

**What are the factors affecting patients with diabetes in regards to their attendance and non-attendance with Diabetes Nurse Led Clinics in Counties Manukau Health?**

A portfolio submitted in partial fulfilment of the requirements for the degree of  
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## **Abstract**

### **Background**

Patient engagement is a crucial part of healthcare provision. It is vital to identify what exactly people with DM need from their healthcare providers. Since NZ has a public funded health system, which utilizes funds generated from its population for its population, to help them manage their health conditions. Thus, it was considered important to explore the factors associated with patients, in regards to their uptake of offered healthcare services. To study this problem, initially an extensive literature review was undertaken, which confirmed an existing gap in national literature and revealed the compelling need for the proposed research in CMH, SA.

### **Objectives**

To report the extent of attendance and non-attendance with DNLCs and explore the patients' perspectives associated with their attendance. To examine whether patients perceive any benefit by attending the clinics. To identify factors that might improve patients' experiences with DNLCs.

### **Method**

A mixed methods approach was utilized to report the extent of the problem and identify the associated factors. Two regions of DNLC provision were selected including Botany and Mangere DNLCs. Qualitative methods involved a retrospective audit for a period of twelve months from 25 March 2016 to 25 March 2017, which included eight DNLCs with 707 patients who were given booked appointments with DNLCs. a descriptive and inferential numeric analysis was utilized. This was followed by a nested sampling approach from two randomly selected DNLCs, where 71 participants were invited and only fourteen agreed to under three levels of attendance. Qualitative data analysis involved descriptive and thematic text analysis.

## **Results**

The quantitative research confirmed the overall extent of attendance and non-attendance as 65% and 35% respectively. This extent varied significantly for age, ethnicity, NZDI, geography and hospital admissions, with patient's attendance (p-value < 0.001). Patients' enrolment with the PPC program, the extent of complications and gender, has non-significant associative factors with patients' attendance and non-attendance. This research has also highlighted, that the duration of DM, initial advice from health professionals, health literacy and self-motivation influences patients' decision making to attend. This study has confirmed 100% patient satisfaction amongst attenders. Patients perceived seeing DNSs as a facilitator to attendance as presented in the literature review, with emerging themes including; *motivation and empowerment, raising health literacy, seeking confirmation and guidance is important and perception of individualized care*. This research has also highlighted the factors and perceived barriers associated with non-attendance, which were categorized under emerging themes of *psychological, social and economic factors*. Areas for improvement were identified, which highlighted patient and clinic related factors, from which recommendations were made. The need to expand the DNS role, with a wider scope to NP persists. In addition, improvement and advertisement of the referral process and patient friendly administrative measures are required.

## **Conclusion**

This research has identified complex factors related to DM self-management and care provision, where new ways of thinking are required to potentially reduce the health in-equalities, raise patient health literacy to promote patient activation and patient engagement, which in return will improve patient health outcomes.

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## Contents

Abstract.....	i
Acknowledgements.....	iii
List of Tables and Figures.....	vii
Chapter 1 Introduction .....	1
1.1 Introduction to the Research portfolio.....	1
1.2 Intended Research Question .....	1
1.3 Background to the research problem .....	2
1.4 Purpose of the study.....	9
1.5 Research Question .....	11
1.6 Existing gap in literature review .....	12
1.7 Summary .....	12
Chapter 2: Literature Review.....	13
2.1 Introduction.....	13
2.2 Background.....	13
2.3 Statement of purpose of literature review .....	14
2.4 Methods of literature search.....	14
2.5 Findings of Literature Review .....	15
2.6 Discussion on literature findings .....	32
2.7 Gap in literature .....	33
2.8 The influence of the literature review on the research project.....	34
2.9 Limits of this literature review.....	34
2.10 Summary of this chapter .....	35
Chapter 3: Research Methods .....	36
3.1 Introduction.....	36
3.2 Research Approach .....	38
3.3 Research Design.....	44
3.4 Setting .....	45
3.5 Participants.....	46
3.6 Sampling Strategy.....	46
3.7 Sample Size.....	48
3.8 Patient recruitment strategy .....	49
3.9 Inclusion and exclusion Criteria .....	51
3.10 Data Collection .....	52
3.11 Data Analysis .....	54

3.12 Ethical Considerations .....	55
3.13 Summary of chapter three .....	56
Chapter 4: Quantitative results.....	57
4.1 Introduction.....	57
4.2 Rate of attendance.....	57
4.3 Demographic characteristics of the study participants .....	59
4.4 Comparison between two regions of service provision with logistic regression analysis .....	66
4.5 Attendance under three levels of attendance - incidental finding of gaps in administration system .....	74
4.6 Summary of Quantitative findings.....	77
4.7 Conclusion .....	77
Chapter 5 Qualitative results.....	78
5.1 Introduction.....	78
5.2 Demographic Data .....	78
5.3 Psycho–socio-economic factors.....	83
5.4 Perceived barriers and facilitators to attendance .....	106
Summary of Section 5.4.....	114
5.5 Participants’ response for potential pre-conceived barriers.....	114
5.6 Diabetes Service Provision .....	116
5.7 Management of referrals to diabetes service, administrative roles and its influence on patients’ expectations – all three levels.....	125
5.8 Summary of qualitative results .....	133
5.9 Conclusion of this chapter .....	134
Chapter 6: Mixed Methods Results: the integration of quantitative and qualitative results .....	135
6.1 Introduction.....	135
6.2 Current extent of attendance and non-attendance and associated factors....	135
Chapter 7: Discussion .....	140
7.1 Introduction.....	140
7.2 Current level of engagement.....	140
7.3 Psycho-Socio-Economic Position of people with Health inequalities.....	142
7.3.1 Geography Matters.....	142
7.3.2 Influence of NZDI as a marker of socio – economic deprivation.....	143
7.3.3 Social and environmental impacts .....	146
7.4 Ethnicity .....	148
7.5 Influence of migration.....	151
7.6 Initial advice on Carbohydrates as a signal to change – do people like it? .	155

7.7 Personal Attributes .....	159
7.8 Role of in-formal support from family and friends .....	162
7.9 Health Literacy and self-activation .....	163
7.10 Role of initial emotions and experience of DM complications influences engagement .....	164
7.11 Service Provision – Patient and Clinic related factors .....	166
7.12 Administrative gaps in service provision.....	166
7.13 Correspondence Failure .....	167
7.16 Conclusion .....	168
Chapter 8 Portfolio Conclusions and Recommendations .....	169
8.1 Introduction.....	169
8.2 Strengths of the study design .....	169
8.3 Limitations of the study design.....	169
8.4 Portfolio Conclusion .....	170
8.5 Recommendations to promote patient engagement .....	171
8.6 Opportunities for future research .....	172
Appendix 1 – Interview Tool.....	184
Appendix 2 – Letter from Counties Manukau Health .....	188
Appendix 3 – CMH Research Office Confirmation .....	189
Appendix 4 – University of Auckland Human Participants Ethics Committee Approval .....	190
Appendix 5 – Participant Information Sheet .....	191
Appendix 6 – Consent Form.....	195

## List of Tables and Figures

Table 1 DHB domicile of European/Other, Indian, Māori, and Pacific people with DM .....	3
Table 2 Summary of findings from the UKPDS, DCCT, EDIC, ACCORD, Kumamoto study and ADVANCE study in reducing the risk of complications (McCulloch et al., 2012) .....	9
Table 3 The nested sample size of the randomly selected DNLCs.....	48
Table 4 Attendance rate among DNLCs in two regions of service provision (Botany and Mangere) .....	59
Table 5 The demographic characteristics of the study participants .....	60
Table 6 Other factors associated with rates of attendance .....	63
Table 7 Chi square test to assess the difference in significance among number of hospital admissions .....	65
Table 8 Attendance rates between two regions of DNLC service provision for each covariate .....	71
Table 9 Other factors associated with attendance of patients .....	72
Table 10 Odd ratios with 95% Confidence interval from the unadjusted and adjusted logistic regression model showing the likelihood of attendance for Botany and Mangere DNLCs .....	73
Table 11 Chi square test to assess the difference in significance among ethnicity characteristics.....	74
Table 12 Sub categorisation of attendance rates into three sub groups and logistic regression table .....	76
Table 13 Age, Gender and unique identifier of participants in three levels .....	79
Table 14 Employment status of participants.....	82
Table 15 Education status of participants .....	82
Figure 1 Ethnicity specific prevalence of dysglycaemia among males in the Auckland region in 2010 by age factor (Chan et al., 2014) .....	4
Figure 2 Strict glycaemic control slows progression of retinopathy .....	8
Figure 3 Factors influencing the choice of paradigm (Chilisa & Kawulich, 2012).....	39
Figure 4 Research methodology in the convergence of three factors influencing the research paradigm choice (Chilisa & Kawulich, 2012) .....	40
Figure 5 Categorisation of attendance in three different levels .....	49
Figure 6 Participants in each level of attendance from both regions .....	51
Figure 7 Challenges faced during the recruitment process .....	51
Figure 8 Attendance rate of Botany and Mangere DNLCs.....	58
Figure 9 Overall attendance rates among DNLCs in two areas of service provision from CMH.....	59
Figure 10 Males attends more offered appointments as compared to females .....	62
Figure 11 Enrolment of participants with PPC .....	64
Figure 12 Overall relation of attendance with hospital admissions .....	65
Figure 13: Hospital admission with acute complications and attendance rate .....	66
Figure 14 Three subgroups representing number and level of attendance in both regions.....	74
Figure 15 Country of birth of participants .....	81
Figure 16 Participants' perception about support with DM self-management .....	92
Figure 17 Participants understanding and their insights towards DM.....	103

Figure 18 Readiness to make lifestyle changes enhances attendance.....	104
Figure 19 Barriers for non-attendance verbalised by Level 2 participants .....	111
Figure 20 Participants responses for pre-conceived barriers .....	115
Figure 21 Feedback from Level 1 participants .....	119
Figure 22 Feedback on areas of improvement by levels 2 and 3 participants .....	124
Figure 23 Expression of non-attendance by level 2 participants .....	127
Figure 24 Correspondence from the scheduler team of Whitiora Diabetes Service..	129
Figure 25 Source of referral to Whitiora Diabetes Care .....	131

## **Chapter 1 Introduction**

### **1.1 Introduction to the Research portfolio**

The lead researcher of this portfolio is an accredited clinical nurse specialist in diabetes mellitus (DM) with advanced clinical assessment and designated nurse prescribing skills. This portfolio is from the researcher's passion to learn and to utilize knowledge gained in daily clinical practice. The theoretical purpose of this portfolio is to fulfil the final requirement to complete Masters in Nursing. The practical purpose of this portfolio is to explore an existing problem, which seems to affect people living with DM, their health outcomes, their whanau, their healthcare providers and their nation. The lead researcher conducts two DM nurse led clinics (DNLCs) as part of her role with Whitiora DM service for secondary care under Counties Manukau Health (CMH). The lead researcher has anecdotally observed a distinct difference in expression of attendance and non-attendance by patients between two geographical regions; Mangere and Botany. This prompted the researcher to explore the exact extent of the problem and the factors associated with the research problem. Therefore, the below mentioned topic was chosen

### **1.2 Intended Research Question**

What matters to our patients with DM in regards to their attendance and non-attendance with DNLCs in the Counties Manukau region?

