Tisdell,

2015). By targeting members of a certain community or group, this strategy can easily identify new information-rich cases (Merriam & Tisdell, 2015).

3.4.3 Participants

Participants were sought who were the parent or caregiver of a child with bronchiectasis, with the child being between ages 0-17 years. Children who had cystic fibrosis or another health condition that may have led to development of bronchiectasis (such as cerebral palsy or another developmental disability) were excluded. While the target age range was specified for the child with bronchiectasis, the participants in the research were their parents or caregivers, as they are likely to be the main people accessing health care for their child. Children over age 17 years were not included, as they may be accessing health care services themselves. Initially, the specified age range was set at 0-10 years, as this is the age range in which NZ children are frequently diagnosed with bronchiectasis (Twiss et al., 2005). Due to recruitment challenges, the age range was expanded (and ethics amendments made) to include children up to age 17 years. This age range was specified because it aligns with Ministry of Health reports on children and young people, in which school-aged adolescents (aged up to 17 years) are identified as under-users of health care services (Ministry of Health, 2004). They are, therefore, an important group to target for this study. Including children up to age 17 years also allowed for inclusion of children and families with a range of experience in the health care system.

3.4.4 Recruitment strategy

Key staff, including nurses and physiotherapists, at the clinics at the two locations were contacted to help with recruitment for the study. The lead researcher was not directly involved in recruitment, to ensure that potential participants would not feel coerced or pressured to participate. The clinic staff at each location were provided with information about the study (by the lead researcher) and the inclusion and exclusion criteria for potential participants. As ethics amendments were made, the clinic staff were updated about the new target age range and study advertisements were adjusted accordingly.

If a potential participant was identified during a clinic, the clinic staff member explained some basic information about the study and provided a flyer. The flyer (see Appendix C) outlined further information about the study, the researcher's details and included a separate form, on which the potential participant could fill out their contact details. They would then return their contact details to the clinic staff member, who could pass this on to the researcher, who then contacted the potential participant. Flyers were also freely available in the waiting

rooms of each clinic location for potential participants to pick up. Interpreting services were available, as required, to ensure language was not a barrier. Patients who had a scheduled appointment but did not attend were still eligible for recruitment. When clinic staff phoned the patient to follow up on the missed appointment, the lead researcher requested that they discuss the study and attempt to recruit potential participants over the phone.

3.5 Data Collection

Semi-structured interviews were undertaken. Semi-structured interviews allow for flexibility in questioning, while having some guidance around areas of questioning (Thorne, 2008), for example different aspects of health care services. This enabled the researcher to probe into interesting responses and encouraged the participant to express themselves freely (French et al., 2001). Each interview lasted between 30-60 minutes. Interviews were conducted between 5 October 2016 and 1 December 2017. Prior to commencing the interviews, the interview schedule was developed, based on focus areas identified in previous literature (Thorne, 2008), and the schedule was piloted with three pilot participants. Feedback was sought on the content of the interview schedule, but no changes were suggested by pilot participants. The researcher adjusted proposed interview questions based on personal reflection (Evers & de Boer, 2012). The final interview schedule is detailed in Appendix D.

When participants verbally consented to taking part in the study, participants were asked if they would like to read information about the study prior to meeting with the researcher. If so, the Participant Information Sheet (Appendix E) was provided via mail or email. The researcher arranged to meet with the participant at a time and location convenient for both parties. Where possible, the chosen location was a quiet, public location, like a meeting room at the Manukau Super Clinic. In some cases, the researcher visited the participant at their home; a Researcher Safety Protocol was implemented (Appendix F).

Before commencing the interview, the participant was provided with another opportunity to read the Participant Information Sheet and ask questions prior to signing the consent form (Appendix G). An audio-recording device was used, so interviews could be captured in their entirety and later transcribed verbatim; this was clearly explained to each participant prior to signing the consent form. Participants also completed a short demographic information form (Appendix H), capturing information that allowed the researcher to characterise participants and ensure variation within the sample.

Each interview was transcribed verbatim by a professional typist, who had signed a confidentiality agreement (Appendix I) prior to commencing transcription. Upon receiving each

typed transcript, the researcher checked the transcript for accuracy, correcting text and re-familiarising herself with the data. Listening to the audio recording in its entirety also allowed the researcher to become more immersed in the data (Bazeley, 2009).

3.6 Data Analysis

Thematic analysis was used to derive themes from the data, using an inductive approach. The researcher used three broad stages of data analysis. The first two stages, reading and exploring the data and mind-mapping, were conducted manually. The third stage was conducted using software and involved re-working codes that evolved in the first two stages, until final themes and sub-themes were developed. Thematic analysis was considered to be the most appropriate method of data analysis for this study, because it allows the researcher to identify and interpret commonalities in the data, without requiring a formulaic approach or adherence to pre-conceived ideas (Braun & Clarke, 2012). Because this study used semi-structured interviews, in which the participant was encouraged to speak freely, thematic analysis encouraged an organic approach to identifying and drawing together ideas from the data. This allowed the researcher to capture the essence of their experiences, developing themes from the stories of the participants themselves. Inductive reasoning starts with the raw data and builds theory from the data (Braun & Clarke, 2012; Thorne, 2008). In contrast, deductive reasoning starts with a prescribed theory, then identifies data to fit within the theory's mould (Thorne, 2008). An inductive approach to thematic analysis was used because, while the researcher comes to the project with a knowledge of the evidence base, the research question centres on participants' experiences. When exploring and detailing participants' own experiences, it is important that the researcher does not enter data collection with predetermined, rigid ideas; rather, the researcher must be flexible and open-minded in the process of analysis and theory-development, so as to be true to the stories of the participants themselves.

The initial stage of thematic analysis was performed manually and included reading and exploring the data. Bazeley (2013) recommends taking time to read, re-read, reflect on, play with, and explore the data in order to become familiar with the data and draw out initial thoughts and concepts. The researcher began this process by reading through each transcript, identifying ideas that are meaningful to the research question and manually applying initial codes to chunks of text. Many of these initial codes applied were descriptive, providing a summary of the section of text - some were *in vivo* codes, which used the words of the participants themselves, while others were gerund-based process codes, which connote action (Saldaña, 2016). These initial, unrefined codes paved the way for the researcher to later merge, tease out and identify patterns in the codes in the second and third stages of coding (Miles, Huberman, & Saldaña, 2014).

As recommended by Bazeley (2013) and Richards (2015), the researcher used mind-mapping (Appendix J) to explore the data further and identify commonalities and linkages between ideas. By playing with, and exploring the data in this way, the researcher was able to visually identify where similarities existed between ideas and stories, as well as contrasts. The researcher was able to reshape ideas by visualising the data as a whole and as a series of inter-connected concepts (Richards, 2015). The researcher concurrently kept memos to track the evolution of ideas and note where changes were made and why (Bazeley, 2013). The initial mind map evolved as further data were added and concepts were narrowed, condensed and refined. The main concepts identified through this process formed the basis for an initial code book (Appendix K) that described larger codes and smaller, nested categories, and detailed the parameters of these (Bazeley, 2013). These codes and categories were used to continue data analysis using software. From this point, data were analysed using qualitative data analysis software QSR NVivo, version 11 (QSR International Pty Ltd., Doncaster, Victoria, Australia). Chunks of data were allocated to each code and category. Codes and categories were again condensed, merged and re-worked, until the final themes and sub-themes developed. The researcher aimed to achieve saturation of themes, whereby new data added to the data set would fit into the framework of existing themes, no longer eliciting new ideas (Bazeley, 2013). The point at which data saturation was reached was decided upon by the lead researcher and this was discussed during peer debriefing, which is described in the following section.

3.7 Trustworthiness

The quality of qualitative research can be assessed using methods developed by Lincoln and Guba (1985). *Trustworthiness* is a term used to describe the concept of rigour in qualitative research, while *credibility*, *transferability*, *dependability* and *confirmability* describe different aspects of trustworthiness (Lincoln & Guba, 1985). This section describes these terms and specific strategies that were employed in the current study to maximise trustworthiness.

3.7.1 Credibility

Lincoln and Guba (1985) consider credibility as akin to internal validity. Strategies to improve credibility are those that improve the probability that findings will be credible and those that demonstrate that findings have been approved by participants of a study. Peer debriefing and member checks were used in the current study to improve credibility of findings.

3.7.1.1 Peer debriefing

The researcher met regularly with two research supervisors to discuss ideas raised in data analysis and explore new ideas and questions that were raised by the supervisors. Peer debriefing helps to ensure that the researcher's biases are recognised and clarifies interpretations, through the researcher listening to her own voice and being questioned by peers (Morse, 2015). Debriefing also helps the researcher to clear the mind, ready to critique existing interpretations and develop new ideas (Lincoln & Guba, 1985).

3.7.1.2 Member checks

The researcher offered the opportunity for participants to check a summary of the results of data analysis. Member checking is a process of testing data, analysis and interpretations with participants of a study (Lincoln & Guba, 1985). The researcher chose not to use interviewee transcript review, as this has often been found to be ineffective, with participants rarely recommending changes and often remarking that the raw data is too difficult to read (Hagens, Dobrow, & Chafe, 2009; Mero-Jaffe, 2011). Instead, the researcher created a short summary of findings and associated quotes. This was sent via email to all participants for review. The researcher asked participants to read the summary and reply by email if they wanted to clarify or change any details, or if they did not agree with the content outlined in the summary. The researcher requested that participants respond within two weeks and added that if participants did not respond, it would be assumed that they had no changes to make. No participants responded to the email, so no changes were made to the results as a consequence of this process.

3.7.2 Transferability

Transferability, described by Lincoln and Guba (1985), is a form of external validity, whereby findings may be transferred to another time or context. While generalisation is not the goal of qualitative research, transfer of theory and analysis to other cases is desirable to give relevance to findings beyond the immediate time and context (Bazeley, 2013). Purposive sampling and thick description have been used by the researcher to improve transferability.

3.7.2.1 Purposive sampling

As has already been described, purposive sampling was used to identify participants from a wide range of backgrounds and contexts, in order to express a diverse range of experiences (Sandelowski, 1995). Purposive sampling allowed the researcher to recruit participants who had the required experience to address the research objectives (Thorne, 2008). This provided rich information that could be comprehensively analysed, leading to thick description of interpretive findings.

3.7.2.2 Thick description

'Thick description' is description of findings that is detailed and has participants words and ideas embedded clearly within it (Lincoln & Guba, 1985). The researcher has presented findings in as much detail as possible, using participants' quotes to support findings. This level of description is necessary to allow a reader to reach their own conclusion about whether transferability of findings to another time and context is appropriate (Lincoln & Guba, 1985).

3.7.3 Dependability

Dependability is related to consistency, or replication, of findings (Lincoln & Guba, 1985). Triangulation (using different methods or researchers to verify findings), replication of a study and inquiry audit are all methods suggested by Lincoln and Guba (1985) to improve dependability. Morse (2015) argues that triangulation is better used to improve validity (credibility) of a study, while replication of a study, which can also be a method of triangulation, provides little gain for substantial effort. Morse (2015) also argues that an inquiry audit should only be used if a researcher's methods or findings are suspect. Morse (2015), in agreement with Guba (1981), rationalises that dependability (reliability) is closely intertwined with credibility (validity), and therefore the concepts need not be separated. For the reasons argued above, no specific strategies were employed by the researcher to target dependability for this study. An audit trail, which may be considered to be important for both dependability and confirmability (Morse, 2015), is described below as a component of confirmability.

3.7.4 Confirmability

Confirmability relates to the ability of a researcher to present processes and findings that are free from overt researcher bias and are able to be agreed upon, or confirmed, by others (Lincoln & Guba, 1985). An audit trail and reflexivity are strategies used to improve confirmability of this study.

3.7.4.1 Audit trail

Through use of a reflective research journal, the researcher made notes about her thought processes and decisions made during the course of the study. In particular, during data analysis, the researcher documented reasons for interpretations made, as advocated by Bazeley (2013); this is illustrated in Appendix L.

3.7.4.2 Reflexivity

The reflective journal mentioned above allowed the researcher to identify and isolate personal beliefs that may influence the way data are interpreted and ideas are developed. Reflections were made after each interview and when changes to the researcher's thought process occurred during the data analysis process. These ideas were also discussed with peers and supervisors. Reflexivity involves researcher self-reflection in order to appreciate their prior knowledge, experience and potential bias before, and during, the research process (Abdul Hadi & José Closs, 2015).

3.8 Ethics

Ethical approval was granted by the Auckland University of Technology Ethics Committee on 26 July 2016 (approval number 16/252). Approval was also granted by the Counties Manukau Health Research Office on 9 August 2016 (application number 129) and the Counties Manukau Health Maaori Research Review Committee (24 July 2016). All approvals included the recruitment of participants who resided in the CMDHB area, from clinics at Manukau Super Clinic (part of CMDHB) or Starship Hospital (part of Auckland District Health Board).

To help overcome challenges with recruiting participants for this study, four amendments to the ethics application were made and approved during the study period:

1. Granted on 15 September 2016, this amendment allowed a short demographic questionnaire to be used, to be filled in by participants at the time of the interview. This allowed the researcher to collate demographic characteristics to inform further recruitment.
2. Granted on 22 February 2017, this amendment allowed recruitment of children up to age 14 years. This amendment was intended to facilitate recruitment by widening the age range of eligible children. The age range up to 14 years was justified, as this is the age that the Ministry of Health (Ministry of Health, 2017b) commonly uses to specify 'children'.
3. Granted on 3 May 2017, this amendment allowed recruitment of children up to, and including, 17 years old. This amendment was intended to facilitate recruitment by again widening the age range of eligible children. This age range was justified as it includes older children and young people, who are known to be under-users of health care services (Ministry of Health, 2004).
4. Granted on 28 June 2017, this amendment allowed snowball sampling to be used. This change again aimed to facilitate recruitment.

The above amendments were made to improve recruitment of study participants. The challenges experienced with recruitment to this study are discussed as limitations, as part of the discussion chapter of this study. The original Ethics Approval letter, approval letters from the Counties Manukau Health Research Office and the Maaori Research Review Committee and each letter received for the amendments above are presented in Appendix M.

Chapter 4: Results

This chapter outlines the demographic characteristics of participants and the results of the study. The themes that arose from thematic analysis are explained, with several sub-themes nested within each theme. Illustrative quotes from participants are used to exemplify the concepts within each theme.

4.1 Demographic Characteristics of Study Participants

Ten people were successfully recruited from eighteen participants who were identified from the clinics at Starship Hospital and Manukau Super Clinic and expressed an initial interest in participating. While potential participants may have been a parent or caregiver of any gender, those recruited were all mothers of children with bronchiectasis. Children were of a wide range of ages, between three and 16 years. Of those who were approached but did not take part in the study, three declined to participate and five were unable to be contacted. Participant characteristics are displayed in Table 2. The women who were interviewed had varied ethnic backgrounds, with five from the Pacific Islands, three Māori, two NZ Pākehā and one 'other' (South African). Ethnicity was reported as multiple responses, therefore these numbers total more than the participant count. All lived in a one-family household, with eight living as a couple with children and two solo mothers with children. Participants came from a wide range of income levels. Participants were asked about the frequency of GP and hospital visits and the cost of their GP, but there is a possibility of inaccurate data recall with this information. All mothers recruited to this study had different levels of experience with the health care system, with one child having been diagnosed with bronchiectasis only a month prior to taking part in the study, while others had been receiving health care for bronchiectasis for up to 15 years.

4.2 Key Themes and Sub-Themes

Data analysis, as described in the methods section of this study, produced five key themes. These themes illustrate the mothers' experiences of accessing health care, from initial stages prior to diagnosis, to accessing care from their GP, specialist clinic and hospital. Mothers placed emphasis on feelings of vulnerability, working to gain confidence within the health care system and the importance of their relationship with their health care provider. As well as this, many mothers described how managing their child's health care could be difficult, but that they found ways to overcome barriers. The five themes of this study were: 1) Searching for answers; 2) (Dis)empowerment; 3) Health care and relationships; 4) A juggling act; 5) Making it work.

Table 2. Demographic characteristics of study participants (n=10).

Characteristic	n (%)
Participant's age	
18-29	2 (20)
30-39	3 (30)
40-49	3 (30)
50-59	2 (20)
60 and older	0 (0)
Child's age	
0-4	1 (10)
5-9	4 (40)
10-14	2 (20)
15 -17	3 (30)
Ethnicity*	
Māori	3 (30)
Pacific Island	5 (50)
NZ Pākehā	2 (20)
Asian	0 (0)
Other	1 (10)
Family composition	
Couple with children	8 (80)
Solo parent with children	2 (20)
Other	0 (0)
Household composition	
One family household	10 (100)
Two or more family household	0 (0)
Annual household income	
Less than \$25,000	2 (20)
\$26,000 - \$50,000	3 (30)
\$51,000 - \$75,000	2 (20)
\$76,000 - \$100,000	1 (10)
More than \$100,000	2 (20)
Number of general practitioner visits in the past year	
None	0 (0)
1-3	4 (40)
4-10	4 (40)
More than 10	2 (20)
Number of hospitalisations in the past year	
None	5 (50)
1-2	5 (50)
3-4	0 (0)
5 or more	0 (0)
Cost of general practitioner	
Free	7
\$1-20	1
\$21-40	1
>\$40	1

* Ethnicity reported as multiple responses; therefore, numbers total more than the participant count.

Each of the themes are detailed below, with sub-themes outlined and participant quotes included to illustrate these themes. Many of the themes and sub-themes use *in vivo* terms (Bazeley, 2013; Saldaña, 2016), reflecting terminology that was used by the participants themselves. Table 3 summarises the five themes with various associated sub-themes.

4.2.1 Theme 1: Searching for answers

Participants described a journey of searching for answers about their child's illness. Most described changing stages over time, from first *being in the dark*, through a stage when *no-one listened*, to finally *having an answer*, then *theorising* about causation and eventually *acceptance* of the diagnosis.

4.2.1.1 *Being in the dark.*

The mothers in the study described a stage, early on in their experience, of knowing something was wrong with their child but not having a clear diagnosis to work with. Eight out of ten mothers described having frequent trips to the GP or accident and emergency (A&E) clinic. They would often see different doctors, be prescribed multiple courses of antibiotics but not get any closer to a diagnosis for their child.

At the beginning when I took her 18 times in 32 days, saying that something is wrong with her breathing and he kept telling me "No it's fine, she looks wonderful" and deep down, ignorantly I believed him. (Participant 6)

Some mothers had been told that their child had asthma, but, when treatment was ineffective, found they were still in the dark about a diagnosis. Later, they would find that their child had been misdiagnosed.

They would always bring up the point about her not breathing and her lungs, signs of asthma, so they diagnosed her with asthma and then we would stay in overnight in Starship, treating it like asthma... (Participant 2)

Well we came to find that out later on that he had misdiagnosed and said she had asthma when in the end we found out that it wasn't true. (Participant 8)

4.2.1.2 *No-one listened*

After having no diagnosis for some time (and in some cases being misdiagnosed), participants described voicing their concerns multiple times to doctors at their GP or A&E, but no-one listened. One mother described not being believed when reporting that her son was unwell.

...He would cough every night until he vomited and no one would really believe us there was a real issue... It got to the stage that I wouldn't give him pamol - I want you to see, you don't believe he is actually really, really sick. (Participant 5)

Five other mothers expressed frustration at the lack of action when they repeatedly voiced their concerns but nothing was done about their child's chronic cough.

Table 3. Summary of findings: Themes and sub-themes

<i>Themes and sub-themes</i>	<i>Description</i>
Searching for answers	The process of seeking a diagnosis, from prior to diagnosis to after; feelings associated with this process, culminating in acceptance.
Being in the dark	Knowing something was wrong with their child, but not having a diagnosis or being misdiagnosed.
No-one listened	Mothers voicing their concerns about their child's health, but being brushed off.
Having an answer	Receiving a proper diagnosis resulted in relief, but also worry.
Theorising	Thinking about possible causes of their child's illness.
Acceptance	Mothers accepting the diagnosis and looking to the future.
(Dis)empowerment	A process of the mother gaining power as she improves her knowledge, finds her voice and feels empowered.
Vulnerability	Mother's lack of empowerment to speak up when concerned about her child's care. This is influenced by not knowing about the disease.
It's just Mum	After gaining more knowledge, the mother started to voice concerns but was met with resistance from health professionals.
Finding a voice	After gaining an understanding of the disease and its management, mothers were actively taking charge of medical care – standing up to health care professionals.
It's a two-way street	A stage of mutual respect between health provider and parent.
Health care and relationships	Relationships with health care providers were crucial to the mother's experience; both positive and unhelpful relationships leave a lasting impression.
Communication	Positive relationships: Clear education to parent, clear communication between services. Unhelpful relationships: Confusing messages from different people, poor communication between health providers.
Familiarity	Positive relationships: Having the same health provider who knows the family well improves continuity of care. Unhelpful relationships: Health providers who are unfamiliar or too familiar with the family.

Going the extra mile	Factors enabling a positive relationship: Health providers who help parents to access financial support, health providers who give priority to unwell children, ease of communication.
Not feeling confident	Parents' confidence lessens when health providers are undecided, or resist seeking another professional opinion.
A juggling act	Mothers were trying to juggle multiple things at once, including work, family and school. Juggling the child's health care can be challenging.
Family impact	Family support enables access to health care; other children in the family may be neglected in favour of the child with greater health needs; parents' roles may change.
Juggling work and school	Work and school schedules may make it challenging to access health care; some parents feel competing pressures between school and their child's health care demands.
Making it work	Practical solutions to potential barriers.
Financial enablers and barriers	Enablers: Free GP visits, social welfare benefits, health insurance. Barriers: Paying for medications, travel costs.
Time and waiting	Barriers: Inflexible appointment times, limited opening hours of GPs and waiting times in hospital.
Transport and distance	Barriers: Significant distance to appointments (particularly Starship Hospital) and difficulty accessing transport.
Managing health care services	Enabler: Hospitals with a more parent-friendly approach. Barriers: When different services are not linked; when public and private services are managed separately and doctors may be very busy, working in both systems.

She has had that wet cough for many years, I think now... since she was maybe three? So it is a long time. So... it always concerned me, but nothing was really done about it... Yeah I always brought it up, every hospital visit, doctor visit... (Participant 2)

Mothers wanted to be listened to and treated as experts on their child.

I know we are not doctors but sometimes... our hunch sometimes... I reckon can be trusted. (Participant 2)

4.2.1.3 Having an answer

After numerous fruitless visits to the GP, once bronchiectasis was diagnosed, several participants reflected that it was pure luck finding someone who identified the possibility of bronchiectasis. Some of the feelings mothers felt at this point of diagnosis were relief, worry, frustration and shock. They also demonstrated resilience, wanting to move on from the diagnosis and look to the future.

...So... yeah, after the results came back it was bronchiectasis, so was a bit hard. So from one extreme and then coming into something new again. It's a little bit frustrating. We soldier on. (Participant 2)

Three mothers were thankful the diagnosis was not something they perceived to be worse than bronchiectasis.

They thought he might have cystic fibrosis as well, so they tested him twice for that, but thank god he doesn't have that. (Participant 1)

Despite the frustration that many mothers felt at having waited a long time for diagnosis, some still acknowledged that the medical team had done their best.

It was ok, I guess... slow to get the answer I think, yeah... I think it was ok, they did the best they could do. (Participant 2)

4.2.1.4 Theorising

In the time following diagnosis of bronchiectasis, many participants started to wonder about the cause of the disease. This was often a process of reflection, thinking back to events or situations in the child's life that may have contributed to the illness. Some mothers thought it may be linked to previous medical conditions their child had experienced in earlier years.

She said, "I think your daughter must have got pneumonia when she was little", which you know, floored us, because we are pretty onto it parents, couldn't have seen how without really knowing it, um... still to this day don't understand that... (Participant 8)

Several participants considered the environment in which they lived, particularly in the early years of their child's life.

The house we were staying in... we had it warm and stuff, but it wasn't properly insulated. The heater had to be on 24/7 so that probably didn't help.
(Participant 1)

One mother could identify a specific situation that she considered to be the starting point for her daughter's bronchiectasis.

I started to notice that she was having breathing problems when she came back from the weekend um... from her grandmother's house... so she slept there for the weekend and when they brought her back she had a wet cough.
(Participant 4)

Several mothers also considered their own actions and wondered whether their child's condition might have been different if they had done more physiotherapy or taken their child to see a specialist earlier.

I think in hindsight that had we even gone earlier, perhaps someone might have picked it up, not to say that the outcome would have been different, but I believe... I believe it would have been different, maybe there still would have been damage to her lungs but not as much. (Participant 6)

4.2.1.5 Acceptance

The final stage in the search for answers was accepting the diagnosis. Participants described learning to deal with the diagnosis and looking to the future. They considered that learning about the disease, having a plan and thinking positively contributed to their acceptance.

We went through all sorts of stages, you know going in emotional, to thinking she is going to die, to being educated, understanding, taking on their [health care providers'] advice. (Participant 6)

4.2.2 Theme 2: (Dis)empowerment

The theme of *(dis)empowerment*, like *searching for answers*, is made up of several chronological stages, moving from disempowerment to empowerment. Participants experienced *vulnerability* during the beginning stage of their child's diagnosis, characterised by a lack of understanding about the disease. As they started to gain some knowledge and started to speak up, they were sometimes met with resistance from health professionals who brushed off their concerns about their children, stating that *"it's just Mum"* (Participant 2). Equipped with more knowledge and confidence, participants described *finding a voice* as an advocate of their child's care. Finally, some participants reached a stage of mutual respect between themselves and their health care provider(s), finding that health care is a *two-way street*.

4.2.2.1 Vulnerability

In the beginning stages of their child's diagnosis, participants experienced a sense of vulnerability, largely as a result of not understanding their child's illness or how to manage it. Mothers felt like they had to trust the doctor, even if they were not sure that the doctor's plan was the right course of action for their child. Several participants described feeling helpless, feeling that they were being "led along" (Participant 5) by the doctor.

Sometimes you are guided by people because you think you have to be. Cos they're the doctor and they know better. (Participant 8)

...he just went on about twenty pumps, twenty pumps of Ventolin. I was like, "Really? Why would you give, like, a five-month-old twenty pumps of Ventolin?" You know, and ah... didn't make sense to me. Went against my grain, didn't understand it, so... very frustrating. (Participant 8)

In contrast, two mothers thought that it was best to follow the doctor's instructions and felt that it was *their* responsibility to seek more information as needed. This, again, added to their sense of vulnerability.

Listen to the doctors - whatever they instruct us to do, just do. Good to get as much information as possible too... I do need to do that myself so I can be more onto it. (Participant 2)

4.2.2.2 It's just Mum

Many participants felt "fobbed off" (Participant 2) and saw that the health care professionals thought "it's just Mum" (Participant 2), disregarding their concerns. This resulted in frustration and mothers feeling like they were not being taken seriously or treated as the expert on their child.

I said "if you just read his notes, like what you can see"... He was like "oh no he doesn't have bronchiectasis; he has chronic lung disease". I was like "call it whatever you want" ... and then he prescribed [my son] Amoxicillin, and he doesn't get better from Amoxicillin. So I tried to tell him that "that's not going to work" but he still didn't listen and gave me Amoxicillin and he still wasn't better. (Participant 1).

Another mother did question the doctor and, after being brushed off, recognised that in this early stage, she had not been able to assert her intuitive knowledge. This resulted in confusion and uncertainty concerning the health provider's advice.

I did ask for the antibiotics, but he said "no he's not really sick, we don't need to give..." I said "are you sure? Cos if he is just getting sick I still need to give it for a week or two, for his sickness to go away, just for him to get a bit better." ... I wasn't really that angry, but I was, like, confused. (Participant 3)

4.2.2.3 Finding a voice

During this stage, the mothers were gaining knowledge and asking questions, improving their understanding of the disease and its management. With time and greater knowledge, participants became more empowered within the health care provider-parent relationship. Many participants came to know what their child needed and would actively ask for it. Some mothers began to question the doctor, “*fighting*” (Participant 5) for what they wanted.

I said to him “well I won’t give the antibiotics unless we get it tested to definitely make sure it is a chest infection”. Then he said “alright then”, and then once we get it tested, sometimes it comes out no that there was no bacteria in the sputum... and then I won’t give her the antibiotics. (Participant 4)

I think I learnt a lot from the experience... don’t just sit back and think... because they are a doctor they know everything. If you think it, your gut doesn’t feel right, then say it doesn’t feel right, speak up. (Participant 5)

4.2.2.4 It’s a two-way street

A few participants eventually found that they experienced mutual respect between themselves and their health provider. They had gained enough knowledge and confidence that they could have a discussion about their child’s health with the health provider and felt empowered to be a more active caregiver.

I explain to them she is a bronchiectasis patient so I tell them she has the chronic lung disease and I tell them what I do during the day with her physio and if she is on orals and that, so I think they are aware. (Participant 7)

One mother even described a relationship whereby she and the doctors were able to teach each other.

...As I knew more and understood my daughter better and bronchiectasis and therapy I was able to say “Well... actually that isn’t the case”. Or “I disagree with what your set opinion is about how it should be”. So I would teach them as well. (Participant 8)

Some participants, however, still felt that health care professionals needed to work harder to get to know their child and work in a more collaborative way with their family.

That would be really good... if GPs had more... what do you call that? Knowing more about the child, interactive and... I dunno, getting personal with the child. (Participant 2)

4.2.3 Theme 3: Health Care and Relationships

All participants commented on relationships they had with different health care providers. Positive relationships were seen to enhance the health care experience. Features of a positive relationship included *communication*, *familiarity* and *going the extra mile*. Unhelpful relationships had a long-lasting negative effect on participants' perceptions of health care experiences. Features associated with unhelpful relationships included poor communication, unfamiliar health providers and parents *not feeling confident*.

4.2.3.1 Communication

Participants who experienced clear communication with their health care provider felt that the relationship was positive. This included communication of information and health care providers who were willing to answer questions. Having information that was tailored to their needs was important to all of the mothers.

They kind of broke it down for me...and explained it to me in that way... I hate reading. Yeah. That's just me though... I would rather talk to somebody one on one and get it explained to me. (Participant 1)

Some participants also noted that communication between services is important for enhancing their perception of health providers. When there were clear lines of communication between health providers at different services, this was helpful.

So they worked together, I would often see their correspondence where I could see one and then they would have a yacka behind the scenes to draw up a plan, you know... (Participant 6)

Poor communication between services was seen as a hindrance to effective health care, often resulting in disjointed care and participants receiving conflicting messages. Poor communication between health providers, when notes were not up to date or when health providers had not read the notes, meant that some participants received conflicting, confusing information. Many mothers were frustrated at having to repeatedly explain their child's background.

But when we have to go to A&E sometimes, that's annoying cos it is another brand new group of brand new doctors every time. They can't access all of his notes. For example, last week when he was unwell, we went to the A&E clinic and the doctor I saw tried to tell me he didn't have bronchiectasis. I was just like, "Really?" I was like, "Really?!" (Participant 1)

4.2.3.2 Familiarity

Identification of a familiar health professional was an important part of the health care experience. Familiarity was associated with increased trust and friendliness. Those

mothers who had a good relationship with one key person at their GP practice or clinic had more positive experiences of health care relationships.

I had found this lady [doctor] and I was like "I don't want to go back into the public [system], I just want to stay with you, I trust you, I trust everything you are telling me, you make me feel confident that we are on the right path." (Participant 5)

Participants did not like seeing different doctors each time they went to the GP or clinic, because they felt that unfamiliar doctors did not know their child. This impacted on continuity of care, meaning mothers had to explain their child's diagnosis again and risked receiving treatment that had previously been ineffective. When mothers did not have an established relationship with the health provider, they reverted to feeling vulnerable within the health provider-parent relationship.

You know, you are so used to one [doctor] telling you about your daughter and then you meet a new one, which you are thinking "Does he really know her, is he aware of her illness? Has he read her notes?" (Participant 7)

Some mothers had such a good relationship with their GP that they felt like their GP was *"more like family"* (Participant 3). One participant, in contrast, described how being *too* familiar with her GP was actually detrimental to their clinical relationship, when the GP was too casual or laughed off her concerns.

It's like they become too familiar, so they become a friend, more than... You know what I mean? Like, yeah... it's quite casual... cos he had been my Dr since I was 8. (Participant 5)

One mother commented that finding one key person was the most important piece of advice she would give to another mother going through a similar experience.

My advice would be to... get to a single person, see the same specialist every time, so that there is that continuous care and understanding. (Participant 5)

4.2.3.3 Going the extra mile

Positive relationships were identified with health care professionals who went out of their way to ensure that families received the best care possible. Five mothers reported that health professionals would help them to fill out forms for welfare or help with parking, which fostered trust within the health provider-parent relationship and enabled easier access to health care for the mother.

[The nurse] is really good. She will fill out any forms that I need for Work and Income and fax them through. She will do anything to make it a little bit easier. (Participant 1)

Some participants explained that their child was given priority at their GP, as a frequent attender or a child with significant breathing problems. This made mothers feel like health providers had a good understanding of their child's needs and that their child's wellbeing was taken seriously. This also helped to nurture a positive relationship between the mother and health provider.