### **1.3 Background to the research problem**

#### ***1.3.1. Alarming prevalence of DM***

The prevalence of DM, particularly type 2 diabetes (T2DM), but also type 1 diabetes (T1DM), is increasing at a rapid pace throughout the world (Krug, 2016). New Zealand (NZ) is also following these same trends, of growing prevalence as observed worldwide (Warin, Exeter, Zhao, Kenealy, & Wells, 2016). According to a most recent study, the current estimated population of NZ is more than 4 million, out of which 1.5 million people are living in the Auckland region, contributing to about one third of the total national population (McLeod, 2018)

The Auckland region has the most diverse ethnic population. After NZ Europeans, there are significant numbers of people from Māori, Pacific and South Asian ethnic origins. In relation to the estimated national prevalence of DM, the prevalence of DM remains higher in the Auckland region (Warin et al., 2016). The prevalence of DM in Auckland further varies significantly from North Auckland, with a prevalence rate of 3.2%, to South Auckland (SA) with 17.3% (Smith, Papa, & Jackson, 2008; Warin et al., 2016). It has been proposed that this disparity in prevalence rate, is influenced by ethnic diversity, health inequalities and deprivation factors among the population living in the South Auckland region (Smith et al., 2008).

#### ***1.3.2. CMH serves the highly prevalent population***

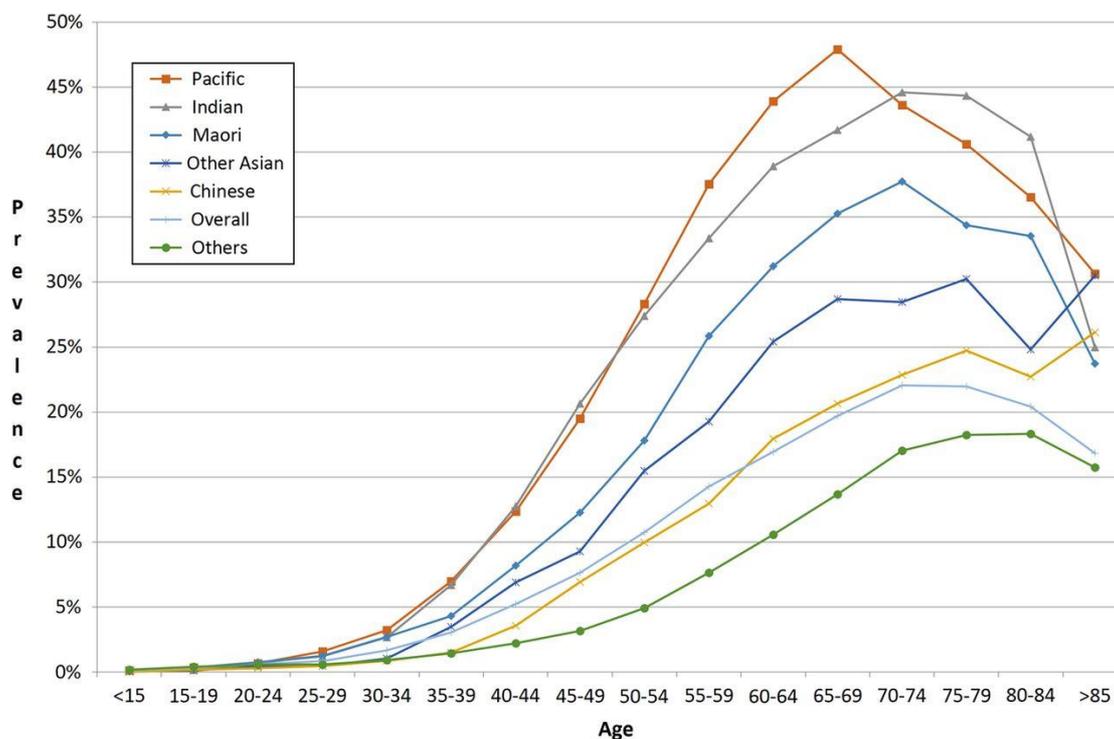
The alarming burden of DM in South Auckland (SA) remains a serious matter of interest, especially for CMH which serves this multiethnic population with the highest prevalence of DM (Warin et al., 2016). The Virtual DM Register statistics (New Zealand Society for the study of Diabetes, 2016) confirms that CMH has the highest

proportion of patients with DM within Auckland and also nationally as mentioned in table 1.

**Table 1 DHB domicile of European/Other, Indian, Māori, and Pacific people with DM**

DHB	Ethnicity (n)				
	European/Other	Indian	Māori	Pacific	Total
<b>Counties Manukau</b>	15,605	5,075	5,420	14,166	40,266
<b>Auckland</b>	12,984	3,859	1,753	5,912	24,508
<b>Waitemata</b>	19,310	2,276	3,950	2,260	27,796

Research has also confirmed that the prevalence of DM is highest among Pacific Island (PI) people followed by South Asians and Māori (Silva, Clinton, Appleton, & Flanagan, 2011; Smith et al., 2008; Warin et al., 2016). The NZ Health Survey states that the prevalence of DM among Europeans is 2.9%, Māori 8%, Asians 8.4% and PI people 10.1% (Joshy & Simmons, 2006). Figure 1 illustrates the prevalence of dysglycaemia within the Auckland region, during the year of 2010, by age and ethnicity. It demonstrates that the estimated age standardised prevalence of dysglycaemia was highest among people of PI ethnicity at 11.4% among males and 11.6% among females, followed by Indian ethnicity at 10.8% and 9.3 % among males and females respectively. Māori follow a similar trend with 8.2% and 7 % of males and females respectively demonstrating dysglycaemia. Others, mainly Europeans, demonstrated a prevalence rate of 3% among males and 2.2 % among females (Chan et al., 2014).



**Figure 1 Ethnicity specific prevalence of dysglycaemia among males in the Auckland region in 2010 by age factor (Chan et al., 2014)**

However, the problem does not limit itself at the level of prevalence of DM in multiethnic population groups in the CMH region. The graph in figure 1 also highlights the significant trend of dysglycaemia at a younger age, by 10-15 years among PI, Indian and Māori ethnic groups as compared to other ethnic groups. Chan et al (2014) described dysglycaemia with an operational definition, confirming a person as having dysglycaemia if he/she has at least one HbA1c of 48mmol/mol, at least one 2 hour post prandial glucose level of 11.1 mmol/L, or at least two random blood glucose levels of more than 11.1 mmol/L. Thus, this study targeted people who already have DM and also those who need follow up review to confirm the formal diagnosis of DM. Other studies have also confirmed that the high risk population groups as described above, have a prolonged exposure to hyperglycaemia and impaired glucose and fat metabolism in their bodies, which increases their risk of developing early onset of DM, its complications and thus increasing morbidity and

mortality rates (Anderson et al., 2006; McGrath, Parker, & Dawson, 1999; Moore & Lunt, 2000). The existing literature from research has confirmed that the poor control of DM and its related risk towards DM complications is a serious burden on a patients' life and the economy of the nation (Anderson et al., 2006; Zimmet, 2003).

### ***1.3.3. Influence of migration***

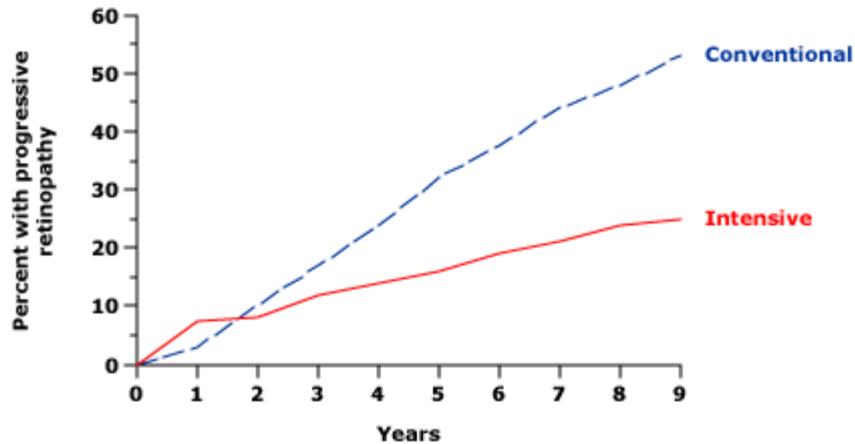
Atlantis, Joshy, Williams, & Simmons (2017) have highlighted the impact of increasing migration of people from the PIs and Asia since the Treaty of Waitangi was signed. In addition, the indigenous people of NZ have shifted from rural to urban regions of NZ. The influence of migration has exposed indigenous people of NZ, Māori and those who have migrated from the PIs and Asia, to the modern concept of westernization. Exposure to westernization has increased the availability of food and encouraged a sedentary lifestyle. These changes in lifestyle have increased the prevalence of obesity and thereby T2DM (Atlantis, Joshy, Williams, & Simmons, 2017).

### ***1.3.4. Engagement of patients with DM self-care and with health professionals matters***

It is a well-established fact that morbidity and mortality among patients with DM in comparison to the general population remains higher, due to microvascular and macrovascular complications. Patients with DM require twice the healthcare dollar to manage their health than those without DM, due to DM related complications particularly cardiovascular disease (CVD), renal disease, eye and peripheral vascular disease (PVD) (Zimmet, 2003). Hence, it is highly important to assess patients with DM for their risk towards complications, with ongoing assessment, examination and evaluation.

In T2DM, disease onset can be insidious and patients' remain asymptomatic for a longer duration, hence diagnosis of the disease is often delayed. During that course of delay, the body is already going through patho-physiologic changes where organs become susceptible to damage. Though the risk of complications remains high among patients with DM, having individualised appropriate assessment and management plans in place, can slow the progression of those complications. Standards of Medical Care in DM reviewed the management approach in 2017 considering the American DM Association guidelines for DM management and prevention of DM related complications (American Diabetes Association, 2017), during which McCulloch reviewed the importance of regular DM checks for DM management, to slow the progression of DM related complications. He found the following essential: history taking, physical examination including foot examination, cardiovascular risk assessment and prediction, monitoring of laboratory findings including glycated haemoglobin, lipid profile, urine albumin/protein excretion, serum creatinine; and routine eye examination for DM retinopathy and macular disease. McCulloch concluded that appropriate individualised interventions can limit the progression of organ damage, by achieving glycaemic control targets which can minimise or delay the progression of retinopathy, nephropathy and neuropathy. Cardiovascular morbidity is one of the major health challenges among patients with DM. Individualised aggressive management of glycaemic control, and co-existing metabolic disturbances in blood pressure and lipid profiles can significantly reduce the risk of cardiovascular morbidity, which can improve a patients' quality of life and the burden of cardiovascular morbidity cost to the nation's economy.

The DM Control and Complications Trial Research group (DCCTGroup, 1993) conducted a randomised clinical trial at 29 multi-medical centres in the United States and Canada, where patients were recruited during the period of 1983 – 1989. The inclusion criteria were patients with Insulin dependent DM between the ages of 13 to 39 years, having duration of DM of 1 to 15 years, with either no or early signs of DM eye disease. This trial examined 1441 patients, out of which 726 patients with nil retinopathy at baseline were placed in the primary prevention cohort group and 715 patients who had mild retinopathy were assigned to the secondary prevention cohort group and were given intensive insulin treatment. A log-linear Poisson regression model was utilized to study the relationship among the risk of an event and time dependant covariate. The selected patients were followed up for the assessment of disease progression for the period of 6.5 years. This study compared the effect of standard glucose control versus multiple insulin injections with an intensive blood glucose control regimen, where glucose levels were targeted to be kept very close to normal glycaemic range. This research trial concluded that intensive therapy slowed the progression of retinopathy, nephropathy and neuropathy by 76%, 50% and 60% respectively. However, this research has also shown that the main adverse reaction of hypoglycaemia, increased by two to three fold within the insulin intensification group. Figure 2 displays the cumulative incidence of progressive retinopathy, among patients with T1DM, with very mild to moderate non-proliferative retinopathy, who were treated with either conventional (dashed line) or intensive (solid line) insulin therapy for nine years. There was an increasing benefit of intensive therapy over time, although intensive therapy was associated with transient worsening in the first year ( $p < 0.001$ ).



Data from: *Diabetes Control and Complications Trial Research Group (1993)*.

### **Figure 2 Strict glycaemic control slows progression of retinopathy**

The DCCT study ended in 1993 but the research continued to follow up about 93% of the participants, (1394 participants) for 11 years. This follow up study was then called Epidemiology of DM Intervention and Control (EDIC) Study (Nathan, 2005). The EDIC study examined the incidence and risk predictors of cardiovascular disease including, stroke, heart attack, relevant heart surgery and other DM related conditions affecting eyes, kidney and nerves. The EDIC study also examined the influence of intensive control versus standard control on quality of life. With an overall mean follow up of 17 years, the EDIC study concluded in 2005, that 31 patients who had tight glycaemic control with intensive therapy, had 46 cardiovascular disease (CVD) events as compared to 98 events among 52 patients with conventional treatment. Thus, intensive treatment lowered the CVD risk by 42% and the risk of non-fatal myocardial infarction, stroke and death from CVD by 57%. Conclusively, the EDIC study confirmed the long-term beneficial effects of tight glycaemic control on cardiovascular disease and microvascular disease.

Both the DCCT and EDIC study results have suggested the implications of prevention of DM related complications in T1DM, which can be well applied to patients with T2DM as supported with the following evidence (McCulloch, Nathan, & Mulder, 2012). Randomised clinical trials including the United Kingdom Prospective DM Study (United Kingdom Prospective Diabetes Study, 1995), the Kumamoto study (Ohkubo et al., 1995), the Action in DM and Vascular disease : Preterax and Diamicon MR controlled evaluation ( ADVANCE) trial (Group, 2008) and the action to Control Cardiovascular Risk in Diabetes ( ACCORD) (Ismail-Beigi et al., 2010) trials, have all concluded that intensive glycaemic control interventions result in improved patient outcomes, by reducing the rate of retinopathy, neuropathy, nephropathy and cardiovascular morbidity and mortality as mentioned in table 2.

**Table 2 Summary of findings from the UKPDS, DCCT, EDIC, ACCORD, Kumamoto study and ADVANCE study in reducing the risk of complications (McCulloch et al., 2012)**

Name of Study	Microvascular disease	Cardiovascular disease
UKPDS	Reduced	Reduced
DCCT/EDIC	Reduced	Reduced
ACCORD	Reduced	Reduced
Kumamoto study	Reduced	Not studied
ADVANCE	Reduced	Not studied

#### **1.4 Purpose of the study**

The above-mentioned research gives evidence that tight glycaemic control can be successfully achieved with the available treatments, which reduces the risk and can slow the progression of DM related complications. Simultaneously, the DCCT study

has highlighted an increase in events of hypoglycaemia by two to three folds, emphasising the need for ongoing assessment and medication adjustments by health professionals. Health professionals like General practitioners (GP), Endocrinologists, Diabetes Nurse Specialists (DNS) and Practice Nurses (PN) are well aware of this evidence suggested by existing research and literature. Health professionals also have governing guidelines which guide them with knowledge to manage DM, but that knowledge will only be useful if utilized for patient care and internalised by the patients.

Lack or delay in treatment and/or non-adherence with treatment or non-attendance for ongoing monitoring and management follow up, increases the risk of DM related complications, which also results in further delay of diagnosis and management of these complications among people with DM (Salas-Salvadó, Martínez-González, Bulló, & Ros, 2011). Delay or lack of treatment affects the health outcomes of patients and their whanau; therefore it is important to identify what matters to our patients in relation to them seeking help to manage their condition. Hence, instead of looking at the success of treatment including or excluding achievement of the targets, it is believed that the understanding of the nature and the extent of the problem in relation to the lived experiences of patients, would be far more beneficial for the service provision viewpoint.

Thus, the motivation for this research arises, to examine this anecdotal expression of patients' attendance and non-attendance to DNLCs, to find solid evidence of the extent of patient attendance and non-attendance. There is also a need to explore the factors associated with their attendance and non-attendance. It is important for DM

services to identify what matters to our patients, in order to tailor the service provision to meet their needs and promote their engagement in management of their condition. Considering DM is a progressive long-term condition, it is already a significant challenge for individuals who have DM and for the healthcare system with ever expanding demand. As the epidemic of DM is growing, CMH DM service needs to identify the gaps and identify better ways to engage with our patients to promote their health. When patients do not attend the offered appointments, it results in treatment delay, which may affect patients' and their families' quality of life in terms of poor health outcomes and personal costs. Non-attendance also affects the service, in terms of wastage of resources for example time, lengthening of the waiting list, cost and underutilisation of limited available resources. It is vital for Whitiora DM Service to identify and acknowledge patients' perspectives, as they are the stakeholders of our outpatient service provision. Considering the above-mentioned compelling reasons for the need for this research, the following research question was developed with the proposed aim and objectives.

### **1.5 Research Question**

What are the factors affecting patients with DM in regards to their attendance and non-attendance with DNLCs in CMH?

#### **1.5.1 Objectives**

The main objectives of the research are as follows:

1. To report the attendance and did not attend (DNA) data.
2. To explore patients' perspectives towards reasons for their attendance and/or non-attendance.

3. To explore whether patients perceive any benefit or difference by attending the clinics.
4. To identify factors that might improve patients' experiences of DNLC visits.

### **1.6 Existing gap in literature review**

The introduction provided background information about the growing prevalence of DM, the trend of growing prevalence amongst specific ethnic groups and the influence of geographical regions on the prevalence of DM nationwide and worldwide. The next chapter will confirm the identified existing gaps in current literature, which highlights the need for this research project.

### **1.7 Summary**

Chapter one presented background to the research problem and highlighted the compelling reasons for this research. This study will highlight the varying extent of the problem and feedback on Whitiora DM service DNLCs provision. The following chapter will highlight the available literature relevant to the research problem.

## **Chapter 2: Literature Review**

### **2.1 Introduction**

This chapter will describe the available literature on the research topic, the search methods undertaken to find the relevant and appropriate literature obtained from different sources. The literature review will also discuss different variables, which influence patients' engagement with health professionals for their DM management. A summary of literature review findings will then be discussed under different themes including; patient-centred care enhances patient engagement, the need for ongoing support, education and sharing knowledge, the need to empower DM patients and the disparate vision among patients and their DNSs. The influence of the literature review on refinement of the research question will also be discussed. The limitations of the literature review will be acknowledged.

### **2.2 Background**

As previously stated, DM is a growing epidemic throughout the world (Krug, 2016). The prevalence of DM in NZ is following the same growing trend as that observed worldwide (Warin et al., 2016). Counties Manukau (CM) region or SA, has the highest prevalence of DM nationally. In addition, CMH caters for the most ethnically diverse population as compared to other geographical regions of Auckland (Silva et al., 2011). Recent research has shown that the prevalence of DM varies significantly between the northern and southern regions of Auckland. The proportion of the population with DM is 3.2% in the North Shore region and 3.4% in Rodney, in contrast with 8.0% in Botany, 15.0% in Manukau and 17.3 % in Mangere (Smith et al., 2008; Warin et al., 2016). This disproportionate prevalence among different regions of Auckland undoubtedly reflects the influence of ethnic diversity, health

inequities and deprivation factors among the populations living in the CM region (Smith et al., 2008). The prevalence of DM was found to be the highest among people from PI, south Asians and Māori (Silva et al., 2011; Smith et al., 2008; Warin et al., 2016). CMH provides healthcare to the population with the highest prevalence of DM. Therefore, it is crucial for the CMH DM Service to identify what matters to our patients and what patients want from our service provision to meet their needs. Acknowledgement of patients' points of view is crucial to enable them to engage with self-care management activities, which will help patients to improve their health outcomes and help professionals to tackle the DM epidemic effectively.

### **2.3 Statement of purpose of literature review**

The intended research question aims to find evidence on the current level of engagement of adults with DM in DNLCs at CMH and to determine what matters to patients in regards to their attendance and non-attendance. To date, clinicians know only anecdotally that some patients with DM do not seem to engage with either primary care services or DNLCs to manage their DM. The purpose of this literature review reflects a critical need to investigate the expression of evidence of current engagement of patients with DM in the CMH region.

### **2.4 Methods of literature search**

A systematic comprehensive computer-assisted literature search was conducted using the databases; CINAHL Complete, CINAHL Plus, Pubmed, Medline (OvidSP) and PsycINFO. Broad search terms were used, which included; type 2 DM OR non-insulin dependent DM, AND clinical nurse specialist OR nurs\* OR nurse led clinic, AND patient engag\* OR adherence OR compliance. A total of 414 articles were

found. The next step was narrowing the search, by adding limits to make the literature search more relevant and appropriate to the research topic. The search results were reduced to 223 articles. These 223 articles were reviewed by reading the title and abstract. A total of 13 articles were identified as relevant to the intended research question. After thorough reading of these articles, nine articles were found to have the greatest relevance to the topic of research.

It was then noted that there is limited research available in relation to patients' attendance and patients' experiences with DNLCs, particularly with the population living in the CMH catchment area. The author sought expert advice from colleagues and explored grey literature. The author also checked the references of studies, which were conducted in the CMH region among patients with diverse ethnic backgrounds. The inclusion criterion for grey literature selection was mainly studies with T2DM or nurse-led clinics within NZ. These studies were not directly relevant to the research topic, but they showed some direction and awareness about the attitudes and beliefs of the target population for this research topic.

## **2.5 Findings of Literature Review**

### ***2.5.1 Crafting the themes***

An integrative review of literature was completed using the Whittemore & Knafl approach (Whittemore & Knafl, 2005), which identifies themes in relation to the proposed research question. The themes identified included: 1) patient-centred care enhances patient engagement; 2) the need for ongoing support, education and sharing knowledge; 3) the need to empower people with DM; 4) disparate vision among patients and their DNSs.

### ***2.5.2 Patient-centred care enhances patient engagement***

A recurring theme in the literature was the significance of patient-centred care as verbalised by study participants in a variety of studies (Bhattacharya, Pickering, McCulloch, Redhead, & Heald, 2007; Edwall, Danielson, & Öhrn, 2010; Edwall, Hellström, Öhrn, & Danielson, 2008; Isaksson, Hajdarevic, Abramsson, Stenvall, & Hörnsten, 2015; Lorenzo, 2013; Silva et al., 2011). The current literature clearly shows that a strong focus on patient-centred care has an impact on enhancing engagement with DNLCs.

In a Swedish study, Edwall et al (2008) interviewed 20 people with T2DM, to determine their lived experience and their interactions with nurses during DNLC appointments. This study used a phenomenological hermeneutic research method to explore patient satisfaction. It found that patient engagement with the DNLC was enhanced, when patients were kept central to the plan of care created by the DNS. Patients felt they were seen as a unique person with unique needs to self-manage their disease condition. Patients felt that the DNS acted as an expert on the disease and offered support after listening to the patient as an expert of their own life and illness. Edwall et al further investigated patients' lived experiences with DNLCs and patients' understanding of consultation with DNSs during the year of 2010. Edwall et al (2010) conducted another similar qualitative research, which also showed satisfactory results about patients' experiences of services. Patients felt their individual needs were considered when they were offered a support plan for continuity of DM stabilisation. Literature supports that such interventions can ensure effective management, while meeting the growing prevalence of DM (Edwall et al., 2010).

These studies were done at two different DNLCs in Sweden, with a similar clinical set-up to the DNLCs within CMH. However, those clinics were under the service provision of primary care, whereas CMH is secondary care. Therefore, those patients received continuous long-term care from the DNSs being primary care providers.

Whereas, in CMH clinics, we mainly serve the patients who are referred to our service with an aim to discharge them back to primary care after a certain time period. The above-mentioned research seems very relevant to the chosen research question, as the researcher explored the lived experiences of patients for their perspectives of living with DM and interaction with DNLC care. There is no clear indication about the severity of DM control mentioned in these studies, as compared to CMH clinics where mainly those patients are referred who have sub-optimal glycaemic control, evident by their laboratory results and existing complications. The research setting and research methods are similar to the proposed research question, while keeping in mind that the research participants are different being from SA a multi ethnic population.