Sometimes I don't even have to see the doctor to get a script written up, if they are fully booked and they can't see him, but he is unwell, they will still do him up a script, they just know. (Participant 1)

One participant even described how her doctors had given her their cell phone and email contacts and were readily available to provide advice over the phone or via email, even after hours.

I would email them and they would ask me what her blood pressure was and I had a machine and I took it and... "No that not good enough, come in and see us." So, you know, if that is normal, then the service is amazing, if that is because of a soft spot they took for her, then I was just lucky. (Participant 6)

4.2.3.4 Not feeling confident

On the other hand, participants described a lack of confidence in health professionals who did not seem welcoming or who did not seem confident making clinical decisions.

I don't really like it when I am at the doctor and they Google, because you know, I could do that myself. (Participant 5)

Several participants described contrasting situations in which their doctor had been *too* confident; in hindsight, they could see that the doctor should have sought another opinion. This left participants feeling less confident in subsequent health care experiences.

I know GPs are a broad range, they are not specialists in a specific area, but I would much prefer that they said "I don't know." (Participant 5)

We have been to see [a private specialist], who was totally a waste of time, because he didn't even bother to get any more opinion, do any research you know, so we go through all that and we come away frustrated. (Participant 8)

4.2.4 Theme 4: A Juggling Act

Participants described the complexity of managing health care alongside the competing demands of family, work and school life. *Family impact* describes the impact of the child's health care needs on family dynamics, the psychological impact on the child and others in the family. *Juggling work and school* describes the difficulties of keeping up with the demands of work and school around the need to access health care for their child.

4.2.4.1 Family impact

The impact of the child's health care needs on the family was substantial. The various demands of providing health care presented a significant burden to all members of the family. Several participants described the challenges of keeping up with medications, physiotherapy and other health care needs – looking after their child had become health care, not just child care. In a few families, these demands were supported by other family members, including other children in the family. Having other family members who could provide support and child care were seen as enablers to accessing health care, while mothers who had little family support reported significant difficulties with accessing health care for their child with bronchiectasis.

It was... kind of good last year cos I had my mum beside me and my sister as well but, um, now my mum passed away and my sister... we got a new house and my sister is hardly with us now so it's kind of hard to find a babysitter and work out transport at the same time with her, especially when it's in Starship... that's the only concern for me... my other kids... especially when she gets admitted cause sometimes we stay there for two weeks but then I have to think of my other five children who are at school, who's going to pick them up and who is going to drop them to school, so it's kind of hard. (Participant 7)

Two mothers described the negative impact of their child's illness on other children in the family, who were “neglected” (Participant 7) because of the greater demands from the child with bronchiectasis.

It has affected my son. He has basically... he just got pushed out and you know, poor bugger, he brought himself up, I think. (Participant 6)

There was also a huge impact on the family dynamics in some families and the changing roles of the parents in the family. This sometimes meant that families and parents had to adjust their plans to fit in with the demands of their child's health care.

It wrecked our family, put it that way... things just stopped, life stopped, holidays stopped... (Participant 6)

If he became sick, me and my partner were both working and I was studying as well, so if there was anything wrong with him I would be more likely to take care of him than my partner cos he earns more than me. (Participant 3)

4.2.4.2 Juggling work and school

Most participants talked about the difficulty of managing work around accessing health care for their child. One participant described how she had to tell her boss and colleagues about her son's illness, so they wouldn't think she was skiving off work. Another mother described her fear of returning to work, because she may need to take time off to look after her daughter if her daughter became unwell.

I am not looking forward to work, I am just worried about her... if she gets sick... if I got a job, what will happen? ... I took on the part time role and it suits me, cos during the school holidays I can look after her, so... we will see how it goes. (Participant 4)

It was also difficult for mothers to manage their child's schooling alongside their health care needs. Some children had to spend a significant time away from school while they were unwell, impacting on their learning and social development.

I mean she has missed a lot of school, so we fear for her future... she was very sick, like really sick... missed two and a half years of school. (Participant 6)

One participant described feeling pressure from teachers to ensure her daughter did not miss too much school, while at the same time feeling pressure from doctors to attend specialist appointments during the day. This presented a huge burden on parents to manage all aspects of their child's health and schooling, while satisfying the expectations of health providers and teachers.

The teacher this year actually, asked me if I could try and make the appointments after school... the doctor wrote a letter to school and said what kind of sickness she has got and why she is missing school... I feel I don't want to take her out cos I know she has been missing a lot of school... um... but it's the right thing to do because she has to go see the specialist... (Participant 4)

4.2.5 Theme 5: Making it Work

Participants acknowledged that while there were many factors that make accessing health care challenging or inconvenient, it was important that they made it work for their child. Some of the factors that affected health care access were *financial enablers and barriers, time and waiting, transport and distance, and managing health care services*. While there were several challenges to accessing different health care services that were identified, on the whole, participants found that they could make adjustments to ensure they could access health care for their child. In the search for ways to improve access to health care services, in this theme, participants' voices may be heard as advocates for improved health systems.

You just have to make it work. (Participant 1)

4.2.5.1 Financial enablers and barriers

Many participants described free GP visits as an enabling factor, allowing them to access health care cheaply and easily. As well as this, some participants also reported that additional enablers, like having a community services card or financial assistance from

welfare, went some way to alleviating costs. Another participant reported that she has always had health insurance for her child, which has eliminated any financial difficulties for her family.

We are lucky, so I have always had medical insurance from the day he was born, because my employer paid for it all... I knew that was something I had to carry on. For his sake, because I don't think anybody would want to touch him! But we were lucky that we could afford to. (Participant 5)

Several participants reported that they sometimes did not have enough money to pay for medications or petrol to get to the GP. One participant reported that while she sometimes could not pay for medications when they were needed, she would save up to get them as soon as she could.

There are times that are stretching it... especially being on the benefit... and on the gas-wise... I mean... now and then... I might not have enough money to get it that week but I will get it the next week. (Participant 4)

Three participants reported that there had been times when they had missed clinic appointments because of cost. Cost was clearly a barrier for these mothers, though all mothers reported that they almost always found a way to get to appointments, even if the cost of gas or parking made it challenging.

4.2.5.2 Time and waiting

Most mothers reported that timing of appointments and spending a significant amount of time waiting for appointments were inconveniences that affected their ability or willingness to seek health care. Not being able to choose times of appointments made it challenging to juggle family, work and school commitments.

The teacher... asked me if I could try and make the appointments after school. So I actually rang to see if I could change it to the afternoon, but then there would be a waiting time again, there would be a waiting time... (Participant 4)

Limited opening hours at GPs also made health care access challenging, as problems could happen at any time. This often meant that parents would have to pay for after-hours care at the A&E clinic or would have to face hours of waiting at the emergency department. Waiting times in hospital were a significant limitation for many participants. One participant reported that she sometimes tried to “*chance it*” (Participant 6) to avoid the hospital because of this. Long hospital stays also make it challenging for mothers to manage their families, sometimes being required to stay in hospital, away from their families, for two weeks at a time.

I had no babysitter, my [six] kids and I actually all went up there that day, cos I couldn't find anyone... we had to stay in for two weeks just for her meds... but they looked at her and she was ok... so they told us to go home and do her oral meds at home... they had to send us back home. (Participant 7)

4.2.5.3 Transport and distance

All participants commented on travel distance as an inconvenience, particularly those whose main point of care was at Starship Hospital, which was a significant distance from their home in South Auckland.

It's a bit of a pain in the arse, it is a morning appointment and we have to come so far. (Participant 1)

Two participants did not drive and reported significant challenges getting to specialist clinics. Despite this, these mothers made sure they found a way to get to appointments, only missing appointments “*once in a blue moon*” (Participant 3) because of transportation difficulties.

If he was really sick I would take him to the doctor by public transport. Sometimes on raining days I found it hard, or if I have the chance I go in the courtesy van. (Participant 3)

While transport and distance were considered inconveniences to accessing health care, they were not barriers – participants almost always found a way to “*make it work*” (Participant 5). Four participants suggested that having bronchiectasis clinics available in CMDHB would make it easier for them to access health care for their child.

Cos you know how Starship is far away, you know, make it more closer to me as well, like... a Bronchiectasis Specialist that can come to this side... would be more easier for me to get to them. (Participant 7)

4.2.5.4 Managing health care services

Many participants reported challenges with navigating the health system – managing different services required for different health problems, working within both public and private systems and linking care between the GP and specialist care. Participants who were managing their child’s health care between different types of services reported that it was difficult to maintain continuity of care.

...Because we have to see Surgical and Bronchiectasis [services], it would be good if we could see them at the same time. But they have already explained to me that they can't. (Participant 1)

The mothers often commented on the quality of care that was received in hospital, from an operational perspective. Hospitals that were welcoming to parents who were staying with their child were preferred. One participant commented that Starship Hospital was preferred because fathers were permitted to stay after visiting hours, whereas another participant preferred the care at Kidz First, where parents were offered food while staying in hospital.

4.3 Concluding Comments on Results

The results of this study identified five main themes that illuminate the experiences of accessing health care for parents of children with bronchiectasis in CMDHB. Participants discussed their feelings of vulnerability and uncertainty in the beginning stages of diagnosis, to having more confidence and finding their voice to speak up about their child's needs in the later stages of the health care experience. They also highlighted the importance of relationships with health providers, the various struggles they experienced when juggling their child's health care with other aspects of their lives, and emphasised that although they experienced barriers to accessing health care, they would almost always find a way to make it work.

These results have identified several barriers, such as transportation and poor communication; and enablers, such as knowledge and positive health provider-parent relationships, to accessing health care for the parents who were interviewed. The results have highlighted several aspects of health care services that are important to users of those services and have uncovered several suggestions for improving health care services from the participants themselves. The discussion section that follows will address these issues in more depth, discussing the results of this study in relation to relevant literature.

Chapter 5: Discussion

This qualitative study explored the experiences of accessing health care for families of children with bronchiectasis in CMDHB from the perspective of the parents (mothers) of those children. Previous literature has identified various factors that may contribute to ease of access to health care services in general populations (Gulliford et al., 2002; Jatrana & Crampton, 2009). Other qualitative literature has considered health care access from the perspective of health care providers (Buetow et al., 2002) or from the perspective of different groups in the population, for example mothers of neonates (Ballantyne et al., 2015) or Māori families (Bolitho & Huntington, 2006). This is the first study to examine the experiences of accessing health care for families of children with bronchiectasis in a NZ population. By creating an opportunity for the people who have experiences of accessing health care to share their stories, this research highlighted new insights into the ways that health care systems, services and health providers are perceived and experienced by consumers. This important information can help those working in the health system to improve services and systems to better cater to the needs of health care users, to provide more tailored, equitable health care.

This study identified five main themes that illustrate parents' experiences of accessing health care for their child with bronchiectasis. While only mothers participated in the study, these findings can be extrapolated to reflect the experience of parents, as the mothers who were interviewed often spoke on behalf of their partners and families. The themes identified in the study encompassed the most important aspects of parents' experiences of accessing health care. These were the process of finding a diagnosis, having the confidence to speak up for themselves and their child, having a good relationship with their health care provider, being able to juggle health care needs with other aspects of their life, and having the practical means to be able to access health care services.

Drawing these themes together with relevant literature, three main discussion points were identified. The first is that parental relationships with health care providers are crucial to the health care experience. The second discussion point is that parents' acquisition of knowledge leads to greater agency and power within the health care experience. The third point is that parents' appreciation of the worth of health care services will enable access to health care.

5.1 Parental Relationships with Health Care Providers are Crucial to the Health Care Experience

Parents' relationships with health care providers presented as a dominant theme of this study; this was discussed at length by all participants. Relationships were also identified in the literature review as an important factor influencing access to health care. Drawing on the socio-ecological model (McLeroy et al., 1988), relationships were the main inter-personal factor influencing health care access. Relationships were also identified as contributing to

institutional factors, whereby communication between health care services enabled easier, more efficient health care access. Relationships were also considered as a community factor, as many cultures (including Māori and Pacific Island people) place importance on relationships, including those with health care providers. Social support was also identified as an enabling community factor. This study has shown that relationships, both positive and negative, left a lasting impression on parents' perceptions of their health care experience. The importance of relationships wove through many of the themes identified, from relationships experienced during the crucial pre-diagnosis period that contributed to feelings of confidence, or, conversely, vulnerability, to relationships that contributed to changing power dynamics, as described in the theme *(Dis)empowerment*.

During the initial experiences of accessing health care, prior to diagnosis, many mothers described having negative relationships with health care providers who did not listen to their concerns. Some mothers described experiences with their GP, while others highlighted significant problems accessing A&E clinics, where health providers were unfamiliar and did not know their child's history. This situation has also been documented by Bolitho and Huntington (2006), who discussed how parents felt unsure about their decision to access care at the A&E when health care providers there were not welcoming and did not communicate effectively with parents. The same study also documented a case of a family presenting to the GP repeatedly over several days, before finally being referred to a hospital for specialist care. This is a situation which several of the participants in the present study encountered. One other study (Arlidge et al., 2009) also documented the experience of parents feeling like they were not being listened to. This was in the context of seeing different doctors in a hospital environment and being asked the same questions repeatedly, leading parents to feel that health providers were not listening to them or communicating with each other (Arlidge et al., 2009). This same experience was repeated by several participants during interviews for the present study, where mothers described how they had signalled their concerns to their doctor, but had not been believed, or had been "*fobbed off*" (Participant 2). Many children had presented to their GP or local A&E many times over several years before being diagnosed with bronchiectasis. This may help to explain how many NZ children, as reported in local epidemiological studies (Edwards et al., 2003; Twiss et al., 2005), have had a prolonged wet cough (an average of 2 years) prior to diagnosis. These findings suggest that health providers are not identifying symptoms of bronchiectasis, or are not considering bronchiectasis as a diagnosis readily enough, despite concerns voiced by parents. Early identification and management of respiratory symptoms must be a priority for health care providers in order to prevent development of bronchiectasis (Edwards et al., 2003; The Asthma and Respiratory Foundation of New Zealand, 2006; Twiss et al., 2005). Interpersonal interactions left a lasting effect for parents in this important pre-diagnostic period, many of whom could recount specific experiences of poor communication by health providers or their concerns not being heard.

Communication is key to the health care experience, both with the parent and child (Arlidge et al., 2009; Bolitho & Huntington, 2006; Diette & Rand, 2007; Konstantynowicz et al.,

2016; Papp et al., 2014; Sime, 2014). Parents want health providers to communicate clearly, providing competent and understandable explanations, and to interact with their child, involving the child in the consultation (Dixon-Woods et al., 2002). Appropriate interaction with the child was mentioned by several parents in the present study as an enabler to accessing health care, particularly with older children. Parents found themselves repeating information when they considered that different health care providers did not communicate effectively with each other. This was particularly the case when parents were interacting with unfamiliar health care providers, or sharing care between, for example, the GP and A&E. Interruptions in continuity of care may occur when there is a break-down in communication between health care providers or between different services, leading parents to feel confused and frustrated (Arlidge et al., 2009; Pullon et al., 2015). In the present study, poor communication between health care providers affected parents' relationships with their health care provider when information was not passed on. This exacerbated feelings of vulnerability when parents perceived that health care providers were not taking adequate care of, or interest in, their child's health care. When health care providers communicated effectively with each other, this enhanced parents' confidence in their health care provider and, consequently, helped to develop a trusting relationship with their health care provider.

While many parents described negative interactions with some health care providers, many parents also reported having a positive relationship with others, particularly their GP and health professionals at specialist clinics. Some parents described their GP as being "*like family*" (Participant 3); this created a positive, caring, trusting health care provider-parent relationship. In contrast, one participant described a situation in which her doctor had become too familiar and too casual, degrading the integrity of the clinical relationship when she felt she was not being taken seriously. An effective clinical relationship was described by Ballantyne et al. (2015) as family-centred, collaborative and non-judgemental. These were traits that enabled attendance at health care clinics. Collaboration is an important aspect of an effective relationship as parents want to feel like their opinion is valid and that they are trusted as an equal partner in the health care interaction (Papp et al., 2014).

Trust in health care providers was considered to be a crucial aspect of the health care provider-parent relationship throughout the health care experience. In the initial stages of accessing health care, parents felt they had to trust their doctor's opinion, even if they were not sure it was correct, because they did not know any better. Some mothers in the present study expressed frustration at the feeling of vulnerability this situation created. This contrasts with some experiences described in international literature, whereby some parents actively distrust doctors' advice, preferring instead to act on their alternative health beliefs (Diette & Rand, 2007; Mansour et al., 2000; Seid, 2008; Sime, 2014). Feelings of vulnerability and distrust have been identified by other families accessing health care for their children (Bolitho & Huntington, 2006). Trust may develop over time. In the present study, participants described the development of trusting relationships with health care providers as they got to know the health care provider and gained more confidence in their own knowledge. Trust in a health

care provider has been identified as crucial for receiving quality health care and must be facilitated by health care providers by providing adequate information to parents, listening to their needs and communicating effectively with both the parent and child (Dixon-Woods et al., 2002; Konstantynowicz et al., 2016; Mansour et al., 2000). This was a significant finding to be drawn from this study and, as will be discussed further in the implications section, may be used as a guide to improve health care practice.