Bhattacharya et al performed a care satisfaction audit in 2007 and used a semi-structured interview questionnaire. The qualitative method was used to compare peoples' views on two different modes of annual DM review care delivery, when led by nurses versus by doctors. The interview questionnaire was posted to 91 randomly selected individuals, who received care from a DNS by attending their DNLC as an alternative to the outpatient follow up. The research setting was in Bishop Auckland General Hospital, a provider of acute and specialist services to the northeast population of England. This audit concluded, that DNLC consultations were more

focussed on their participants' living situations and individualised needs. Whereas the doctor-led consultations were more focussed on screening for diseases, DM control, risk of complications, pharmacological management for DM and DM related established complications. The participants' perceived satisfaction was very positive about the care they received by DNLCs and the participants highlighted their perception that the nurse-led clinics were more relevant to their needs as they live with the disease of DM. The study participants expressed that the DNS acknowledged them as an individual with individualised needs in the context of their life and family (Bhattacharya et al., 2007). The participants shared their experience of being supported and empowered with DM self-management skills. They also highlighted that nurses had detailed knowledge about the disease condition and acknowledged their individual life within a family context. The study participants felt empowered to self-manage their DM and suggested the existing need to get ongoing support and the need for expansion of such hospital operated DNLCs. Patients said such a clinic would be well received and benefit the management of DM nationwide.

The above study seems very relevant to the chosen research question, as it has explored patients' opinions about the care they received. The clinical setting is similar to Whitiora DM service, in respect of acute and specialist care provision instead of being a primary care provider. However, this study has compared two different modes of service delivery; clinics led by doctors versus DNLCs. The chosen research question will not compare clinics led by doctors versus nurses. Only clinics led by DNSs will be studied and compared for certain variables, depending upon research findings. The proposed study will focus on exploring patients' perspectives from two clinics of different geographical regions under the care of CMH, which are managed

slightly different from each other in respect of administration and management processes.

Isaksson et al (2015) conducted a study with an aim to describe perceptions and associations of empowerment among DM patients, their self-management ability and assessed the need for support with self-management. The study was undertaken during the year of 2015, among people with T2DM who lived in a rural community of Northern Sweden. A total of 159 people with DM answered a questionnaire, with questions related to DM self-management and the need for ongoing support. A linear regression model was utilized to study the associations among the variables. The study highlighted that higher DM empowerment was associated with longer duration of living with DM, in those that received support with self-management from health professionals and relatives. The study has also shown that women ranked higher than men for the need of self-management support. The study highlighted that non-retired people rated a significantly higher need for self-management support than those who were retired. The study has also highlighted that those people who were living in extended families, expressed a higher perception of emotional support from relatives and involved their relatives in clinic visits, as compared to those living alone.

This study found that not only do newly diagnosed patients rate the need for support with self-management to strengthen DM empowerment highly, but also those with duration of DM of 10-15 years with established self-empowerment. This study recommended family-focussed care, education and training in a person-centred approach provided by DNSs (Isaksson et al., 2015).

The above study was conducted in a rural area of Sweden and study participants were selected from a local primary health care practice. The study setting for the proposed research question will be different, as Whitiora DM Service provides secondary care and caters mainly to urban residents with a minor proportion of rural residents. However, the limited access to support services in those from rural areas can be related to underserved communities in the multiethnic population of SA for the proposed study. Secondly, this study lacks the information on socio-economic status and education of participants, which can be an integral part when studying the associations among the selected variables. The proposed study will explore participant's education, employment and socio-economic status as independent variables, in order to examine the different associations among these variables in respect to living with DM. Thirdly, the authors are unclear whether DNSs provided the care, or whether it was a package service provision by community nurses, physicians and /or DNSs, whereas the proposed research will only interview participants who were offered appointments with DNSs to explore their perspectives towards living with DM, self-management abilities, formal and informal support, and DM empowerment regardless of their attendance.

Lorenzo (2013) further supported the need for patient-centred care, by providing a review of the best practice evidence for clinical management of DM for nurse practitioners (NP). This review highlighted the numerous models of care, with available tools and strategies to enhance patients' engagement to promote health and improve health outcomes. Lorenzo sourced the data from online search sources including Pub Med, Ovid, CINAHL and Cochrane's Database of systematic reviews. Lorenzo stated that patients have a full right to either accept or decline the offered

plan of care. Considering holistic care, respecting patients' rights and respecting their autonomy; it is crucial to plan the care that addresses patients' unique needs with their participation. Lorenzo concluded that engaged, informed and activated people with DM working in partnership with health professionals, might enhance clinical outcomes.

The above-mentioned studies were done overseas, hence the participating population differs from the proposed study's culturally sensitive population, especially in respect of the most multi-ethnically diverse and socio-economically deprived region of NZ. The study seeks to confirm that there is limited availability of literature to address cultural differences and ethnic disparities seen among the population of NZ. However, there is increasing evidence (peer reviewed, commissioned reports and anecdotal/clinical) that demonstrates that within the NZ setting, ethnic or cultural sensitivity is the most important component for achieving success in engagement with patients.

Silva et al conducted a cross-sectional study in which they applied a DM self-management education (SME) programme, during the year of 2007-2008, with an aim to evaluate this SME programme in SA, NZ (Silva et al., 2011). A total of 192 subjects participated, with an age range of 21 to 87 years old. Primary health organisations in SA employed facilitators to lead four to six patient group education sessions. While considering patients' language and cultural needs, Māori and Pacific facilitators were involved who acted as cultural interpreters and added cultural variations to the group education sessions on SME. Participants were assessed for their attitudes and behaviours towards self-management of their DM, prior to

implementation of the programme and three months post joining the programme. Quantitative data was analysed by using SPSS software. Qualitative data was gathered using a health attitude and health behaviour questionnaire and findings were analysed with thematic analysis by using NVivo software. The study results showed an improvement in attitude amongst patients towards self-care and also in their metabolic indicators of blood pressure, glycated haemoglobin results and body mass index. This study concluded that self-management education could be effective through utilisation of appropriate resources while considering patients' needs in context to sensitivity of their language and culture.

Silva et al (2011) further emphasised that psycho-social issues like beliefs and behaviours are already complex areas in relation to bringing a change; language barriers among professionals and patients may make the engagement process further complicated. This study also highlighted the fact, that resource-intensive input is a challenge when serving a multiethnic community.

This study is very relevant to the proposed research, due to the application of multiethnic diversity amongst the participating population, though they have only studied two ethnic groups; Māori and Pacific including Samoan and Tongan. This research was conducted in the primary health sector, whereas the proposed study setting will be secondary care. The focus of the study was group sessions for self-management of DM, whereas for the proposed research the focus will be care provided by DNLCs. In context to addressing the psycho-social issues, this research seems relevant because amongst socio-economically deprived populations, it's almost

impossible to engage people and work in partnership, without acknowledging their individual psycho-social needs in context to enhance the self-management of DM.

### ***2.5.3 Need for ongoing support, education and sharing knowledge***

The literature review supports that those patients with long-term conditions, require ongoing support to encourage them to make lifestyle changes and to remain motivated (Edwall et al., 2010; Edwall et al., 2008; Isaksson et al., 2015). This was further supported by Lorenzo (2013) who described an adaptation process which most patients with a chronic disease condition undergo, when health professionals inform them about the need for change in their routines to improve their health. People only accept the need for change if they are aware of the identified problem and its possible consequences. Therefore, health professionals need to make patients aware of the need for change, by providing education and sharing their knowledge with patients. Listening to patients' concerns, understanding their point of view, assessing their needs and consideration of their educational background, are important factors while formulating their care-plan (Lorenzo, 2013).

As mentioned earlier, Isaksson et al (2015) asked 159 people with T2DM to describe their perceptions of the need for self-management support in a rural community of Sweden. The study results have shown, that women and non-retired persons needed more support, compared with men and retired persons. Patients who were newly diagnosed with T2DM and those who had been diagnosed for 10-15 years, alike expressed the need for ongoing self-management support. Participants needed support from health professionals and also from family members, due to living in a rural community and having limited access to healthcare facilities. Considering this

information and the CMH region, although most of CMH patients are not from rural regions, still patients may have limited access to services due to limitations of personal and/or financial resources.

Simmons & Flemings (2000) conducted a cross-sectional study to describe the prevalence of non-attendance and to identify the characteristics among patients with diagnosed DM in SA. Patients were compared among each other depending upon two categories; those who have ongoing care and those with no ongoing care. A household survey was conducted where 1709 subjects were interviewed during the year of 1991-1994. All houses in three districts of SA were visited by multiethnic team members, to confirm people living in-house with a diagnosis of DM and their contacts with GP and/or a DM service. The survey questionnaire was designed to gather peoples' basic knowledge of DM, their satisfaction with DM care provision and their attendance with general practitioner (GP) care and/or DM specialist care in the previous 10 months. Quantitative data was analysed using SPSS and logistic regression was undertaken with a direct approach. The results revealed that overall 6.3% of patients did not see a GP or DM specialist service in the previous 10 months. A significant ethnic difference in non-attendance was noted. Non-attendance was highest in Māori patients, followed by Pacific, European then others. Dissatisfaction with care provision was 8% among attenders and 29% among non-attenders. Patients' beliefs and perceptions were not explored by this study. This study concluded that those patients who do not attend care facilities, have a variety of mitigating factors which are based on their own decisional perceptions towards their perceived benefits or disadvantages of attending or not attending the DM service facilities. Decisional balance was seen as possible problem behaviour. The study also highlighted the

association among diagnosis of DM, when the person was asymptomatic, with the tendency to default from ongoing DM care. Hence, this study warned health professionals to be cautious of conducting population-based DM screening programs (Simmons & Fleming, 2000).

The above-mentioned study is very relevant to the research question. The study has the same population, which showed the multiethnic diversity and their characteristics in relation to their non-attendance. However, the study design was different to the proposed research. This study was undertaken by a home visit approach, where patients were interviewed for their default with primary and/or secondary care provision, whereas the proposed research is to be held in clinics where patients were offered care by a DNS. Study participants will be interviewed about their lived experience of DM and DNLC consultations regardless of their attendance. In this study, a quantitative research approach was utilised, where associations among the different variables with non-attendance were examined. This study did not explore patients' perspectives in regards to their default of the DM care. Considering patients' perspectives and their beliefs are the key steps to find the fundamental aspects of the problem and suggest problem-based solutions. The proposed study will enquire about patients' experiences of living with DM, their perspectives towards their condition and feedback on care provision from a DNS will be sought. Hence, a mixed methods approach will be utilized to analyse the data of the proposed research study.

This above-mentioned literature review has emphasised the importance of individualised assessment of each patient prior to designing the package of education, the need for ongoing support and sharing of knowledge to maintain engagement.

Edwall et al (2008 & 2010) have further supported the importance of patients' needs

for ongoing support, to maintain patient engagement with self-management activities in their studies. The lived experiences of patients' with their DNS regular check-up was narrated by patients with T2DM during the year 2008 and the meaning of the consultation with the DNS during the year 2010.

The literature also supports the association between failure to attend or engage with ongoing DM care either with the GP or specialist clinics, and a direct co-relation with rising morbidity and mortality rates, which raises significant cost to the economy of the country (Simmons & Fleming, 2000).

#### ***2.5.4 Need to empower DM patients***

Empowerment refers to helping patients to use their own ability to help themselves, to self-manage their own disease condition (Funnell & Weiss, 2009). Empowerment enables patients to be in charge of managing their DM. The DNS can support empowerment by providing required support and education. Bhattacharya et al (2007) performed an audit to compare participants' perspectives towards annual DM review by DNLCs and doctor-led clinics in England. A semi-structured interview based questionnaire was posted to 91 randomly selected patients who attended both styles of clinic, out of which only 68 people responded. The results revealed that patients perceived DNLCs to be more relevant to their needs compared with doctor-led clinics. The patients' viewpoint was 100% positive in regards to nurse-led clinic service. The participants expressed the need for expansion of DNLC services. The study also suggested that empowering patients may improve long-term health outcomes (Bhattacharya et al., 2007).

Lorenzo (2013) conducted a review of best practice for clinical management of DM and revealed the strategies and tools to enhance patients' engagement with DM management. This review emphasised the role of psycho-social strategies and behaviour action plans as tools to promote health by empowering, motivating and helping patients to make desired changes and sound decisions to improve their health outcomes. Lorenzo believed this approach would enhance patient engagement, when professionals work in partnership with patients, whilst empowering patients to develop self-management skills for their everyday life (Lorenzo, 2013).

Another study conducted in a rural region of Sweden, highlighted that higher DM empowerment was seen among patients with longer duration of having T2DM (Isaksson et al., 2015). Higher empowerment among people with long duration of DM somehow reflects acceptance of the disease after understanding the illness and then negotiating about their wellbeing and disease management (Isaksson et al., 2015). The development of this change in mindset usually takes time, due to the process of internalisation of chronic disease. Internalisation of chronic disease is always individualised by people on the basis of their own exposure to seriousness and threats of poor consequences of the disease, emotional or personal goals and individualised expectations from life (Isaksson et al., 2015). This study also emphasised that greater empowerment among patients with T2DM can save cost resources for the care of patients with this growing disease, without affecting the quality of life and wellbeing of patients.

Wilson and Simon conducted a study in 1992, to describe the need for development of community-orientated recommendations aimed at primary and secondary preventions

of DM in SA, where a high proportion of Māori and PI people live. A face-to-face interview was done with a total of 555 patients. This study initially developed 68 recommendations for a SA DM plan to support the community, through community-orientated programmes, which were further consolidated into 38 recommendations. Eight recommendations were towards the need to empower communities and patients with DM research to enhance engagement and DM management. Nine recommendations focussed on access to care provision. Sixteen recommendations were to improve the standardisation and co-ordination of care. Five recommendations were to define DM diagnosis and detection (Wilson & Simmons, 1994). In 2000, the implementation of the SA DM plan including the above-mentioned recommendations was revised to identify the barriers to achieving success. The identified barriers included; patients' lack of personal interest towards self-management, lack of financial support and lack of care co-ordination among care providers between primary and secondary level (Simmons, Kenealy, & Scott, 2000). This revision highlighted many key areas for development, which remained underfunded. This study strongly recommended the need for geographically defined approaches, considering the socio-economic deprivation scale with patient co-ordinated systems. The key component of the recommended plan remained the same, due to failure of successful application of the SA DM plan towards empowerment of patients and DM communities.

### ***2.5.5 The disparate vision among patients and DNS***

There are often differences reported in perception and opinions towards engagement in self-care activities amongst patients and their DNSs (Boyle, Saunders, & Drury, 2016; Gorter, Tuytel, de Leeuw, Bensing, & Rutten, 2011; Hernandez, 1999; Wu,

Tung, Liang, Lee, & Yu, 2014). Wu et al (2014) has examined the difference between the perceptions of people with DM and their DM nurses, in regards to completing the self-care activities and patient's DM related educational needs. This was a cross-sectional survey, which was conducted in three regional teaching hospitals in Taiwan. Convenience sampling was done while selecting patients with T2DM above the age of 18 years with an ability to speak and understand Mandarin or Taiwanese. DNSs who were involved in their care were also invited for participation. Study results have shown a significant difference in the perceptions of DNSs in contrast to patients' perceptions towards their self-care activities. Results revealed that patients believed they were performing better for their self-care of DM, as compared to their nurses' perceptions. A significant difference was seen while identifying patients' health education needs. Nurses' believed patients needed more health education in regards to self-management, whereas patients perceived lower needs (Wu et al., 2014). This study concluded that in order to make an effective self-management plan for patients, it is important to match these identified gaps among patients and care providers. A plan of care can only be successful if it is based on the patients' need for empowerment, not on the professional's thoughts or assumptions.

Another qualitative exploratory study conducted by Hernandez, who explored patients' and their practitioners' perspectives in regards to assimilating DM into patients' daily lives (Hernandez, 1999). This study used a semi-structured interview tool to interview 51 Mexican American adults and 35 practitioners, who had direct patient contact to deliver DM care. The results highlighted a significant difference between patients' and practitioners' goals for care. Patients were more focussed on integrating DM into their daily life activities, with higher emphasis on behaviour

control rather than glycaemic control. However, practitioners were more focussed on improving the glycated haemoglobin (HbA1c) levels or fasting blood glucose levels. Results also revealed that professionals related poor glycaemic control as a signal of poor behavioural control amongst patients with DM. Patients verbalised the factors like poor financial state, fear of losing their job by declaring their disease at the workplace and treatment cost related worries. However, professionals ignored financial factors, with some relating these financial issues to cultural factors and others not acknowledging these financial factors in the treatment styles.

Gorter et al (2011) conducted a survey in 2011, to explore attitudes of patients with T2DM when undertaking responsibility for self-managing their disease, goal setting and their willingness to take regular medications. The results revealed that 62% of participants agreed to take responsibility towards self-empowerment, 89% of participants were keen to set goals under the guidance of a physician or DM nurse and 40% were ready to take regular medications to manage their DM (Gorter et al., 2011). This proportion advises that not all patients are ready to engage towards self-empowerment. Therefore, it is important to assess the readiness of the person to engage, prior to designing the care-plan. Hence, DNSs should perhaps identify patients' expectations from their lives and determine their treatment targets prior to designing the care bundle for them.

Boyle et al (2016) conducted qualitative research in Australia, to explore patients' experiences of T2DM care, when served by GP nurses as compared to medical practitioners. The study design used a qualitative interpretive approach, where data was collected with purposeful sampling with semi-structured face-to-face interviews.

The results revealed that patients appreciated the time that they spent with GP nurses, but they did not realise the purpose of that consultation. All patients presumed that the interaction with the nurse was a clinical assessment in preparation for the consultation with the general practitioner. The results suggest that the GP nurse's role in terms of DM care provision needs development to ensure patients understand their role and can have effective communication about the disease. Hence, it can be extrapolated that patient engagement does not always come to willingness or unwillingness of patients to engage; sometimes it is the expression from health professionals in providing relevant DM care (Boyle et al., 2016).

Kenealy et al (2004) have also explored PNs' roles, attitudes and concerns in relation to DM care, to inform the need for further development of the primary health care system. A longitudinal survey was undertaken, including questionnaires sent to all GP nurses in SA during the years of 1990 and 1999. This study has emphasised identification of barriers including time devotion for DM care, restricted control on their own time management and work schedules, opportunistic training and lack of national DM education to enhance effective management of DM by PNs. This study also emphasised on the need to build nurses' knowledge to meet the growing demand of the service in respect to growing prevalence of DM in NZ. This study concluded that PNs have gained postgraduate DM education, which has enabled them to work with more confidence with DM patients and has increased their involvement in DM care. This study also concluded that PNs were more likely to adjust DM treatment during the year of 1999 as compared to 1990 (Kenealy et al., 2004). This study seems relevant to the proposed research, as it was conducted within the context of the NZ population and it directs the involvement of GP nurses in DM management.

## **2.6 Discussion on literature findings**

Existing literature has highlighted the importance of consideration of patients' experiences and their perspective in regards to their care on the basis of their goals and expectations from their lives. Literature has also highlighted that patients with T2DM appreciate patient-centred care, and that it enhances patient engagement. This review also depicted the need for ongoing support among all patients with DM, irrespective of the duration of having the disease.

DM empowerment is considered as a crucial intervention internationally. However, some unclear understanding of patient empowerment and reluctance is present among DNSs, regarding the level of freedom patients may have in making decisions towards their own condition (Isaksson et al., 2015). There is a gap amongst the vision of patients and their DM nurses in regards to plans of self-care, the need for empowerment and the need for DM related education. Filling this gap between the perceptions of patients and their care providers may make DM related interactions more effective, which will influence patients' engagement towards their self-care (Wu et al., 2014). The literature review has also reflected the importance of readiness of patients, by explaining that professionals can guide patients but they cannot make patients undertake self-management (Gorter et al., 2011). Therefore, empowering, motivating and helping patients may involve stages of change towards acceptance of the disease, and help patients to realise the need for change (Lorenzo, 2013). It may take time for patients to realise the need for change, but when they do, they become activated to get engaged.

All the studies conducted in relation to patients' experiences used qualitative methods and two studies followed the phenomenological hermeneutic approach conducted by Edwall et al (2008 & 2010). This study design is an appropriate study design for exploring people's perceptions, experiences and opinions. Studies conducted by Silva et al & Simmons & Fleming (2011 & 2000) in NZ settings have utilised a quantitative method, where researchers have only gathered quantitative information. A qualitative approach may have better explored patients' beliefs and perceptions towards their commitment to self-care activities including engagement with DM clinics.

## **2.7 Gap in literature**

The literature review has confirmed that no published research has been done to date, to assess the level of engagement that patients have with DNLC in the Counties Manukau region. This integrative review provides the insight towards experiences of people with T2DM living internationally in different settings. However, there is a need to explore experiences of people from multiethnic origins and backgrounds in relation to meeting their needs from service provision in DNLCs at CMH. Some studies have acknowledged financial factors and limited access to health provision, which can also be related to health inequalities in NZ. The existing literature lacks the expression of the cultural component in terms of patients' needs, while establishing a plan of care and the model of service provision in overseas studies.

Further research is required, to identify the influence of Immigration to NZ from different ethnic backgrounds, which may also influence differences in patients and DM nurses' perceptions and opinions, especially when management involves lifestyle, and dietary changes with or without pharmacological interventions.

Immigration brings differences within patients' lives in respect to language, changes in food availabilities, lifestyles, financial difficulties, lack of social support and different work commitments; all of which makes patients' engagement with service provision further complex and complicated. This gap in literature can be explored to identify the influence of migration on attendance and non-attendance with DNLCs. There is a need to identify the health literacy amongst our patients, which may have influence on their understanding of their condition. There is a need to identify whether early interventions and/or effective communication with patients from primary level of care when they get diagnosed, plays any beneficial role in ongoing engagement. There is a need to identify the current degree of engagement that our DNLCs have in CMH. There is a need to explore patients' experiences to find out what matters to them, in terms of their attendance and non-attendance to the DNLCs.

## **2.8 The influence of the literature review on the research project**

As a result of this literature review, a refined research question evolved as:

“What are the factors affecting patients with DM in regards to their attendance and non-attendance with DNLCs in CMH?”

## **2.9 Limits of this literature review**

The lack of relevant available published research undertaken in NZ is the biggest limitation of this literature review. This literature review included studies that were done overseas with patients from different cultural backgrounds. The international study participants lack the variety of multiethnic patient perspectives present in the NZ population, particularly SA and CMH region. This integrated review can be generalizable internationally, but its application to the multiethnic population in SA

can be questioned. The author of this literature review has explored grey literature, which is specific to patients with T2DM, and their experiences with DNLC service provision. Studies were included from the grey literature review, with a purpose of gaining insights towards patients' attitudes and experiences in the NZ population, in the context of nurse-led clinics with a set inclusion criteria.

### **2.10 Summary of this chapter**

Chapter two has confirmed the alarming prevalence of the DM epidemic and challenges of serving a multi-ethnic population with high needs. This chapter has also highlighted knowledge gaps particularly that there is a critical need for research, to identify the ways to engage patients with self-management of DM and DM care providers. There is a need to explore the influence of immigration of patients, which may suggest bringing changes in care provision. There is a need to understand patients' needs and their experiences, which may guide strategies to enhance engagement with the service provision. There is a need to address consumers' views, which may direct decisions towards the need to tailor service provision with a proposal of change in policies and practices to promote patient engagement for their disease management. The proceeding chapter three will address the research methodology to answer the above-mentioned question.