Relationships are considered to be particularly important for Māori and Pacific Island people, who hold a holistic view of health care (Bolitho & Huntington, 2006; Cram et al., 2003; Slater et al., 2013), and perhaps less so for Pākehā, who may be satisfied with a more Western, biomedical approach to health care. The present study indicates that relationships are important for people of all cultures and backgrounds. All participants commented on the importance of having a good relationship with their health care provider. While culture was identified in the literature review section as an important factor contributing to ease of access to health care (Bolitho & Huntington, 2006; Buetow et al., 2002; Diette & Rand, 2007; Gibson et al., 2015; Pullon et al., 2015), this was rarely discussed by participants in the present study. Two participants did make comparison to health care services in their home countries (the Cook Islands and South Africa), but both commented that NZ health care services were superior to those in their home country. This perception that the NZ health care system is superior to other countries' (particularly the Pacific Islands, where half of participants were from) may be a reason that cultural needs were not raised as a factor that affects health care access in this study. It may be that participants felt that their needs were being adequately met in terms of the quality of the service, so they were not focussed on the cultural aspect of their care.

Participants often reported that having a key contact person at their GP or specialist clinic was important; this person was someone they felt comfortable talking to, who understood them and their child and who they could trust. This key person often helped with other tasks, like filling out forms for welfare or assistance with transportation. Having someone who understood the varying demands experienced by families accessing health care for their child with bronchiectasis was helpful and enabled parents to access health care more easily. Papp (2014) also discussed the importance of having one person to coordinate an individual's health care, reducing the number of health providers that a parent has to tell their story to and receive potentially conflicting information from – a sentiment that has been repeated in numerous studies (Arlidge et al., 2009; Bolitho & Huntington, 2006; Buetow et al., 2002; Sobo et al., 2006), as well as the present study. A large Australian study investigating care coordination for adults with chronic respiratory disease found that utilising GPs and nurses as care coordinators did not reduce hospitalisations, increased health care costs and produced only a modest improvement in quality of life (Smith et al., 2002). The authors suggested that as participants in the study had advanced disease and complex health care needs, care coordination was not enough to produce meaningful health benefits. Care coordination may be more important during the diagnostic stage of illness, when streamlining services and

engaging patients in education can improve patient satisfaction and adherence (Walton et al., 2013). Streamlining care may improve continuity of care and strengthen the health care provider-parent relationship. These are two things that parents in this study considered to be important aspects of a positive health care experience.

This study has shown that parents' relationships with health care providers leave a lasting impression and are fundamental to the experience that a person has with accessing health care. Health care providers must appreciate the importance of the relationships they forge with patients and their families and work to develop positive, trusting relationships.

5.2 Parents' Acquisition of Knowledge Leads to Greater Agency and Power Within the Health Care Experience

Many parents who were interviewed for this study described a process of learning and acquiring knowledge about their child's condition, in order to gain confidence, agency and power in their health care experiences. Again, these experiences are closely linked with relationships, relating back to the inter-personal level of the socio-ecological model (McLeroy et al., 1988). While power dynamics were not identified as a significant element of relationships in the literature review of this study, this was an important finding from interviews conducted for this study. Power was related to knowledge, which, by way of health literacy, was considered under the intra-personal level in the literature review of this study. From the results of this study, knowledge and power developed over time. Initially, when health care experiences were new, and their child had no diagnosis (or an early diagnosis of bronchiectasis), parents were vulnerable and disempowered in the health care provider-parent relationship, as well as in relationships with their employer and teachers at school. Parents described not knowing what the correct course of action should be and feeling like they had to trust the doctor because they did not know any better. As they gained knowledge, they were able to speak up and advocate for their child, gained a greater sense of agency and became empowered within relationships. Some parents described reaching a later, more collaborative stage in their health care experience, whereby their relationships with health care providers were characterised by respect and shared learning.

In the early stages of their health care experiences, parents described "*not knowing*" (Participant 1) about managing their child's health and feeling vulnerable in their experiences of accessing health care. This was a time in which health care became a significant part of the parent's role, in addition to child care. Parents alluded to significant power imbalances in various relationships in their, and their child's, lives. In the early stages of their health care experiences, parents indicated that they had little power in their relationships with their GP, doctors at the A&E, their employers and teachers at their child's school. Doctors at specialist clinics seemed to hold more power than any of these groups. Parents talked about having to explain their whereabouts to their employers and feeling pressure to disclose information about their child's health when they had to take time off work to look after their child. This situation

has also been depicted in literature, in which employment has been described as both an enabler and a barrier to accessing health care - an enabler because of the financial benefits of work, but a barrier when parents find it difficult to get time off work to take their child to appointments (Ballantyne et al., 2015; Bolitho & Huntington, 2006; Pullon et al., 2015). Parents were also under pressure from teachers at school, who sometimes expressed concern at the amount of time their child was having off school because of illness. In addition, specialist clinics were perceived to be the most important service, causing parents to feel significant pressure to attend, when they were already contending with competing pressures from employers and teachers.

Power dynamics between health providers (especially doctors) and patients are well documented (Goodyear-Smith & Buetow, 2001). In the present study, parents described numerous experiences of going to the GP and A&E, where they had expressed concerns about their child's health but were not believed; they felt vulnerable and unable to speak up about their child's needs. The paternalistic model of health care, whereby health providers have control and hold power over patients, has traditionally been the norm (Grünloh, Myreteg, Cajander, & Rexhepi, 2018). Many health providers, however, are moving towards a more patient-centred model of care (Aujoulat, d'Hoore, & Deccache, 2007; Papp et al., 2014), whereby health care relationships are a partnership, rather than a hierarchy. While there is an expectation among many health care providers that patient-centred care is desirable, there is resistance from many health providers, who may feel that their power is being eroded (Goodyear-Smith & Buetow, 2001; Grünloh et al., 2018). In a recent qualitative study, Grünloh et al. (2018) investigated doctors' perceptions of patient participation through use of online shared notes. They found that while doctors initially favoured the use of shared notes as a way to encourage patient participation, in practice, they largely rejected the practice, fearful of losing their authority with patients and perceiving patients' mistrust when patients asked informed questions. While physicians want informed patients, they also, paradoxically, feel threatened when patients ask questions (Grünloh et al., 2018). Goodyear-Smith and Buetow (2001) also note that improved information sharing, by way of the internet and media, has led to a shift in the power relationship between doctors and patients, and this has led to disempowerment of doctors, reduced trust from patients, and the practice of more reserved, "defensive medicine" (p.452).

Grünloh et al. (2018) contend that using the term 'empowerment' is unhelpful, as this suggests that for patients to gain power, this necessarily means a loss of power from doctors, and a degradation of the patient-provider relationship. Rather, they suggest striving for participation, and emphasise learning in patient-provider relationships. In contrast, Aujoulat et al. (2007) argue that empowerment is the outcome of a patient-centred approach and is founded on learning experiences. Similarly, Anderson et al. (2010) note that empowerment is the result of a partnership between the health care provider and patient, where, through a process of learning and support, the patient is encouraged to think critically, make informed

decisions and achieve greater self-efficacy. Regardless of the terminology used, it is clear that patient-provider relationships must be adjusted to allow both parties to be on an equal footing in health care experiences, with health care providers facilitating this role-shift (Aujoulat et al., 2007). Some parents in the present study had the experience of reaching a stage like this, where their relationship with health care providers was one of mutual respect and shared learning. As expressed by Bolitho and Huntington (2006) and several mothers in the present study, parents know their child best and want to be treated as experts on their child. This sentiment indicates that empowerment was important for parents in the present study, allowing them to feel more confident and experience more fulfilling health care experiences.

All of the parents in this study talked about the importance of seeking information and gaining knowledge in order to better care for their child's health. Parents discussed the best ways to access information. Many parents preferred to be provided with information in person, by health providers at their GP or at specialist clinics. The health provider's role in presenting information has been discussed extensively in literature. Education is seen as an integral part of a doctor's role, but often something that is not given enough attention or is limited by time, according to parents and patients (Dixon-Woods et al., 2002; Konstantynowicz et al., 2016). How parents comprehend the information provided by health providers may be influenced by their level of health literacy and their health provider's engagement with them (Hwang et al., 2017). Hwang et al. (2017) found, in a study exploring mothers' trust of physicians' advice, that mothers who had limited formal education were less likely to trust their physician's advice about infant care. The authors proposed that this may be linked to health literacy, suggesting that these mothers were less able to process and appraise their physician's advice. Other literature has also pointed to the importance of health literacy in health care interactions (Buetow et al., 2002; Diette & Rand, 2007; Schneiderman et al., 2010). Health information must be tailored to patients' abilities, whether information is communicated verbally or in written form (Kickbusch et al., 2013). Health information is frequently aimed at a level that is too sophisticated for the average adult (Kickbusch et al., 2013). While the present study did not evaluate parents' education levels, findings revealed that health literacy was important for the mothers interviewed, as indicated by their emphasis on seeking health information to better understand, appraise and act on their health provider's advice. All mothers indicated that they were eager to gain more knowledge to better engage with health providers. Grünloh et al. (2018) identified that encouraging patients to participate in their health care experiences through shared decision-making could improve patients' health literacy. The study by Hwang et al. (2017) also revealed that physicians' engagement with mothers was important; mothers who were asked their opinion about infant care options were more likely to trust physicians' advice. This finding aligns with the importance of relationships that was emphasised in the present study, and the desire for mothers to be treated as experts on their child.

While providing information is, and should be, considered the responsibility of health care providers, patients (and parents) frequently seek their own information from various

sources, particularly the internet. Some parents in the present study considered that seeking information was *their* responsibility, or preferred to seek their own information on the internet. Several studies have explored health information-seeking behaviours, particularly with respect to internet use. A Portuguese study found that while young people were fervent internet users and frequently used the internet to supplement their doctor's information, they still regarded their doctor as the most trustworthy source of information (Mendes, Abreu, Vilar-Correia, & Borlido-Santos, 2017). Sivakumar and Mares (2017) also found that participants considered their doctor to be the most credible source of information, though also noted that participants were poor judges of quality when appraising health websites. This could lead to patients accessing inaccurate health information and making ill-informed decisions. Another UK study (Bowes, Stevenson, Ahluwalia, & Murray, 2012) explored patients' experiences of taking information sourced from the internet to their GP. Participants in the study explained that they sought information independently in order to appear more engaged with, and committed to, their health. They highlighted that their GP's response to the information they brought (whether the GP was engaged in discussion or, conversely, appeared threatened or rejected the information) influenced their ongoing relationship with the GP. If the GP appeared disinterested or dismissive of the information, this was damaging to the health care provider-patient relationship, sometimes to the extent that the patient changed their doctor (Bowes et al., 2012). These findings demonstrate the significant influence that health providers (doctors in particular) have on patients and their confidence to seek, and discuss, health information. While health care providers should continue to be considered as credible sources of information, it must be acknowledged that patients are likely to seek information on the internet, as a way of saving time in GP consultations and presenting themselves as engaged and committed to their health (Bowes et al., 2012; Mendes et al., 2017). Findings from the present study also showed that parents were engaged in sourcing their own information on the internet, though many parents indicated that most information was gathered face-to-face from their GP or specialist clinic. The findings of the present study resonate with many of the concepts that emerged from the studies by Bowes et al. (2012) and Grünloh et al. (2018), including the importance of the health provider-patient relationship in fostering trust and patients' desire to be respected and treated as partners in the health care experience. Patients want health providers to listen to their concerns and engage in meaningful discussion about their health, rather than feeling threatened and dismissing questions and information brought to the consultation (Bowes et al., 2012).

The acquisition of knowledge was important to mothers in the present study as a way to feel more empowered and confident within the health care provider-parent relationship. By seeking knowledge from health care providers and the internet, parents gained agency in the relationship and became more active users of their child's health care. Power dynamics in health care provider-patient relationships are changing as information becomes more readily available to consumers; this may require a shift in the traditional roles of health care providers to enable a relationship based on partnership and equality, rather than power.

5.3 Parental Appreciation of the Worth of Health Care Services will Enable Access to Health Care

Parents in this study described a range of potential barriers that needed to be overcome when accessing health care services, but they also indicated that, knowing their child's health was important, if the health care service was perceived to be worthwhile, they would "*make it work*" (Participant 1). Some of these barriers were identified as intra-personal factors in the literature review of this study, such as finances and transport. Others were considered as community factors, like social support and juggling health care with other life demands. Another barrier was identified as an institutional factor – navigating the complex health care system.

Some barriers to accessing health care that were faced by parents were practical difficulties like financial barriers, transportation and lack of social support. While GP visits are free for children in NZ, some parents described sometimes having difficulty buying medication for their child or accessing care at the A&E because of cost. Some parents described that financial barriers were eased by their child having a disability allowance, which has also been described in another NZ study (Bolitho & Huntington, 2006). Financial barriers to accessing health care have been well documented in international literature, as many other countries charge for health care services, making it much less accessible (Ballantyne et al., 2015; Wendt et al., 2012). As well as service charges, there are indirect costs to accessing health care as well, like taking time off work and transportation costs (Ballantyne et al., 2015; Pullon et al., 2015). While the financial cost of transportation was mentioned by a few participants in this study, it was the travel distance that presented the greatest barrier to most. Transportation challenges and parking costs have, similarly, been described in both local and international literature (Ballantyne et al., 2015; Bolitho & Huntington, 2006; Sobo et al., 2006). Social support may act as an enabler to accessing health care, because of assistance with transportation and child care (Arlidge et al., 2009; Ballantyne et al., 2015; Bolitho & Huntington, 2006). The importance of social support was also raised in the present study, whereby those parents who had little social support found it much harder to overcome potential barriers to accessing health care. Most parents, however, were able to overcome any potential barriers and rarely missed appointments. Many parents living in South Auckland had a significant distance to travel to clinics at Starship Hospital (>20km) but, despite the significant cost (for petrol and parking) and time involved, they all reported that they would still attend scheduled clinics because they knew that specialist care was important for their child's health. Parents' willingness and determination to overcome these barriers was motivated by their perceived worth of the health care service.

The results of this study highlighted that parents of children with bronchiectasis are often juggling many competing life demands, as well as looking after the health of their child. These other demands, such as work, school and family responsibilities, presented as further potential barriers to accessing health care. Again, parents in this study expressed their

determination to “make it work” and would manage these demands to access health care for their child. Work and school commitments made it challenging for parents to find time to get their child to appointments. This has been found to be the case in other similar studies (Ballantyne et al., 2015; Bolitho & Huntington, 2006; Sobo et al., 2006). As well as this, managing family responsibilities can also present a challenge for parents, as exemplified by several parents in this study, one of whom was a solo mother looking after six children. Family, work and school responsibilities create difficulties for many parents who are trying to schedule GP or clinic appointments, which are usually during standard working hours (Ballantyne et al., 2015; Bolitho & Huntington, 2006; Sobo et al., 2006). As identified by Dixon-Woods et al. (2002), parents want to be recognised as consumers of their child’s health care in their own right, as carers and advocates for their child. This means acknowledging that in order for parents to access health care for their child, they need to fit their child’s appointments around their own competing schedules (Dixon-Woods et al., 2002). Creating outreach clinics with informal ‘walk-in’ appointments has been found to be effective for Aboriginal Australians using a rural paediatric clinic (Thomas et al., 2015). Outreach clinics have been found to improve health care access in disadvantaged (Reeve, Banfield, Thomas, Reeve, & Davis, 2016; Spencer, 1993) and rural populations (Agostino, Heazlewood, & Ruben, 2012; Stanzel, 2016). Spencer (1993) noted that while outreach clinics improved health care access for many people in a disadvantaged Australian population, high non-attendance rates continued, indicating that the problem of non-attendance and poor access to health care was much more complex than geographical proximity could influence. Indeed, the present study has identified many more factors that may influence health care access. As in the successful model of care described by Thomas et al. (2015), an outreach clinic must also cater specifically for the population it services, providing culturally appropriate health care as well as local, efficient care. Outreach clinics may be an effective solution for parents like those in this study, who may find that closer, more flexible appointments may allow them to schedule health care around the competing demands of life and family. In fact, this was a suggestion specifically given by several participants in the study. While competing work, school and family commitments may present as barriers to accessing health care, parents in the present study and another local study (Bolitho & Huntington, 2006) usually managed to overcome these barriers in order to access health care for their child.