## **Chapter 3: Research Methods**

### **3.1 Introduction**

The previous chapters have highlighted the purpose and aims of the study, and the relevant current available literature on the research question. The available literature was also reviewed, for the purpose of selecting a suitable research design to best answer the proposed research question. This chapter will present the justification for the choice of research methods, by explaining the rationale for the suitability of this method to the research question. The general research design, setting, participants, data collection and data analysis will be explained. Identified ethical issues, challenges and strategies to manage those issues, ethical principles and their application to this research study will also be described.

Nursing Research is an exciting adventure, which involves critical thinking and dedication to find an answer to a problem or a research question. To provide safe and high quality service, evidence based clinical practice remains the most crucial component of the foundation of clinical knowledge and application of that knowledge in every day clinical practice (LoBiondo-Wood & Haber, 2017). Hence, evidence based practice contributes towards quality improvement projects and its application may enhance improvement in patients' health outcomes. Though current nursing practice is based upon evidence, the need for change exists, as the population of our stakeholders is changing with the increasing influence of migration, a multi-ethnic population, sedentary lifestyle, morbidity and mortality. It is essential that current practice and current thinking is challenged, to identify the existing gaps and to find answers to the existing problems (Moule, Aveyard, & Goodman, 2016). For example, in this research study the author is an accredited DNS who conducts DNLCs and has

seen an anecdotal expression of attendance and non-attendance of patients to DNLCs. The motivation of this research is to explore what exactly our patients perceive and what they want from our service provision, to promote their attendance and engagement for self-management of DM. The decision to attend or not attend an appointment remains a subjective call for patients with DM, which is considered to be based upon their understanding of their disease condition and their need for support. Hence, it is essential to find out what exactly matters to our patients.

As mentioned in the previous chapter, different medicines and treatment regimens are well established for their effectiveness for patients with DM. Research focused culture in medicine, continues to contribute on-going improvements in treatment for disease prevention and management. However, patients' personal and psycho-social factors remain under-investigated, which plays a crucial part in engaging therapeutically, as it comes to the patient's decision whether to take that medicine or not, and whether to follow the advice given by health professionals which is evidence based and well supported by research findings. Hence, it's considered crucial to find out what exactly matters to our patients in regards to their engagement with service providers, their perceived experience with our service provision and their self-management.

The scope of nursing practice has broadened and progressed towards taking additional responsibilities from medical roles (Casey et al., 2015). There has been a successful shift in models of care, away from traditional ways of only doctor-led clinics, to nurse-led service provision by involving the nursing workforce as clinical speciality nurses, clinical nurse specialists, designated nurse prescribers and NPs. This shift highlights the ability of nurses to meet patients' needs and increasing demands of the

population from the healthcare system as the population expands (Horrocks, Anderson, & Salisbury, 2002). However, while practicing at an advanced level of nursing, it remains vital to assess patients' perceived level of satisfaction and identify what their needs from service providers are.

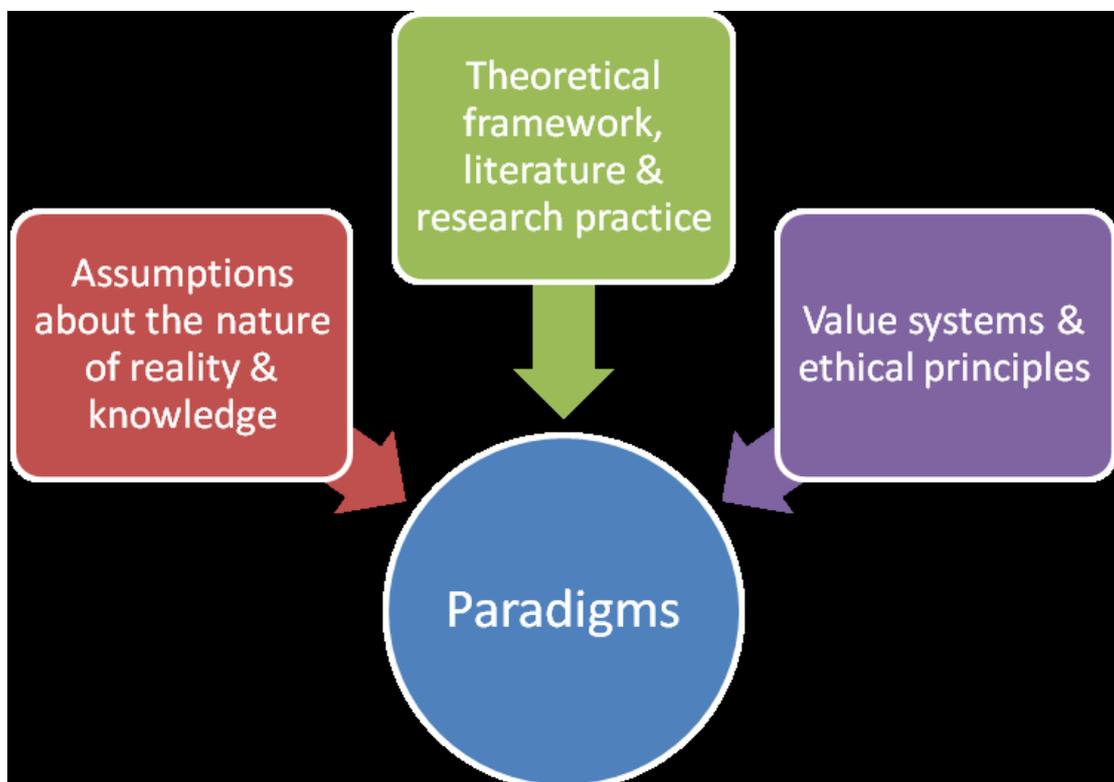
Nursing and medicine obviously are two distinct professions with different roles and responsibilities. Nurses are often continually present with patients, as compared to periodic appearance of doctors for consultation (Mulhall, 1998). Existing literature has confirmed that nurses tend to know their patients more in personal, psychological and social respects, in addition to their medical needs, as they spend significantly more time with patients (Casey et al., 2015). Lately, nursing and medicine research has started to overlap, by acknowledging the strengths and different perspectives that each profession brings, to enrich the matter of enquiry or research (Mulhall, 1998). The multi-focussed approaches of acknowledging the perspectives of health conditions and quality of life, involves inclusion of patients' physical, psychological and social aspects, and implies the need for careful consideration of research methodology to answer the research question (Bowling, 2014). The following section shall describe the chosen research paradigms, methodology and research methods

## **3.2 Research Approach**

### ***3.2.1 Research Paradigms, methodology and methods***

During the initial planning of the research, it is crucial to identify which research approach can best answer the research question. A research paradigm is described as a shared belief that guides the researcher as to how a problem can be resolved within disciplines (Denscombe, 2008). The selection of the research paradigm reveals the

researcher's own understanding, and their own views and knowledge about the research problem. Hence, the direction to answer an existing problem that is the research question is a reflection of the researcher's approach. During the process of research, the researcher not only investigates the research problem among the participants, but simultaneously the research satisfies his/her own need to fill the gap in knowledge, through their own internalisation about the problem and the application of gained knowledge into their practice. Figure 3 sums up the above information about research paradigms. (Chilisa & Kawulich, 2012).

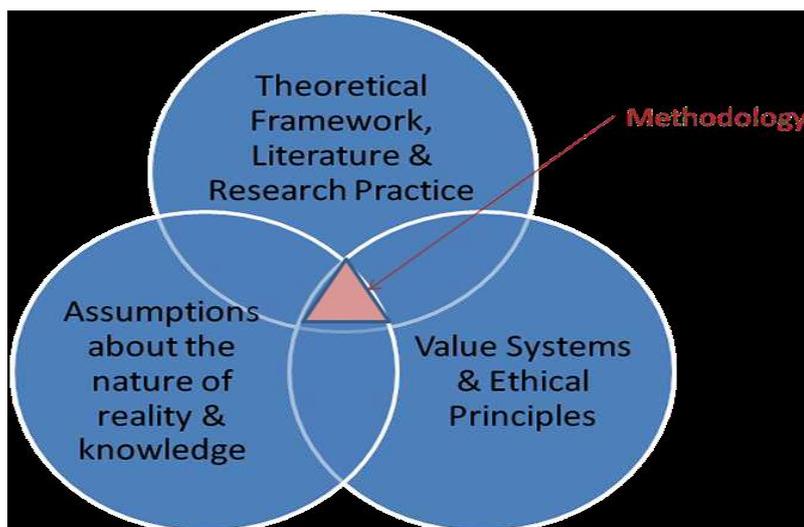


**Figure 3 Factors influencing the choice of paradigm (Chilisa & Kawulich, 2012)**

### ***3.2.2 Research methodology***

A paradigm may be associated with certain methodologies. As discussed earlier, a positivism approach is generally assumed to be aligned with quantitative

methodology, whereas a constructivism approach is generally assumed to be linked with qualitative research methodology (Chilisa & Kawulich, 2012). Therefore, it is crucial for the researcher to understand the research paradigms and associated research methodology, their strengths and weaknesses and their involvement in the history, as knowledge will be gained and reflected from the research outcomes according to the methods utilized. No paradigmatic framework is correct or incorrect, provided the chosen paradigm and methodology answers the research question (Schneider & Whitehead, 2013). Methodology is where the assumption about the nature or anecdotal expression of the problem overlaps the reality, knowledge and the theory and practice on a selected research problem (Chilisa & Kawulich, 2012). As described in figure 4, research methodology is the conjunction among the three important parts of rationalisation, when choosing the paradigm.



**Figure 4 Research methodology in the convergence of three factors influencing the research paradigm choice (Chilisa & Kawulich, 2012)**

### **3.2.3 Research methods**

There are mainly three methodological communities to research including quantitative, qualitative and mixed methods. The quantitative methods orientation approach was the most utilized and least questioned methodological approach, which was well known in the field of social and behavioural science during the 20<sup>th</sup> century (Chilisa & Kawulich, 2012).

Quantitative methodology is well associated with positivist/post-positivist paradigms. The researchers present the research findings in numerical state. However, during the last quarter of the 20<sup>th</sup> century, qualitative research methods emerged as an alternative to quantitative research orientation. Here qualitative researchers, through rich narrative text, critique the use of traditional quantitative methodology (Teddlie & Tashakkori, 2009). Positivism is based upon the process of testing the hypothesis and finding the truth or fact on the basis of rigid rules and principles (Schneider & Whitehead, 2013).

Positivist and post-positivist paradigms will be used in the quantitative analysis. Since, the researcher is naïve to the exact proportion of the current extent of the problem of non-attendance, a positivist approach seems to be very suitable to the research question (Creswell & Creswell, 2017). Positivist researchers seem to believe that the value-free research can produce results to measure social phenomenon and those results can be largely generable on the basis of the context of the research application. This is also called naïve realism, as the researcher is independent of data awareness and maintains the state of meeting the objective of the research (Wahyuni, 2012). A post-positivist approach also seems to believe in generalizability of the

research findings, however this approach can challenge the research finding, by acknowledging that the established knowledge or the results are the result of social habituation. The post-positivist approach will enable the researcher to understand the interlinkage among the different variables effecting the main results of the research, while being independent of human thoughts, views and pre-existing knowledge (Creswell & Creswell, 2017; Wahyuni, 2012).

Qualitative methods are defined as a technique of gathering, interpreting and analysing narrative information and then subscribing the information as constructivism, identifying variants to portray the research findings in a narrative state instead of numerical form (Teddlie & Tashakkori, 2009). It is important for a researcher to understand the differences between quantitative and qualitative research methods, to best understand and interpret the research findings if utilizing these methods.

Considering the research question, to explore the factors affecting attendance and non-attendance of CMH patients with DNLCs, it was also crucial to identify the exact extent of the problem of non-attendance. After careful consideration of; in-depth understanding of research methods, the supreme likely finest fitting approach to the research problem and acknowledging researchers existing knowledge and skills, a mixed methods approach was considered the best means to satisfy the research question, including quantitative and qualitative research methods. It was considered that this approach will draw on the strengths of each method and shall neutralize the limitations of a single methodological approach to best answer the research question (Elizabeth & Louise, 2015; Walker, 2005; Welford, Murphy, & Casey, 2012). This

research has an objective, to report the current level of attendance and non-attendance and the associated factors, which will be best answered by a numerical approach through quantitative methodology. However, understanding the patients' perceptions and experience of living with DM and DNLCs, will need a more sensitive approach of understanding, to interpret the content of narratives and dialogues (Barg et al., 2006). Interpretive paradigm or constructivism will be utilized in the qualitative research. This approach enables researchers to understand people's experiences and perceptions. Since the objective of this research is to explore patient factors in regards to their experience of DNLC service provision and the researcher is also living the research topic, this paradigm seems most suitable as it will enhance the value of subjectivity. Researchers utilize this paradigm to understand subjective experiences and utilize the narrative form of analysis of social phenomenon to add detail to the reality of the research problem, give detailed reason behind the situation and explore the subjective meaningfulness and motivating actions from peoples' perspectives (Wahyuni, 2012).

The mixed methods approach has arisen as a third paradigm, when studying social factors. It has developed rapidly in recent years of the 21<sup>st</sup> century, due to the incorporation of its distinct ability to utilize the strengths of two different research approaches (Denscombe, 2008). A mixed methods approach itself, describes the flexibility of utilizing the compatibility of quantitative and qualitative research methods in a sequential manner, which was desired within this research study (Teddlie & Tashakkori, 2009). Different researchers have highlighted that a mixed methods approach can also favour the sequential involvement of quantitative and qualitative methods to clearly state the priority of data collection and data analysis;

mixed methodology can add clarity to research findings by categorical presentation of quantitative and qualitative research aspects, while amplifying the prominence in which triangulation is used in the research study (Denscombe, 2008). The most common philosophical orientation associated with most mixed methodology is Pragmatism; the evaluation of theories and beliefs based on success when applying them periodically (Teddlie & Tashakkori, 2009).

### **3.3 Research Design**

The literature review confirmed that there was no research done on this topic previously in the chosen study setting. Hence, a quantitative research methodology was considered ideal, to gauge the current rate of attendance with DNLCs and to check the association of factors influencing attendance. Whilst qualitative methodology was considered as the most suitable option, to explore the patients' living experiences with DM and perspectives towards their needs and subjective decision towards attendance or non-attendance with DNLCs.

Therefore, to identify the current rate of attendance and non-attendance, a quantitative retrospective audit approach seemed appropriate. Other variables of interest including demographic characteristics (age, gender, ethnicity, NZDI representing socioeconomic decile) and other factors which may be associated with attendance of patients including patient's enrolment with the planned proactive care (PPC) programme, existing DM related complications and number of hospital admissions in the selected time period, were also studied. This approach collected statistical data to find the current state of the research problem. A positivist approach was followed within quantitative research, to identify the statistical information available in relation

to the real worldview (Sousa, Driessnack, & Mendes, 2007). However, a quantitative research approach alone will not be sufficient to answer the research question, regarding patients' reasons and perspectives for their attendance and non-attendance. To explore complex phenomenon in relation to human experiences, a qualitative research design seems most suitable to answer that aspect of the proposed research question (Hibberts & Johnson, 2012).

Thus, a qualitative descriptive approach was followed in the second phase of research. This approach identified and explored patients' perspectives in relation to their attendance and non-attendance of DNLCs. A pragmatic approach was then followed within the qualitative research method approach, which highlighted the phenomenological relations among patients' perspectives and reasons towards their attendance and non-attendance (Creswell & Creswell, 2017). The results of the mixed methods approach were integrated during the data analysis phase, to generate relations and comparisons among the results.

### **3.4 Setting**

The research was conducted at outpatient DNLCs under the secondary care service provision of CMH SA. DNLCs from two regions of service provision were chosen namely Mangere and Botany. Quantitative data was collected from PIMS within CMH. Qualitative data was gathered by face-to-face interviews, which took place in the same clinics where the participant was offered an appointment to attend the clinic. A few participants preferred telephonic interview, hence telephonic interview was considered another mode of data collection. Patient preferences were further

considered and for those participants who preferred an interview separate from the same clinic setting, Middlemore Hospital was offered as a venue for interview.

### **3.5 Participants**

The populations of interest for this research are the adult patients with DM, who were offered an appointment with a DNS in the Botany and Mangere regions of the outpatient DNLC in CMH, over the last 12 months and between the dates 25<sup>th</sup> March 2016 to 25<sup>th</sup> March 2017. The period of 12 months allowed the involvement of dependent and independent variables such as weather, life commitments (work, childcare, traffic) that may act as a barrier or a facilitator for patients to attend the offered appointments. The inclusion and exclusion criteria for participants will be discussed further down in this chapter.

### **3.6 Sampling Strategy**

The study utilized a mixed sampling design, that is a nested sampling sequence from the quantitative phase to qualitative phase (Hibberts & Johnson, 2012). During the first phase of research, the quantitative method included the information of all patients who were booked an appointment to attend a DNLC in the last 12 months, 25 March 2016 to 25 March 2017 in Botany and Mangere. The quantitative data extract confirmed a total number of participants for the study was 707 from both regions of service provision. There were 408 subjects from Mangere clinics and 299 subjects from Botany clinics. The quantitative sample was then categorized on the basis of four main sub-categories as follows:

- i. **Level 1:** Those patients who have not attended any offered appointments.

- ii. **Level 2:** Those patients who have attended the first offered specialist appointment (FSA) but have not attended any follow up appointments.
  
- iii. **Level 3:** Those patients who have not attended the FSA but have attended the follow up appointments. This level was always questionable in the researcher's mind. If patients do not attend the FSA then that patient should remain categorized as FSA in the system. A manual review of the subjects in this category on PIMS, confirmed that 46 patients were supposed to be under Level 1 and five were mislabeled as did not attend FSA but attended follow up whereas that first follow up appointment should have been classified as a FSA. Therefore, they were categorized under level 2. Hence, there was no level 3.
  
- iv. **Level 4:** Those patients who have attended all the offered appointments including FSA and follow up appointments. Since there was no level 3, consequently level 4 will be called level 3 for the continuum of the research activities.

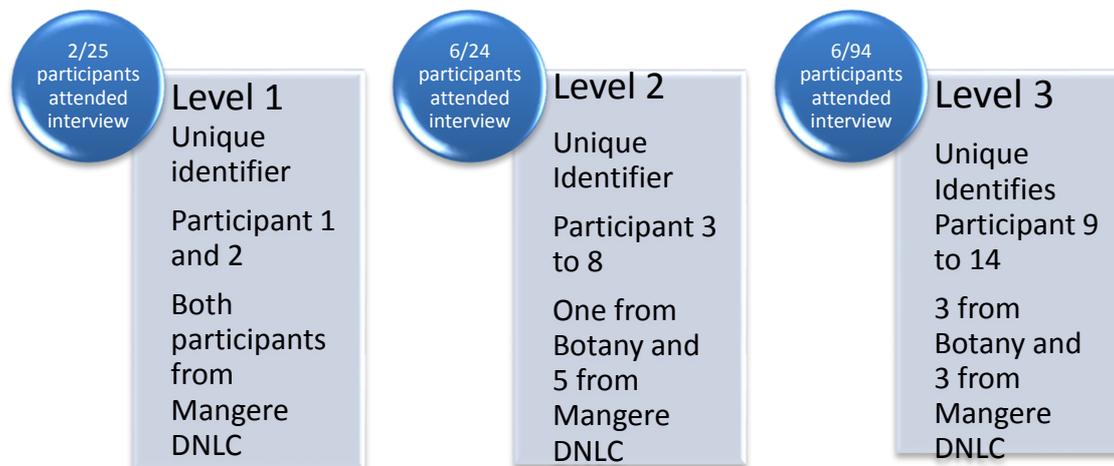
Qualitative methodology was followed in the second phase of the research, where purposive sample selection occurred from the quantitative sample. Two clinics were randomly selected from each region of Botany and Mangere. The researcher's own DNLCs were purposefully excluded from the list of clinics at the time of random selection, in order to follow the principles of ethics. All six clinics were labeled from Clinic 1 to 6. These labeled clinics were sent to the research supervisor via email. The research supervisor was not aware of the clinician's name, thus there was no bias upon the random selection of one DNLC from each region of service provision.

### 3.7 Sample Size

The sample size in the quantitative phase was dependent upon the number of patients who were offered an appointment to attend the DNLCs in Botany and Mangere. The sample size was 707 patients who were offered 1550 appointments collectively. The randomly chosen clinics had the sample sizes as mentioned in table 3 and figure 5.

**Table 3 The nested sample size of the randomly selected DNLCs**

Levels of group	Number of participants in Botany DNLC N = 128	Number of participants in Mangere DNLC N = 109	Attempted to contact for the invitation of interview
Level1	12	13	All of the participants
Level 2	12	10	All of the participants
Level 3	69	25	Until data saturation of themes occurred or patient number exhausted
Excluded	35	61	
<b>Total number of subjects</b>	93	48	



**Figure 5 Categorisation of attendance in three different levels**

The researcher consulted the University of Auckland statistical team for sample size; however for this qualitative research, the impetus remained on achieving data saturation. The sample size for the qualitative research phase was determined by two factors; when data saturation point was achieved and when there were no more patients available in that particular sub-category or level of grouping for attendance. Difficulty in recruitments process remained a restriction especially for those patients who were in non-attendance subgroup.

### **3.8 Patient recruitment strategy**

The patient care assistant (PCA) made initial contact with research participants. The PCA posted out the participants' information sheet to invite the participants. The information sheet described a brief overview of the research study including; introduction, rationale, possible benefits and risks related to the research. The PCA followed up the invited participants by a phone call, to confirm their interest to attend

the interview. The recruitment strategy was to contact three patients from each category including level 1, level 2 and level 3 as mentioned in figure 6. Upon the response of the first three eligible participants with their decision to participate or not; then the next three patients on the list were contacted. The recruitment process then continued until the researcher reached the point of data saturation or until there were no more patients left to be interviewed in that particular sub-category. The PCA then informed the researcher about participants who were willing to participate. The researcher organized a suitable time and venue with the participant. At the time of written consent to participate prior to interview, participants were again reminded about the research process and were offered another opportunity to decide on their preference to participate or withdraw. Once they agreed to participate, a written consent form was signed prior to proceeding with the interview.

There were some challenges in recruiting as mentioned in figure 7. There were challenges in contacting patients and patient's acceptance to participation the study. There were two research participants who agreed to participate on the phone, then decided to opt out just prior to signing the written consent form prior to interview. The lead researcher respected the participant's decision to opt out, hence no rationalization behind the patients' decision was established.