Parents in this study described how navigating different services within the health care system could be challenging. Some children were under the care of different DHBs for their bronchiectasis and sometimes for other health problems, while others used both public and private health care services. Despite sometimes finding these different services difficult to manage, parents would “make it work” for a service they believed to be valuable. Communication between services was often cited as a challenging factor – clinic teams at the two DHBs were sometimes found to have poor communication with each other and with primary health care services. As well, different health services (for example respiratory and surgical services for one child) were not linked, meaning that information and appointment schedules were not well coordinated, and appointments were often at different hospitals.

Fragmented health care systems were also described by Sobo et al. (2006), noting that the distrust that was fostered by disorganisation of care led to a perception of suboptimal care. Other research has described parents' challenges with understanding what services were available to their child and how to access those services (Arlidge et al., 2009; Buetow et al., 2002; Papp et al., 2014). As well as this, some parents in the present study described experiences of using both public and private health care services. One parent described wanting to use only private health services, as she perceived private services to be more efficient and comprehensive. However, other parents had poor experiences with private health services, acknowledging that public services had better links to a wider range of specialties and were easier to access in the first instance. Two Australian studies have investigated patients' perceptions of accessing care at both public and private hospitals (He, Toloo, Hou, & FitzGerald, 2016; Ward et al., 2017). Both studies found that the main factor that initiated use of private hospital care (for those with health insurance) over public was waiting times. As well, people who had previously had a negative health care experience in a public hospital felt distrustful of the public system, while those whose main concern was cost of treatment were not deterred by long waiting times and were generally trusting of the public health system (Ward et al., 2017). Like the participants in the present study, participants in the study by He et al. (2016) also perceived public hospitals to have better access to specialist services and better continuity of care. Access to private services may also be determined by the referring practitioner. Papp et al. (2014) pointed to participants' frustration with the 'gate-keeper' role of the GP, whereby GPs must provide a referral for specialist care, which many patients see as an unnecessary step in the process of accessing specialist care. This was also experienced by participants in the present study. Despite the inconvenience of navigating different aspects of health care systems, which can be challenging and cumbersome at times, parents always prioritised access to necessary health care services for their child.

Parents of children with bronchiectasis experience many potential barriers to accessing health care. Some of these barriers are practical challenges that must be overcome, some are related to parents' busy work and home lives, and others arise from the complexities of the health care system. Parents in this study often expressed that despite these potential barriers to accessing health care, if they appreciated the worth of the service being provided, they would find a way to access the health care service for their child.

5.4 Implications for Practice

This research has identified several important areas for practice, service delivery and research to improve health practice and health systems to improve health care access for families of children with bronchiectasis. This generated three recommendations for practice. Firstly, a greater emphasis on patient-centred care, particularly on fostering relationships between health care providers and families. Secondly, improving channels of communication between parents, between health care providers and patients and between services. Thirdly,

using technology to assist with communication and to improve links between key groups involved in a child's care.

Patient-centred care is described as care that is respectful and considers patients' needs, preferences and values (Institute of Medicine, 2001). This framework of care aims to focus on the patient and their individual circumstances, rather than the illness they present with (Dwamena et al., 2012). While this is not a new idea and is taught in many branches of health care practice, the present research suggests that it is not well practised. The experiences described in this research indicate that some health care providers did not spend enough time or effort focussing on patients and families, resulting in ineffective clinical relationships and poor communication. Patient-centred care was identified by Ballantyne et al. (2015) and Papp et al. (2014) as an important aspect of a positive health care experience. Health care providers need to be cognisant of patients' and families' perceptions and emphasise the quality of the relationships they develop. Educational interventions and teaching strategies for patient-centred care have been found to be helpful for improving patients' health behaviours and outcomes (Dwamena et al., 2012). These interventions may be helpful for all health care providers who are working with families of children with bronchiectasis to re-orientate the focus of health care interventions. As well as this, a more significant philosophical shift in the way that health care provider-patient relationships and the roles that are played out within those relationships may be necessary (Aujoulat et al., 2007). A shift of power from the traditional paternalistic health care provider-patient relationship to a relationship built on partnership and shared learning will be crucial to the development of patient-centred care and meaningful health care experiences (R. M. Anderson & Funnell, 2010; Aujoulat et al., 2007; Grünloh et al., 2018).

Improving channels of communication may help to improve health care experiences for families of children with bronchiectasis. Three channels of communication may be strengthened: firstly, between parents, secondly, between parents and health care providers and thirdly, between health care providers themselves. Considering that the process of taking part in an interview seemed to be helpful for many participants, improved communication between parents of children with bronchiectasis, in the form of a support group, may be useful. Support groups were suggested by parents in low-income Canadian families with children with respiratory problems (Stewart et al., 2016) as a way to improve contact with peers and share information. Online support groups have also been helpful for parents of children with asthma (Sullivan, 2008) and children with special health care needs (Baum, 2004). Online support groups still provide much-needed social, emotional and informational support for parents of children with complex health care needs, while allowing more convenient access via an online framework (Baum, 2004; Sullivan, 2008). Social support groups may be helpful for participants in the present study, either online or face-to-face, according to the preferences of, and accessibility to parents. Support groups could be facilitated solely by parents, through online interactions, or may be facilitated by charity organisations, such as the Bronchiectasis Foundation.

Improved communication between health care providers and parents is crucial, as was identified by many parents in the present study. This may be achieved through a focus on patient-centred care, or through the use of open notes or email communication. An American study by Esch et al. (2016), in a population of adults engaging in general practice services, trialled the use of open, online notes that were accessible to patients. They found that patients experienced improved understanding, better relationships and improved self-care. While patients participating in the study by Grünloh et al. (2018) also found benefit from the use of open notes, that benefit was not often felt by doctors, who felt they were being questioned and mistrusted. Despite the negative reaction from doctors, the improvement in patient experience and understanding suggests that this is an interesting innovation that merits consideration in NZ health care settings. In another study, Rosen and Kwoh (2007) investigated the use of health care provider-patient email communication in a paediatric population, finding that emailing allowed for efficient, effective communication. Families reported improved communication and access to health services and the service was accepted by physicians. Privacy was considered a potential issue with email communication, though this was ameliorated through informed consent given by patients. Another problem that was encountered infrequently during the course of the study was that some patients used the email service to communicate urgent health matters, that would have been better addressed on the phone or even by calling emergency services. The use of email communication was discussed by one participant in the present study; this participant reported excellent communication between herself and her child's doctors. Email may be an effective, efficient way to improve communication between health care providers and parents. Consideration must be made, however, to ensure that patients' privacy is maintained, that there is a process for triaging or re-directing more urgent matters, and that patients' health literacy levels are respected and information is targeted at an appropriate level.

Improving communication between health care providers is also imperative – both within and between services. The use of open notes and email communication may also be a useful tool in this respect. As well as this, using technology to improve sharing of patient information would assist health care providers to work together to provide optimal care to patients and their families. Information-sharing between different services, particularly between hospital providers and GPs, has been problematic for some time, often resulting in inadequate, or slow, exchange of information and mistakes or omissions in information provided (Kripalani, Jackson, Schnipper, & Coleman, 2007). This has particularly been the case when paper discharge summaries have been the main form of communication between services (Frankel, Chinitz, Salzberg, & Reichman, 2013). The emergence of electronic information-sharing systems has allowed for more efficient transfer of information between services, even those that span different organisations (Harlan et al., 2010; Kripalani et al., 2007). Development of electronic systems has not occurred without interruption. Eason, Dent, Waterson, Tutt and Thornett (2012) described the challenges of integrating electronic information-sharing systems between services in the UK. Although this study focussed on adult

stroke services, it attempted to integrate a range of services from inpatient to outpatient and general practice care, so findings may be applied in some part to the present study. While individual electronic systems were efficient and effective, different services often had different platforms for electronic records, reflecting the unique needs of that service. This made it difficult to integrate care between services and between electronic systems. Proposed national systems, while increasing efficiency and streamlining of information-sharing, would not enable the tailoring of needs between services, so may be seen as too constraining. The authors suggested that local agencies need to cooperate to develop systems that work for numerous services. The use of electronic records appears, on the surface, to be a useful, efficient way to share information between services. As indicated by Eason et al. (2012), this may present significant challenges, so systems need to be developed carefully and completely, with all relevant stakeholders involved. This may be a framework that continues to be developed to allow for streamlining of health care information in the future.

The use of technology may also improve collaboration between health services and key stakeholders in a child's care, like schools. Improving collaboration between all groups involved in a child's care may reduce the competing demands placed on parents, improve communication between health care providers and may allow schools to be more involved in a child's health care, to improve their engagement in the child's health care and reduce the burden on health professionals. An electronic asthma action plan has been shown to be an effective tool to improve communication and collaboration between schools and health care providers and improve health care knowledge and confidence of school staff (Hanson, Aleman, Hart, & Yawn, 2013). A similar, bronchiectasis-specific, action plan (Lavery, O'Neill, Parker, Elborn, & Bradley, 2011) is currently being trialled with adults in Ireland. Another innovative technological programme, iMOKO™ (Navillus Medical Ltd., 2016) is already being used in some areas of NZ, whereby staff in schools can use an app to communicate children's health problems to a remote GP, who can then arrange an immediate management plan. Using technology in this way may improve efficiency and access to health care if schools can be more involved in monitoring a child's health and feeding back to health care providers.

5.5 Strengths and Limitations of this Study

There are many notable strengths of the presented study. First, the focus of this study was on the parents and their experiences of accessing care for their children, thereby creating a space for parents' stories. Unlike other literature that has interviewed only health professionals (Buetow et al., 2002) or has used surveys to collect data (Seid, 2008; Wendt et al., 2012), this study used interviews to capture rich narratives from consumers of health care services themselves. As well as this, parents were given an opportunity to speak openly and freely about their experiences, which the researcher perceived to be helpful for many participants. Through discussing their experiences, some participants expressed that they were able to rationalise aspects of their experience that they had not previously considered, which may have been remedial for some.

Another strength of this study is that this is the first study to examine the experiences of accessing health care for parents of children with bronchiectasis in NZ. This is of particular importance in NZ, and especially the CMDHB area, considering the high (and worsening) rates of bronchiectasis in these areas. The study recruited participants from a range of ethnic and socioeconomic backgrounds, who were largely representative of the CMDHB population. This study has provided insight into the experiences of accessing health care for families, which has helped to identify strategies that may improve early access to health care for vulnerable children. It is crucial that the problem of bronchiectasis is addressed to improve health outcomes and equity in the NZ population.

Despite these strengths, some limitations of this study should be noted. These include: that only parents who attended clinics were recruited, only females were recruited, the researcher only represented one ethnic/cultural background and that the study did not reach the target sample size of 12-15 participants, instead including only ten participants. Participants were recruited through three DHB-based clinics, whereby staff working at those clinics were asked to identify and assist with recruiting potential participants. If potentially eligible participants did not attend the clinic, the researcher asked that a staff member contact the potential participant (as they would routinely do to find out their whereabouts) to ask them if they would be willing to participate in the study. Unfortunately, none of these potential participants were identified by clinic staff, so only parents who attended the clinics in person were recruited. This presents 'elite bias', whereby the most articulate, easy-to-reach participants will be most likely to participate in a study (Sandelowski, 1986). Those parents who were unable to attend clinics are likely to experience the most barriers to accessing health care, and their experiences, therefore, would significantly add to this study. One way to overcome this may have been to conduct and record interviews over the phone; this could be considered in future research.

While the inclusion criteria for this study included all parents or caregivers of children with bronchiectasis, only mothers were recruited for the study. No fathers or non-parent caregivers volunteered to participate. This presents a limitation in the gender diversity of the study, whereby a male parent's view may be different to that of the female parent. As well as this, the experiences of a non-parent caregiver may be different to that of a parent. Greater diversity in gender and family make-up may have presented more varied perceptions and experiences of accessing health care.

The researcher's ethnicity may have limited open discussion of cultural aspects of accessing health care. While participants from a range of ethnicities and cultures were recruited, this was not matched by the Pākehā researcher. The researcher's Pākehā ethnicity may have hindered open discussion about culture, as participants from different cultures may not have been willing to discuss their cultural needs frankly with a Pākehā person, who may be considered to be allied with the Western health system they were discussing. Culture was

not identified as a significant aspect affecting access to health care, and this may be one reason. Arlidge et al. (2009) utilised researchers from varied cultural backgrounds to interview different families in their study. This was a strength of that study and, as a consequence, the researchers produced some meaningful results about cultural experiences of accessing health care.

This study experienced significant difficulties with recruitment of participants, resulting in a smaller than expected sample size. Recruitment of participants was slow, taking over a year to recruit ten participants. The researcher attempted to address this limitation by expanding the inclusion criteria to include wider age groups of children and also added snowball sampling as an additional method of sampling. Despite these changes to the research protocol, recruitment was still challenging. Factors that limited recruitment were that the staff who were asked to recruit from clinics were busy with their clinical work and frequently forgot to discuss the study with potential participants. As well, because these staff were not directly involved in the study, they were not as motivated as the researcher to recruit participants. Lastly, eight potential participants, who initially expressed interest in taking part, later declined to be involved or were unable to be contacted. This may be a reflection of the socioeconomic or cultural makeup of the population under study, whereby, from the researcher's experience, those in lower socioeconomic groups may be difficult to contact, and people from some cultures may find it difficult to decline invitations to participate (and disappoint the staff member or researcher) in the first instance. Despite these challenges with recruitment, the study sample represents a diverse range of age groups, ethnicities and income groups, and the researcher believes that saturation of themes was reached, because later interviews did not generate many ideas, codes or themes that had not already been identified from earlier interviews (Bazeley, 2013).

The qualitative nature of this study means that findings can not necessarily be generalised to the whole population. Findings can be attributed to the participants who were interviewed and may be extrapolated to the families of those participants, as participants often spoke about their families' experiences as well. While qualitative findings usually cannot be generalised to other members of the population (Nicholls, 2009), some findings may be applicable to other, similar, populations and contexts. The results of this study may, therefore, be useful to health care providers aiming to consider and improve the experiences of users of other health care services.

Chapter 6: Conclusion and Future Research Recommendations

This qualitative study investigated the experiences of accessing health care for families of children with bronchiectasis in the CMDHB area of Auckland, NZ. This was an important group to study, because bronchiectasis is particularly prevalent in NZ, and especially in CMDHB (Telfar-Barnard & Zhang, 2017; Twiss et al., 2005). Māori, Pacific Island and disadvantaged people are disproportionately affected by bronchiectasis (Telfar-Barnard & Zhang, 2017). One of the factors that may lead to increased rates of bronchiectasis in these groups is limited, or inefficient, access to health care (Ministry of Health, 2017b; Twiss et al., 2005). To better understand the barriers and enablers of accessing health care for children with bronchiectasis, this study sought the perspectives of families of children with bronchiectasis in CMDHB, to highlight their experiences as users of health care services.

This study showed that parents of children with bronchiectasis have often had numerous health care experiences, both before and after receiving a diagnosis of bronchiectasis. Their health care experiences highlighted the importance of their relationships with health care providers, the power dynamics within those relationships and the shift of power in relationships as parents gained more knowledge. Their experiences also highlighted that while many parents have competing responsibilities that they must juggle, they are resilient and will almost always find a way to access health care for their child.

This research has identified several implications for practice, including the development of support groups for parents, a greater emphasis on patient-centred care and improved communication between parents and health care providers, possibly using technology to facilitate this. As well as these practice implications, this research has identified several gaps in research. Further research in this area should focus on hard-to-reach groups, on health professionals' experiences and perceptions and may consider the effectiveness of the practice implications that have arisen from this study.

The present study did not succeed in recruiting parents who have significant difficulties with accessing health care. While attempts were made to recruit parents who did not attend clinic appointments, none of these parents were recruited. The views of parents who have significant difficulty accessing health care are paramount to unravelling the most significant barriers faced by parents of children with bronchiectasis. Future research should place more effort on following up on parents who do not manage to attend clinics and appointments and exploring the barriers to accessing health care faced by those parents. Telephone interviews may be one way to approach this population. As well, future research should consider the use of a research team with multiple and varied cultural understandings. This may aid recruitment of people from different cultural backgrounds and may facilitate connections with some of the hard-to-reach parents who have been unable to attend appointments. Researchers with different cultural backgrounds may facilitate identification of cultural factors that limit or enable

access to health care, as participants may be more likely to share these insights with researchers from a similar culture to their own.

Further research may also explore the experiences and perceptions of health providers, in order to identify the barriers to early diagnosis of bronchiectasis, especially in primary care. By learning more about what hinders identification and diagnosis of bronchiectasis and doctors' experiences of caring for this vulnerable population, further interventions may be put in place to ensure that children who present frequently with a productive cough are identified, diagnosed and managed early. By focussing on early identification and management of bronchiectasis, research could identify the impact this may have on clinical and social outcomes for children and families, for example the disease trajectory, absences from school and work, and quality of life. Early identification of respiratory infections and subsequent bronchiectasis may also positively impact on rates of bronchiectasis in the community by focussing on prevention of the disease.

Several implications for practice have been recommended. Further research will be necessary to examine the efficacy of such suggestions before they are implemented in practice. As such, research may consider the role of patient-centred care and educational interventions to target this. Research may also consider ways to improve communication in a local setting, through support groups for parents, the use of open patient notes, email communication between health care providers and patients and the use of electronic records to support communication between services. Lastly, research may evaluate the use of technological innovations to include schools and other stakeholders in children's care, as carers working in partnership with health care providers.

This study has contributed to filling an important gap in our knowledge around health care access for families of children with bronchiectasis. The study has put the experiences of health care service-users at the centre of its investigation, detailing the experiences of these families and their own unique perspectives. By exploring their experiences, this study has identified barriers and enablers to accessing health care for a vulnerable population and has identified several areas for practice and research to continue to improve the health care experiences for this group of people and others like them.

7. References

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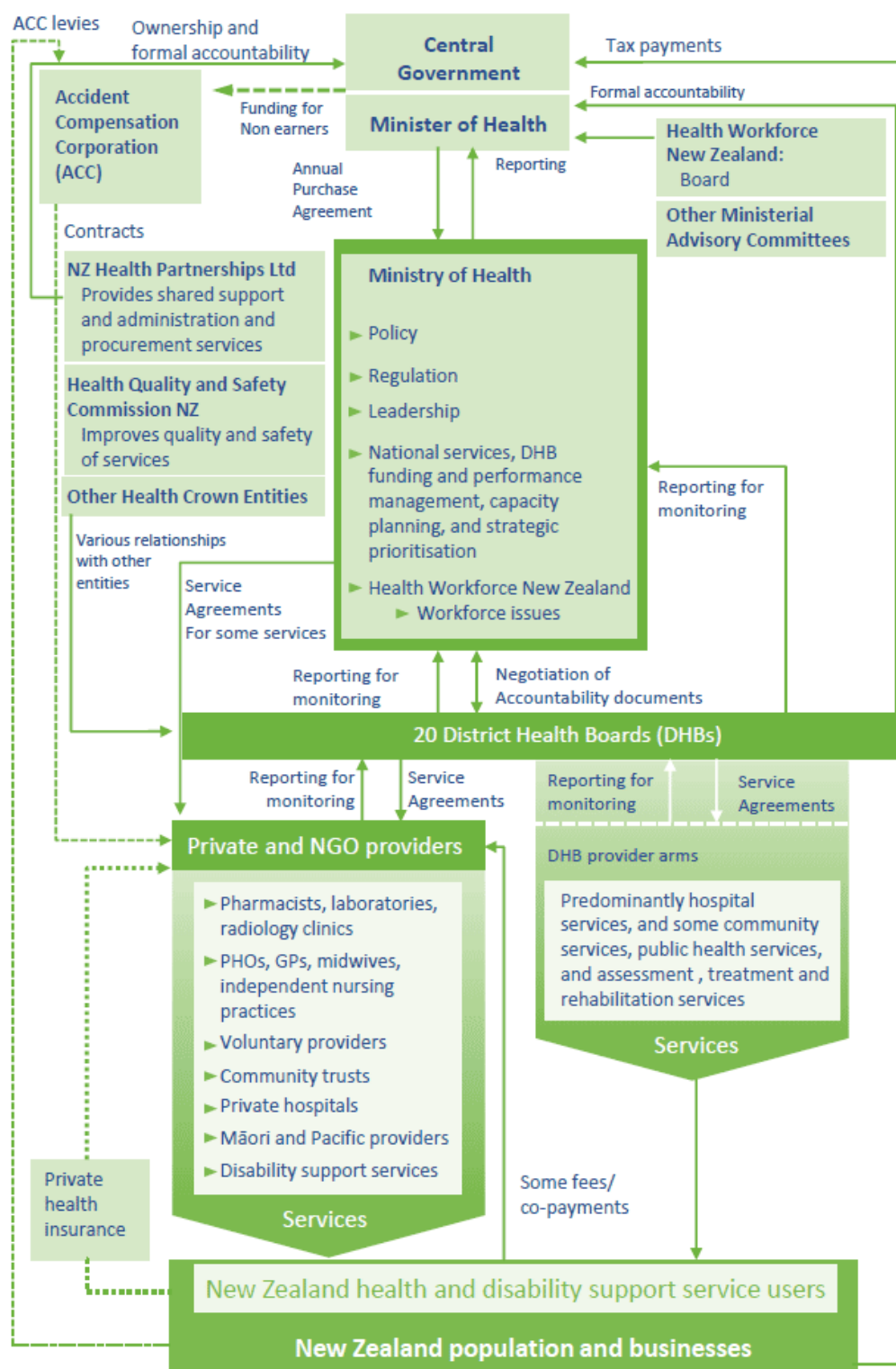
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8. Appendices

8.1 Appendix A

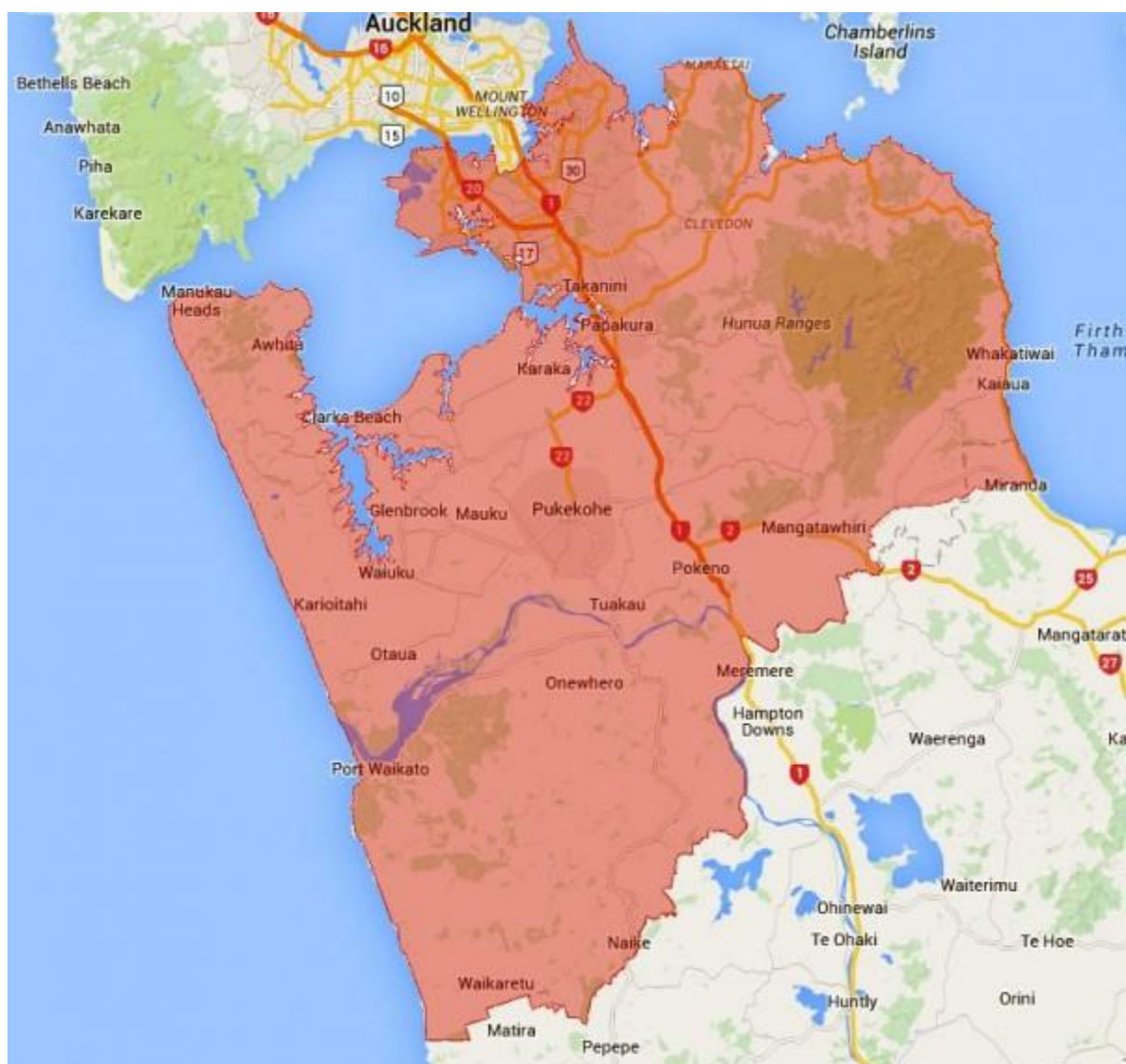
The structure of the New Zealand health and disability sector



Ministry of Health. (2017). Overview of the health system. Retrieved 6 November 2017, from <https://www.health.govt.nz/sites/default/files/images/nz-health-system/structure-nz-health-disability-sector-oct16.png>

8.2 Appendix B

Map of Counties Manukau District Health Board



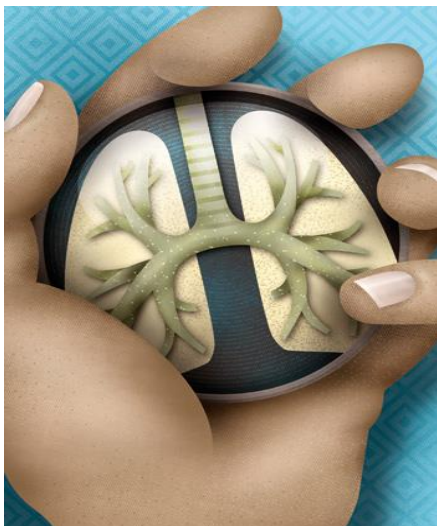
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8.3 Appendix C

Flyer used for recruitment

Would you be willing to be involved in my research project?

I'm interested in hearing about your experiences of accessing health care for your child with bronchiectasis



<http://www.bpac.org.nz/bpj/2015/september/asthma.aspx>

Nicola (Nicky) Jepsen

A research project through Auckland University of Technology & Counties Manukau DHB

I am a physiotherapist at Middlemore Hospital and a Master's student at AUT. I would like to find out more about how children with bronchiectasis and their families access and experience health care.

I would love for you to help me out with this. If you fit the description on the right hand side of this flyer, please contact me, or write your details on the attached form and I'll get in touch with you.

Thanks - Nicky.

AUT

TE WĀNANGA ARONUI
O TĀMAKI MAKĀU RAU

Are you:

The parent / guardian
/ caregiver of a child
with bronchiectasis?

Over 18?

Is your child between
the ages of 0-17?

Is bronchiectasis your
child's main health
problem?

**Do you live in the
Counties Manukau
area in South
Auckland?**

*Please contact me (see
below), or write your
details on the attached
form.*

NICOLA JEPSEN

Nicola.jepsen@middlemore.co.nz
021 100 5232
921 9999 x7951
Physiotherapy Department,
Middlemore Hospital
Private Bag 93311
Otahuhu
Auckland 1640

If you are willing to be part of this research project and you would like me to get in touch with you to provide more information, please provide your contact details below.

Name:

Child's name and age (optional):

What is the best way for me to contact you?
Please fill in any or all of the following information:

Phone number:

Alternative phone number:

Email address:

Mailing address:

Thanks! I'll be in touch soon. You can hand this form back to clinic staff, or you can send it to me.
Nicky.

8.4 Appendix D

Interview Schedule

Domain	Example questions
Knowledge & self-management, individual factors	<ul style="list-style-type: none"> • Please can you start by telling me about what it's been like for you and your whānau since [child's name] has had these breathing problems? • Please can you tell me about how [child's name] came to be diagnosed with bronchiectasis and what was that like for you? <ul style="list-style-type: none"> • Probe: How was information given to you about the diagnosis? Was that helpful / unhelpful? • How did you find out about how to manage [child's name]'s breathing problems? • What do you think are the most important things to help [child's name]'s breathing problems?
GP experiences	<ul style="list-style-type: none"> • Can you tell me about what it's like for you when you take [child's name] to the doctor? <ul style="list-style-type: none"> ○ Probe: How has your family doctor been helpful / unhelpful? ○ Probe: What makes attending the GP easier/harder?
Clinic experiences and other community health experiences	<ul style="list-style-type: none"> • Can you tell me about the first time you went to the breathing clinic (at Superclinic / Starship) and what that was like for you? <ul style="list-style-type: none"> ○ Probe: How have those clinics been helpful / unhelpful? • You must have had to get medicines for [child's name] – can you tell me about how you get the medicines?
Hospital experiences	<ul style="list-style-type: none"> • Has [child's name] ever had to go into hospital for his/her cough? Can you tell me what it was like for you, being in the hospital with [child's name]? • What impact did that have on your whānau?
Participants' suggested strategies	<ul style="list-style-type: none"> • If another child in your whānau got bronchiectasis, what would be the most important advice you'd give their mum/dad? • What do you think have been some of the barriers (or difficulties) to accessing health care for [child's name] and your family? • Based on your experiences with accessing health care services, is there anything that could be done differently that might make it better or more helpful for families of children with bronchiectasis?

8.5 Appendix E

Participant Information Sheet



Participant Information Sheet

Date Information Sheet Produced:

30 May 2016

Project Title

The experiences of accessing health care for families of children with bronchiectasis in Counties Manukau District Health Board, New Zealand: A qualitative study.

An Invitation to take part in my project

My name is Nicola Jepsen and I am a physiotherapist at Middlemore Hospital and a student at AUT. This is an invitation, asking you to take part in my research project. I would like to have a conversation with you to find out about your experiences of using health care services for your child. This information sheet will give you some more information about the project, explain what you will need to do and talk about the possible benefits and risks of taking part.

I am asking you to take part because you are the parent or guardian of a child with bronchiectasis (sometimes called 'scarring of the lungs') and you live in the Counties Manukau District Health Board (DHB) area.

I am doing this project as part of my work towards a Master of Public Health degree. I am hoping to find out more about how families of children with bronchiectasis use health care services in Counties Manukau and find out about what things make it easier, or harder, to get the care that your child needs. I hope that this research will help to improve our health care services, so that everyone can have the health care that they need.

If you would like to take part, we will arrange a time to meet for an interview. During the interview, I will ask you some questions about what it is like for you to access health care for your child. Taking part in this research project is voluntary, and you may pull out of the project at any time, without judgement. Taking part in the project will not affect the health care you, or your child, receive in any way.

If you would like to take part in this project, please contact me directly – my contact details are at the end of this information sheet.

What is the purpose of this research?

This research will provide information about your (and other participants') experiences of accessing health care for your child. Children with bronchiectasis often need to use a lot of health care services. Many families of children with bronchiectasis find it hard to access health care, because of cost, transport issues or other reasons. This project will find out about these and other reasons that it might be hard to access health care, and will find out about the good things, too. By finding out about this, we might be able to improve health care services so that everyone has access to the health care they need.

When I have finished the research, I will write a paper to hand in to the university, I will publish the research in an academic journal and will present the results at a conference. I will invite you to read a short report on what I found out, or attend a presentation with other participants to hear about the results.

How was I identified and why am I being invited to participate in this research?

You were identified \ because you have a child with bronchiectasis, you live in the Counties Manukau area and your child was referred to a clinic at Counties Manukau or at Starship Hospital. You would have picked up, or were given, a flyer at the clinic. If you did not attend the clinic, you would have been contacted by someone from the whānau support team at Counties Manukau DHB as part of a routine follow-up process, and they have then asked if you would like to receive this information about the research.

What will happen in this research?

You will need to take part in one interview, in which I will ask you to tell me about what it is like for you to access health care for your child. The interview will take approximately one hour. We will decide between us the best place for the interview to take place. If you would like the help of an interpreter, I can arrange this. I will record the interview using an audio-recording device, and I might take some notes. After the interview, I will get the interview typed up by a typist, then I will use the audio and typed words to think about and analyse the content of the interview. When I have finished, you will be invited to read or hear about my findings.

What are the discomforts and risks?

It is possible that you could find it hard to talk about accessing health care for your child, especially if you have had bad experiences or memories. You do not have to answer any questions if you do not want to.

How will these discomforts and risks be alleviated?

If you do find it hard to talk about anything in the interview, I will do my best to make you feel more comfortable. You are welcome to bring a friend or whānau member to the interview if you like. You can contact the Health and Disability Commission Advocacy Service on 0800 555 050. You can also contact the Māori Support Team at Counties Manukau DHB on 276 5004.

What are the benefits?

By taking part in this project, you will help me to learn more about what it is like for families of children with bronchiectasis to access health care in Counties Manukau DHB. You will be able to share your ideas and suggest how health care services could be better. This research will help me to get a Master's qualification when I finish the project. I will also learn about how to carry out research and about health care in Counties Manukau DHB. This project will help people who work in health care by helping them to find out about what parts of their service are working well and what parts could be better. Lastly, this project will help the community because it will help to ensure that health care is available and accessible for everyone in need.

How will my privacy be protected?

No information about you or your child will be available to anyone except for me and my two supervisors. The typist (who will type the audio recording) will sign an agreement to ensure that all information from the interview remains confidential. If an interpreter is used, they will also sign an agreement to ensure that all information from the interview remains confidential. If you decide to withdraw from the study for any reason, all information relevant to you, including interview recordings and transcripts, will be destroyed.

What are the costs of participating in this research?

The interview is expected to take about an hour, so you'd need to set aside at least this time, plus any travel time. You will need to find your own way to the interview location. Between us, we will decide on the best place to do the interview – it could be at the hospital, at your home or at a different location. We can choose somewhere that works for both of us.

What opportunity do I have to consider this invitation?

You have two weeks to think about this invitation. After that time, if I haven't heard from you (and if it is ok with you), I will give you a call to check if you are interested in taking part. If you do not want me to call you, you can let the nurse at the respiratory clinic (where you got the flyer) know.

How do I agree to participate in this research?

If you would like to take part in this project, you will need to complete the consent form that was given to you with this information sheet. You can send the consent form back to me in the mail, or you can contact me using my contact details below, so we can arrange a time for me to pick up the consent form and organise a time for the interview.

Will I receive feedback on the results of this research?

After the interview, you will have the opportunity to read the typed version of the interview to check it is correct. When I have finished the project, you will be able to read about what I found out in a short written report, or hear about the research findings in a presentation to participants.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Nadia Charania, nadia.charania@aut.ac.nz, 09 921 9999 x 6796.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Nicola Jepsen

Mailing Address: Physiotherapy, Acute Allied Health, Ground floor Edmund Hillary Building, Middlemore Hospital

nicola.jepsen@middlemore.co.nz

09 921 9999 x 7951 (work); 021 622 703 (mobile) or 0800 U BREATHE (0800 8273 2843 - free to call mobile)

Project Supervisor Contact Details:

Dr. Nadia Charania

Nadia.charania@aut.ac.nz

09 921 9999 x 7659

Dr. Sarah Mooney

samooney@aut.ac.nz

09 921 9999 x 6208

8.6 Appendix F

Researcher Safety Protocol

Researcher Safety Protocol

*Project title: **The experiences of accessing health care for families of children with bronchiectasis in Counties Manukau District Health Board, New Zealand: A qualitative study.***

*Researcher: **Nicola Jepsen***

*Research supervisors: **Dr. Nadia Charania, Dr. Sarah Mooney***

This protocol will be utilised when the primary researcher is conducting interviews in a potentially risky location, away from Middlemore Hospital or AUT, for example at a participant's home. The researcher will comply with all policies and procedures set out below to ensure her safety in these situations.

Policies

- If possible, the researcher will arrange to complete interviews in a safe public location, for example at Middlemore Hospital or at AUT.
- Interview locations will be agreed upon by both the researcher and the participant.
- The researcher will only arrange an interview in an environment she is comfortable with.
- The researcher will carry her cell phone on her person at all times.
- Both research supervisors will be notified of the exact date, time and location of the interview prior to the interview taking place.

Procedures

1. Prior to the day of the interview taking place, the researcher will inform both of her supervisors of the time and location of the interview. One of the supervisors will indicate that they are available to be contacted on the day of the interview.
2. On the day of, and immediately prior to the interview, the researcher will contact the nominated supervisor by text message or phone call to indicate that she will be meeting the interviewee shortly.
3. Immediately following the interview, the researcher will contact the nominated supervisor by text message or phone call to indicate that she has exited the interview.
4. If anything happens during the interview that makes the researcher uncomfortable, she will cease the interview and leave the environment. She will notify her supervisor, or, if necessary, call emergency services using her cell phone.

8.7 Appendix G Consent Form



Consent Form

Project title: *The experiences of accessing health care for families of children with bronchiectasis in Counties Manukau District Health Board, Auckland, New Zealand: A qualitative study.*

Project Supervisor: *Dr. Nadia Charania, Dr. Sarah Mooney*

Researcher: *Nicola Jepsen*

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 30 May, 2016.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- ☐ I understand that participation in this research will not affect the health care I, or my child, receive in any way.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a summary of the research findings (please tick one): Yes ☐ No ☐

Participant's signature:

Participant's name:

Date:

**Approved by the Auckland University of Technology Ethics Committee on 26 July 2016, AUTECE
Reference number 16/252.**

8.8 Appendix H

Participant Demographic Information Form

Demographic Form - Caregiver*For use by research members only*

Study Participant Number: _____

Date: _____

- 1) Child's age: _____

- 2) Your age at your last birthday: *(please circle one)*
 - a. 18 - 29 years
 - b. 30 - 39 years
 - c. 40 - 49 years
 - d. 50 - 59 years
 - e. 60 years and over

- 3) Your sex: *(please circle one)*
 - a. Female
 - b. Male

- 4) Ethnicity: *(please circle as many as apply)*
 - a. Māori
 - b. Pacific Peoples *(please specify)*: _____
 - c. Asian *(please specify)*: _____
 - d. Middle Eastern, Latin American, African *(please specify)*: _____
 - e. European *(please specify)*: _____
 - f. Other ethnicity *(please state)*: _____

- 5) What area (suburb) do you live in? _____

- 6) Family type: *(please circle one)*
 - a. Couple with child(ren)
 - b. One parent with child(ren)
 - c. Other *(please state)*: _____

- 7) Household composition: *(please circle one)*
 - a. One-family household
 - b. Two or more family household
 - c. Other multifamily household
 - d. Other *(please state)*: _____

- 8) Approximate annual household income: (*please circle one*)
- a. Less than \$25,000
 - b. \$26,000 - \$50,000
 - c. \$51,000 - \$75,000
 - d. \$76,000 - \$100,00
 - e. More than \$100,000
- 9) How many times has your child visited the doctor (GP) for their breathing in the last year?
- a. None
 - b. 1 – 3
 - c. 4 – 10
 - d. More than 10
- 10) Approximately how much does your GP charge per visit?
- _____
- 11) How many times has your child been admitted to hospital because of their breathing in the last year?
- a. None
 - b. 1 – 2
 - c. 3 - 4
 - d. 5 or more

8.9 Appendix I
Confidentiality Agreement: Transcriber

Confidentiality agreement for transcriber

Project title: ***The experiences of accessing health care for families of children with bronchiectasis in Counties Manukau District Health Board, Auckland, New Zealand: A qualitative study.***

Project Supervisor: ***Dr. Nadia Charania***

Researcher: ***Nicola Jepsen***

- ☐ I understand that all the material I will be asked to transcribe is confidential.
- ☐ I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- ☐ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature:

Transcriber's name:

Transcriber's Contact Details:

.....

Date:

Project Supervisor's Contact Details:

Dr. Nadia Charania

Nadia.charania@aut.ac.nz

09 921 9999 x 7659

Approved by the Auckland University of Technology Ethics Committee on 26 July 2016, ATEC Reference number 16/252.

Note: The Transcriber should retain a copy of this form.

8.10 Appendix J

Mind maps showing evolution of themes

This appendix includes two initial mind maps (Figures J1 and J2), created directly from the data. Figure J3 synthesises ideas from the initial mind maps and shows early development of themes. Two themes have been selected and their development and final representation are shown in greater detail in Figures J4 and J5.

Figure J1: Initial mind map arising from thematic analysis

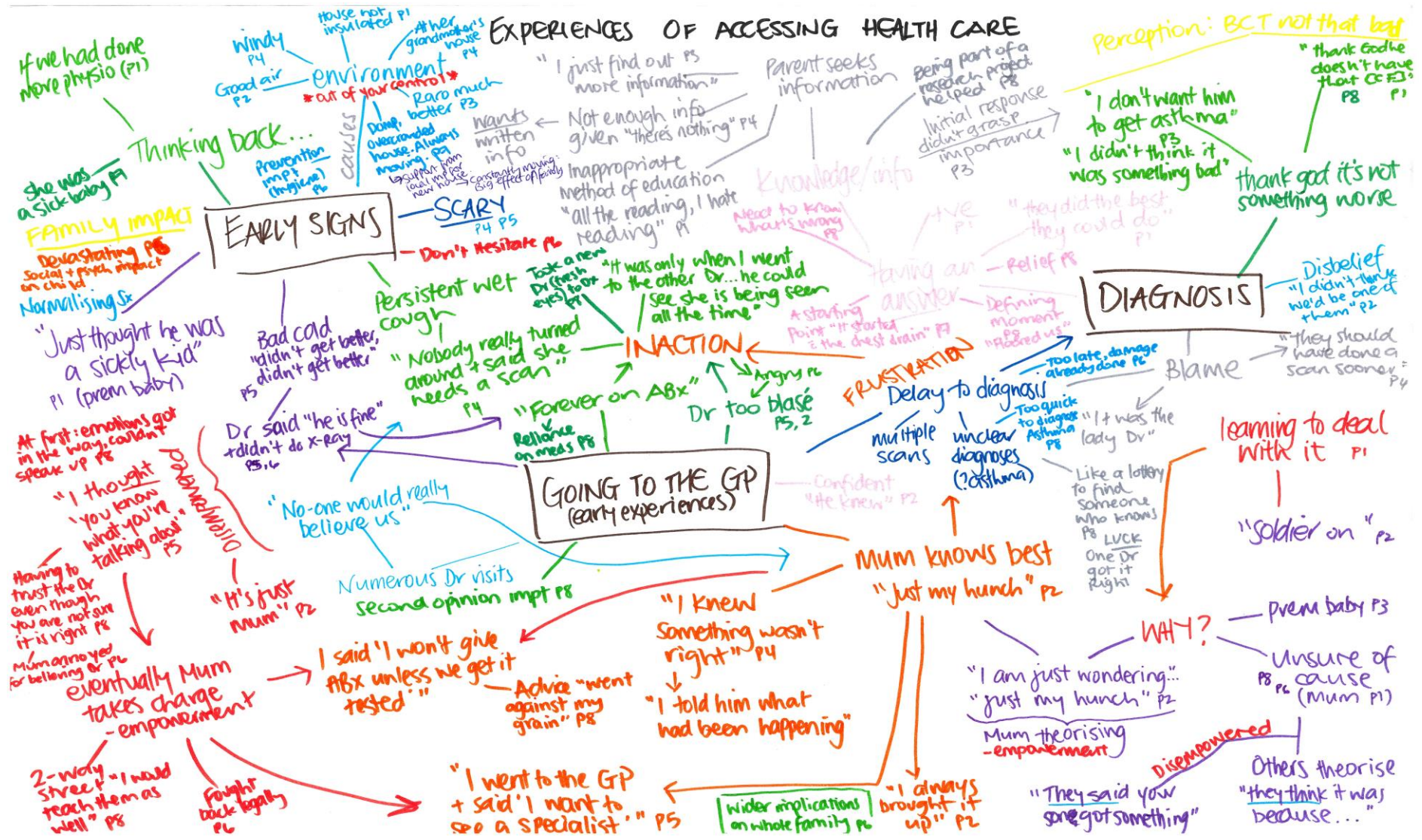


Figure J2: Continuation of initial mind map arising from thematic analysis



Figure J3: Developed mind map showing early development of themes

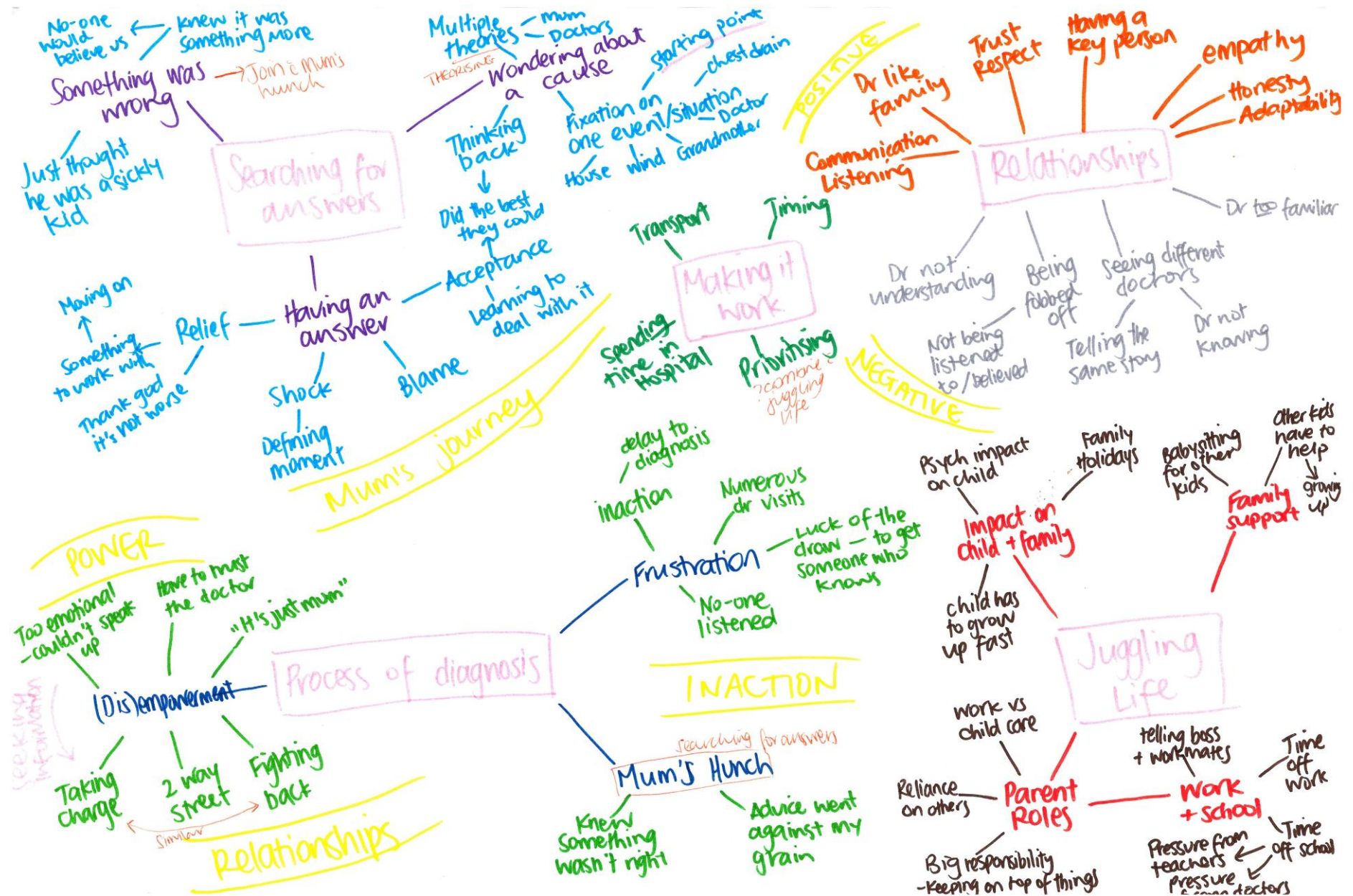


Figure J4: Developed mind map showing development of two selected themes

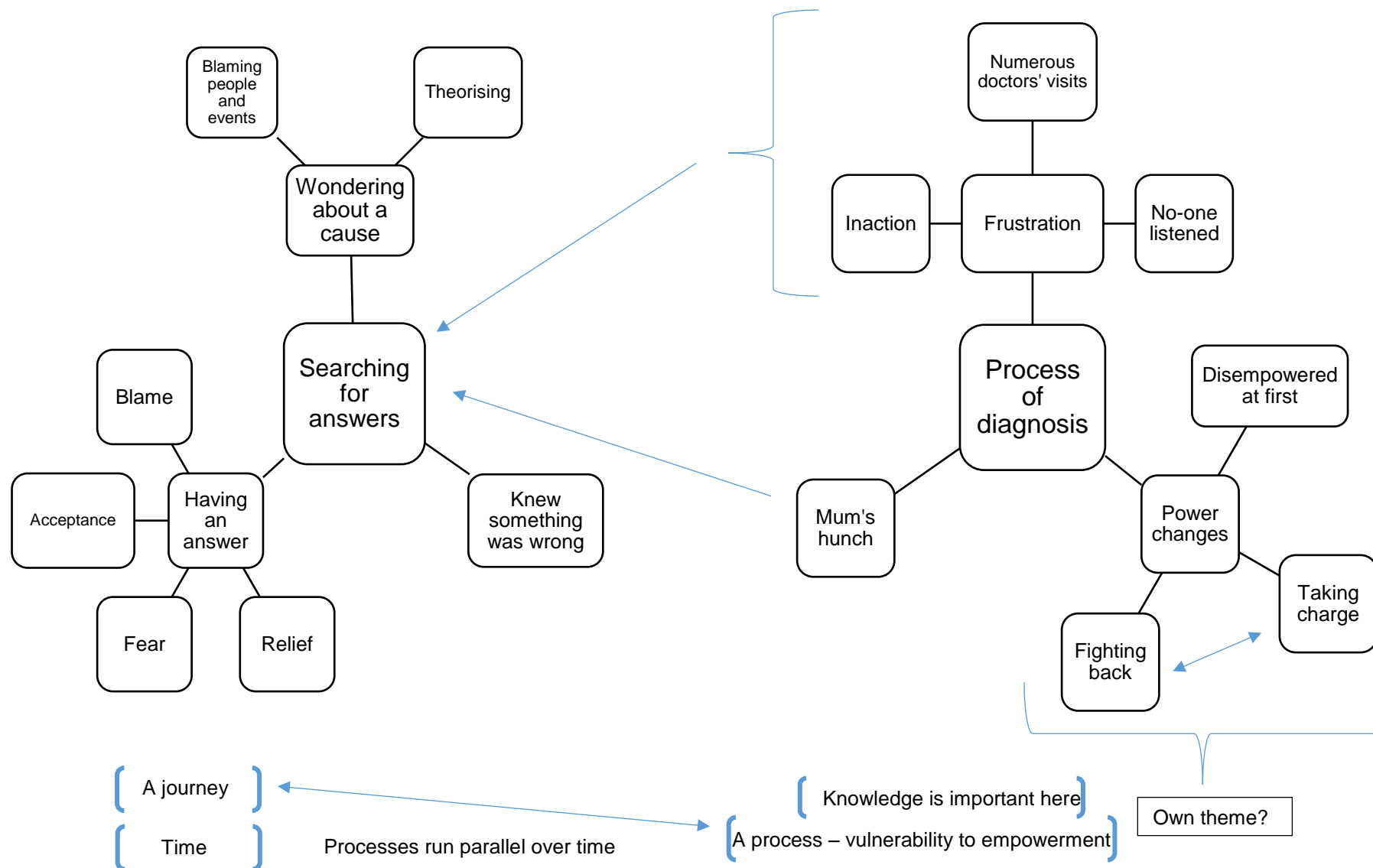
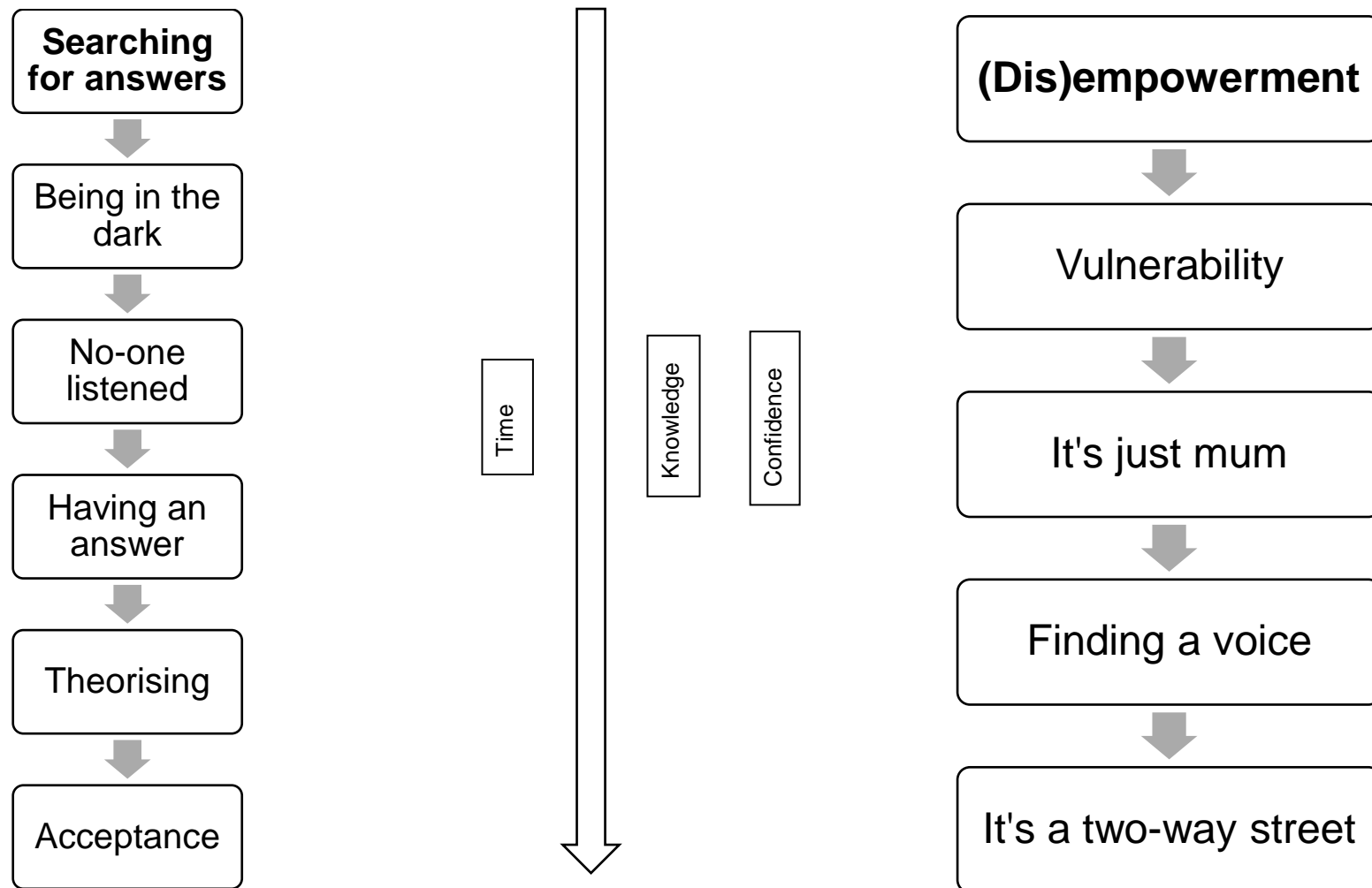


Figure J5: Final representation of two selected themes



8.11 Appendix K

Initial code book

Category (bold) • Codes	Description
Searching for answers	Prior to diagnosis, mum is wanting to know what is wrong with her child. Also anything about mum knowing something was wrong - having a hunch. At the time of diagnosis, feelings around finally having an answer
• Mum's hunch	Knowing something was wrong but others didn't see / believe it
• Theorising	Wondering about a cause - mum thinks of what the cause may be. Events/ situations/ people that may have triggered / caused the illness.
• Having an answer	Feelings around the defining moment of diagnosis, including feelings of blame.
• Acceptance	Learning to deal with it, accepting the diagnosis
(Dis)empowerment	Anything about power changes, mum finding her voice and relationships with power at play (e.g. between doctor, teacher, etc).
• It's a 2-way street	Any situation in which there seems to be mutual respect between mum and health care professional
• Vulnerability	Any situation where mum does not feel she knows enough or is brave enough to stand up to the doctor / suggest a different course of action (having to trust the doctor). Also any situation in which mum feels vulnerable.
• It's just mum	Any situation in which mum feels belittled by the doctor (i.e. they do not respect her opinion)
• Taking charge	Any situation where mum starts to take control of the situation and gains power and confidence
Inaction	Situations in which mum is frustrated at the lack of action by health care professionals, leading to delayed diagnosis
• No-one listened	Descriptions of health care professionals not hearing mum's concerns
• Luck of the draw	Finding one person who finally listened / suggested bronchiectasis as a diagnosis
• Numerous doctors' visits	Descriptions of going to the doctor again and again and getting nowhere
Making it work	Practical solutions to potential barriers/ you just make it happen somehow
• Prioritising health problems	Prioritising of health problems - if child has multiple health problems, which is the priority?
• Transport or distance as an inconvenience	Anything about physically getting to appointments
• Time	Anything about timing of appointments and things that make it harder or easier. Also finding time to go to the GP, etc. Also the inconvenience of waiting, spending a long time in hospital, etc.

<ul style="list-style-type: none"> Financial barriers and enablers 	Enablers may be community services card, work, etc. Barriers - real or potential
Relationships with health care professionals <ul style="list-style-type: none"> Positive relationships Negative relationships 	<p>Anything about forming a relationship with a health care professional - both positive and negative</p> <p>Good relationship experiences; attributes that are important in a health care professional</p> <p>Negative interpersonal experiences; difficulty forming relationships (e.g. seeing different doctors all the time)</p>
Juggling health care with life <ul style="list-style-type: none"> Family support enables access Juggling work and school Family impact Changing parent roles Health care hard to manage 	<p>Trying to juggle multiple things at once and fitting child's health care into that</p> <p>Anything about having support from other family members - other children included</p> <p>Any experiences where mum has had to negotiate challenges with the work place or taking time off work; challenges with taking child out of school</p> <p>Includes psychological / social impact on child; impact on family dynamics and family relationships</p> <p>Anything about parents having a different role because of the BCT; different roles that two parents may have; taking on the responsibility of child care and health care for the child</p> <p>Descriptions about the challenges of keeping on top of the illness or being unable to get well</p>

8.12 Appendix L
Audit trail example

Theme and codes	Explanation	Notes	Final theme and subthemes
Positive relationships			Health care and relationships
Familiarity	Parents like having familiar health providers but they can't be <i>too</i> familiar	Could incorporate unfamiliarity from below – 2 sides of the same coin	Communication <ul style="list-style-type: none"> - Both positive and negative - Includes communication between parent and health provider and also between providers
Important attributes	Trustworthy, friendly, helpful	Elements that could be incorporated into other themes	
Communication	Health providers who are willing to take calls / emails, talk to the child too	Openness is important. Comes up a lot.	Familiarity <ul style="list-style-type: none"> - Having familiar health providers - Include the opposite experience – seeing different people all the time (negative experience) - Also: being <i>too</i> familiar
Efficiency	Health providers who get tests etc. done in a timely manner, who are helpful	Could merge with going the extra mile	
Going the extra mile	Health providers who do extra things like fill out forms	Usually an individual who is extra helpful	
Key person	One person - continuity	People like having one person to guide their care	Going the extra mile <ul style="list-style-type: none"> - Positive relationships when health providers go out of their way to help
Negative relationships		Opposite of positive relationship items - maybe merge into one big theme	
Unfamiliarity	Seeing different doctors all the time	Merge with familiarity	Not feeling confident <ul style="list-style-type: none"> - Feelings or experiences that reduce confidence in health provider
Feeling belittled	Parents feeling like health care provider puts them down	Only 3x entries. Merge with vulnerability sub-theme (part of (dis)empowerment theme)	
Poor communication	Telling the story all over again	Merge with communication – opposite experiences	

Bad experiences	One experience results in long-lasting negative feelings, e.g. Misdiagnosis or unpleasant hospital admission	Sometimes people describe a feeling rather than an experience - maybe re-code 'not feeling confident' or 'not feeling welcome'	
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8.13 Appendix M

Letters of Ethical Approval



AUTEC Secretariat

Auckland University of Technology
D-88, WU406 Level 4 WU Building City Campus
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

26 July 2016

Nadia Charania
Faculty of Health and Environmental Sciences

Dear Nadia

Re Ethics Application: **16/252 The experiences of accessing health care for families of children with bronchiectasis in Counties Manukau District Health Board, New Zealand: A qualitative study.**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 25 July 2019.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 25 July 2019;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 25 July 2019 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,



Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Nicola Jepson, njepson@aut.ac.nz

Dear Nicola Jepsen (CMDHB),

Application Registration Number: 129

Ethics Reference Number (if applicable): N/A

Application Title: The experiences of accessing health care for families of children with bronchiectasis in Counties Manukau District Health Board, New Zealand: A qualitative study

I am pleased to inform you that the CM Health Research Office has approved this project with you as the CM Health Co-ordinating Investigator.

Your project is approved until 31 Dec 2017 or as specified on your ethics approval letter.

For amendments or extensions please contact the Research Office.

For research, you are required to complete and upload a final report template. Please note your final report will be available to all CMDHB employees.

If you wish to view your application please click on the following link:

[Click to view application](#)

We wish you well in your project.

Yours Sincerely

Dr Shamshad Karatela

Research Manager

Counties Manukau Health

*Under delegated authority from CM Health Research Committee and
Director of Hospital Services*



24th July 2016

Teena koe Nicola,

Ngaa mihi rangatira mo ouu whakaaro ki teenei kaupapa rangahau Hauora

Re: The experiences of accessing health care for families of children with bronchiectasis in Counties Manukau District Health Board, Auckland , New Zealand: A qualitative study.

The CMDHB Maaori Research Review Committee (MRRC) has appreciated the opportunity to engage with you regarding the relevance of this research.

The committee **approves** and is able to support your research study with guidance regarding a Te Ao Maaori perspective and Maaori Kaupapa to be conducted in the auspices of CMDHB.

Please do not hesitate to contact us should you require any further support..

We wish you every success in your research study and would appreciate a copy of your outcomes when completed.

Kia piki te ora

A handwritten signature in blue ink, appearing to read "D. Hall".

Devi Ann Hall

Chair

Maaori Research Review Committee

DDI: 09 262 9576 Mob: 021 2215 225

DDI: +64 9 262 9576

AUTEC Secretariat

Auckland University of Technology
D-88, WU406 Level 4 WU Building City Campus
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics



15 September 2016

Nadia Charania
Faculty of Health and Environmental Sciences
Dear Nadia

Re: Ethics Application: **16/252 The experiences of accessing health care for families of children with bronchiectasis in Counties Manukau District Health Board, New Zealand: A qualitative study.**

Thank you for your request for approval of an amendment to your ethics application.

The minor amendment to your ethics application allowing the addition of a short demographic questionnaire has been approved by the Chair of AUTEC.

I remind you that as part of the ethics approval process, you are required to submit the following to the Auckland University of Technology Ethics Committee (AUTEC):

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 25 July 2019;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 25 July 2019 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,



Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Nicola Jepson , njepson@aut.ac.nz

AUTEC Secretariat

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22 February 2017

Nadia Charania
Faculty of Health and Environmental Sciences
Dear Nadia

Re: Ethics Application: **16/252 The experiences of accessing health care for families of children with bronchiectasis in Counties Manukau District Health Board, New Zealand: A qualitative study.**

Thank you for your request for approval of an amendment to your ethics application.

The minor amendment to the inclusion criteria for an extension of the age range of the children is approved.

I remind you that as part of the ethics approval process, you are required to submit the following to the Auckland University of Technology Ethics Committee (AUTEC):

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 25 July 2019;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 25 July 2019 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,



Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: njepsen@aut.ac.nz; sarahmooney@freenet.co.nz

AUTEC Secretariat

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www.aut.ac.nz/researchethics



3 May 2017

Nadia Charania
Faculty of Health and Environmental Sciences
Dear Nadia

Re: Ethics Application: **16/252 The experiences of accessing health care for families of children with bronchiectasis in Counties Manukau District Health Board, New Zealand: A qualitative study.**

Thank you for your request for approval of an amendment to your ethics application.

The minor amendment to the inclusion criteria (extension of the include age range of the child participant) has been approved.

Note: Persons 16 years or older may consent for themselves.

I remind you of the Standard Conditions of Approval.

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: <http://www.aut.ac.nz/researchethics>.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. If the research is undertaken outside New Zealand, you need to meet all locality legal and ethical obligations and requirements.

For any enquiries, please contact ethics@aut.ac.nz

Yours sincerely,



Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: , njepsen@aut.ac.nz; sarahmooney@freenet.co.nz

AUTEC Secretariat

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28 June 2017

Nadia Charania
Faculty of Health and Environmental Sciences
Dear Nadia

Re: Ethics Application: **16/252 The experiences of accessing health care for families of children with bronchiectasis in Counties Manukau District Health Board, New Zealand: A qualitative study.**

Thank you for your request for approval of an amendment to your ethics application.

The minor amendment to the recruitment protocols to include snowball sampling is approved.

I remind you of the Standard Conditions of Approval.

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>.
3. Any amendments to the project must be approved by AUTEK prior to being implemented. Amendments can be requested using the EA2 form: <http://www.aut.ac.nz/researchethics>.
4. Any serious or unexpected adverse events must be reported to AUTEK Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEK Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEK grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. If the research is undertaken outside New Zealand, you need to meet all locality legal and ethical obligations and requirements.

For any enquiries please contact ethics@aut.ac.nz

Yours sincerely,



Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: njepson@aut.ac.nz; sarahmooney@freenet.co.nz