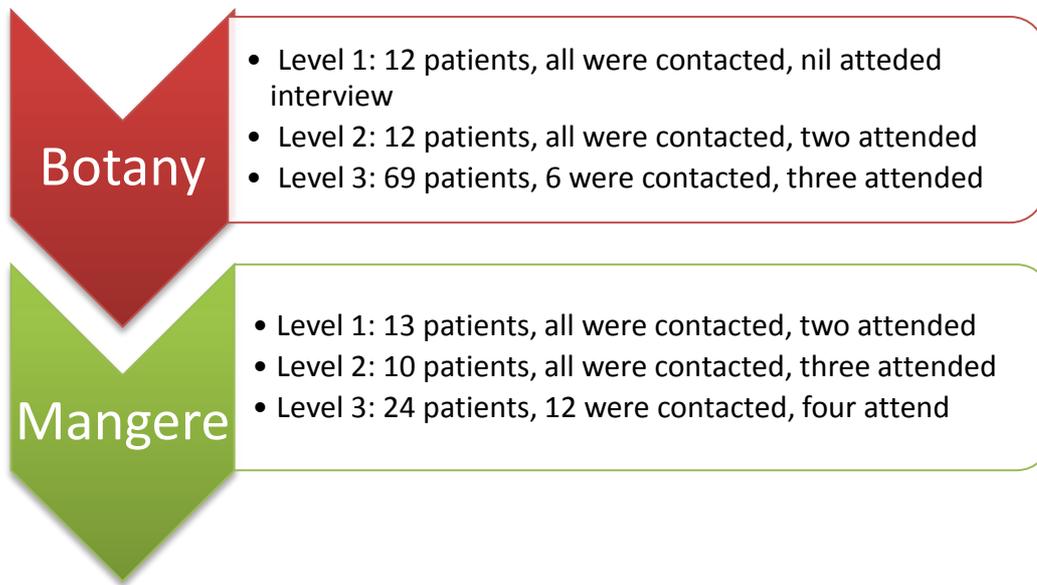


Figure 6 Participants in each level of attendance from both regions

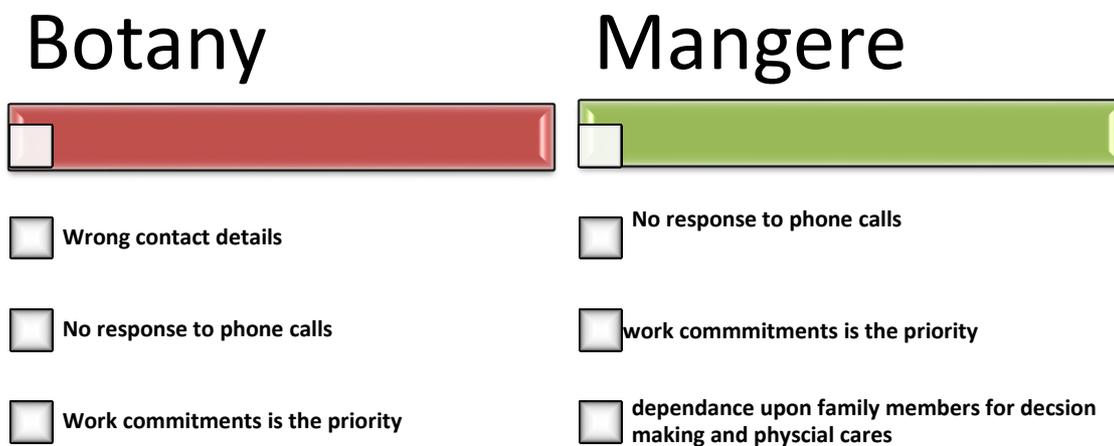


Figure 7 Challenges faced during the recruitment process

### 3.9 Inclusion and exclusion Criteria

Adults aged 16 years, with T1DM and T2DM were included. The majority of patients (90%) had T2DM and 10% had T1DM, which is a reflection of the incidence of T2DM versus T1DM in the general population. For the quantitative data, all patient data was included. However, for the qualitative data, patients with acute mental

illness were excluded whilst those patients with a past history of mental illness were included. Those patients, who only had the follow-up appointments with no FSA in the chosen one-year period of study, were also excluded. Upon experience with inpatient eligible clients, it was decided later in the study to exclude inpatients. None of the participants were chosen from the lead researcher's own DNLC, to avoid position pressure upon clinical patients.

### **3.10 Data Collection**

The data collection process for sequential mixed methods research included two consecutive phases; quantitative data collection followed by qualitative data collection (Elizabeth & Louise, 2015). The quantitative research phase involved a retrospective survey. Data was collected from randomly selected DNLCs in each region of service provision in the last twelve months' time period, 25 March 2016 to 25 March 2017. The data was sourced from PIMS. Quantitative data was arranged at two different levels. The first level included identification of the proportion of attendance and non-attendance. The second level of quantitative data collection examined the relationships among the variables including; demographic, age, gender, ethnicity and NZDI.

NZDI refers to social deprivation for residents from a specific geographical region. NZDI is believed to provide strong connections to socioeconomic status and is a means to measure the variation in inequities of health delivery (W. C. Chan et al., 2008). The NZDI scale 1 refers to the least deprived population of a geographical region and NZDI scale 5 refers to the most deprived population of a region (W. C. Chan et al., 2008).

The other causative factors for patients' attendance including enrolment with the PPC programme, complications and hospital admissions, were also studied for their association or influence upon the attendance rates. The PPC programme is a collaborative approach, mainly utilized for patients with long-term conditions, where all the care providers develop a comprehensive and co-ordinated patient-centered care-plan, which is communicated via an electronic tool.

During the second phase of research, qualitative data was collected, by inviting participants for semi-structured face-to-face interviews (Sandelowski, 2000). The qualitative data will be gained with a questionnaire as attached in Appendix 1, using open-ended questions and a Likert scale. Open-ended questions invite descriptive narratives in relation to the research problem (Creswell & Creswell, 2017). A semi-structured interview invited a variety of elicited views and opinions from participants (Creswell & Creswell, 2017). Face-to-face interviews are the preferred technique for qualitative data collection, as compared to telephonic interviews; they provide superior and rich information (Creswell & Creswell, 2017). However as a means to access, telephonic interviews were kept as an option for those patients who had not attended any offered appointments with DNLCs and who could not attend the offered face-to-face interview (Sturges & Hanrahan, 2004).

Qualitative data audio recording was undertaken. Interviews were audio taped and transcribed by the researcher. An interpreter service was available for those participants who had English as a second language. Only one patient chose to utilize an interpreter for the interview and selected a family member.

### **3.11 Data Analysis**

Quantitative research data was collected on an excel spreadsheet, where initial information was organized following a descriptive and inferential numeric analysis, as recommended by Seers & Critelton (Seers & Critelton, 2001). The data was then transferred to SPSS that is Statistical Package for Social Sciences. Descriptive numeric analysis counted the percentage to describe the data using mean, median and standard deviations, whereas Inferential Numeric Analysis compared the numbers and percentages to categorize the data (Thomas, 2006). Categorizing into different age and ethnic groups further refined the data. Chi-square test/ Fisher exact test was carried out to assess the association between each of the patients' demographic characteristics in each group, and significance upon the research findings. Two samples, T tests (parametric test) or Kruskal – Wallis (non-parametric test) were used to test significant difference in the continuous variables in the groups(Alton et al., 2015).

The results will be presented from un-adjusted and fully adjusted models, in terms of odds ratio with 95% confidence interval (CI) and p-value (Davidian, 2017).

Interactions between the clinics and each covariate will be assessed across two clinics; depending upon which covariate level they will belong to.

Qualitative data analysis involved descriptive and thematic text analysis. The data will be described as a portion of total response. Thematic text analysis will be done by identifying, analyzing and reporting re-occurring themes in the qualitative data (Braun

& Clarke, 2006). NVivo software will be utilized to code the data with nodes. Data was revised multiple times to generate themes.

### **3.12 Ethical Considerations**

The researcher sought and gained ethics approval from the University of Auckland Human Participant's Ethics committee (UAHPEC), CMH ethics committee and the Northern Region Ethics committee, prior to commencing the research project. The four ethical principles of autonomy, non-maleficence, beneficence and justice were considered throughout the research (Beauchamp & Childress, 2001).

Privacy and confidentiality of participants and participants' information was maintained throughout the research. Participants' identification data was secured in case statements. Participants were assigned numbers as unique identifiers.

Participants' information and recorded tapes were safeguarded in a locked cupboard, in a secure building. Participants were given opportunity to read back their transcripts to check accuracy of interpretation. None of the participants opted to read their transcripts. However, some participants requested to receive the research results. At the completion of this study, participants will be posted the research abstract.

Attention was given to potential identified ethical issues, which may possibly arise from this research. The research setting was out of the researcher's clinical context to avoid the power imbalance of clinician upon participant (LoBiondo-Wood & Haber, 2014). Therefore, none of the researcher's own clinics were selected for qualitative research interviews. Other DNLCs were randomly selected in each area of service provision.

A PCA who was a non-clinical person initially contacted potential participants to again avoid the position pressure from researcher. Participants received the participants' information sheet by post, which explained the research study. Thus, information of those participants who made an informed choice to participate was forwarded to the lead researcher. On arrival to the interview, the participant information sheet was again reviewed by participants, who were again given the choice to proceed or decline interview. Participants were then given a written consent form to sign. Verbal consent was also included in the audiotape of the interview. Participants' choices were respected throughout the research project. Participants were assured that refusal to participate or withdrawal from the research at any time, would not affect the care provided through the CMH DNLC.

A cultural advisor was available to patients in relation to appropriate language and sensitivity of research questions. However, patients did not express the need to use a cultural advisor. The option of an interpreter was available to assist with patients who had English as a second language upon participants' agreement. An interpreter was used for one interview where the participant preferred a family member instead of a formal interpreter.

### **3.13 Summary of chapter three**

Chapter three has explained the research methods, data collection process and data analysis utilized in this research. The steps of research process have been discussed while acknowledging strengths of each methodological approach. The following chapters will present the findings from quantitative retrospective audit and qualitative findings from participant interviews.

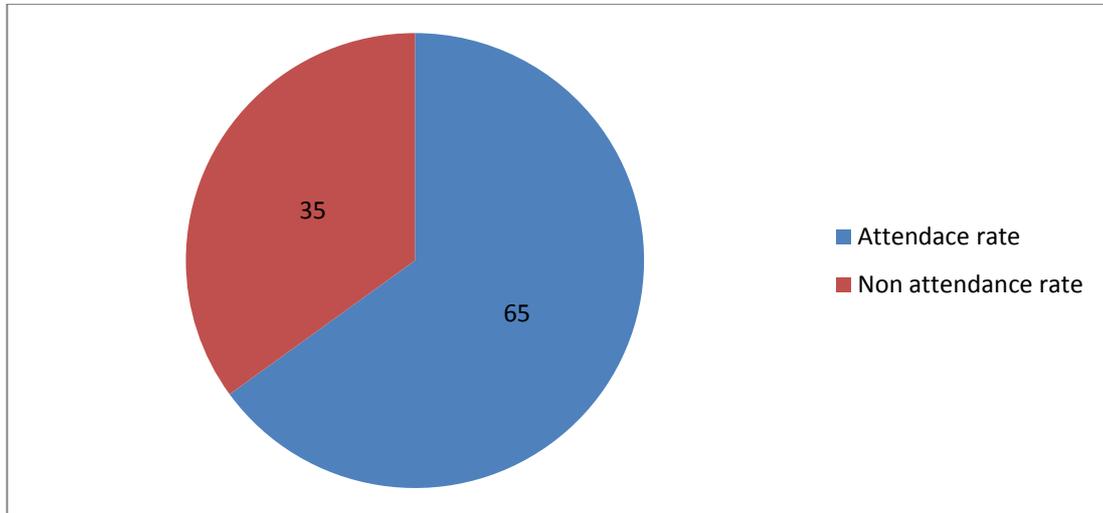
## **Chapter 4: Quantitative results**

### **4.1 Introduction**

This chapter presents the findings from a retrospective audit for attendance and non-attendance in DNLCs, in two regions of service provision (Mangere and Botany). The quantitative research results will be presented in four main sections. Section one will present the rate of attendance and non-attendance in the chosen study settings. Section two will highlight the demographic characteristics including; age, gender, ethnicity, NZDI and other factors which may be associated with attendance of patients including; enrolment with the PPC programme, existing DM related complications and number of hospital admissions in the selected time period. The third section will compare both areas of DNLCs for attendance and variables. The descriptive and inferential analysis of the retrospective audit results shall be discussed in relation to the rate of attendance and non-attendance within DNLCs. The fourth section will present the attendance and non-attendance rates under three sub-categories including level 1, level 2 and level 3. This categorisation will help to study the influence of dependant and independent variables. The demographic factors will be further studied, while comparing non-attendance in between two groups. The demographic factors and other variables will be contrasted with univariate and multiple logistic regressions, to check the possible significance among the different variables.

### **4.2 Rate of attendance**

The mean rate of attendance between the two regions of service provision was found to be 65% as shown in the figure 8 below.

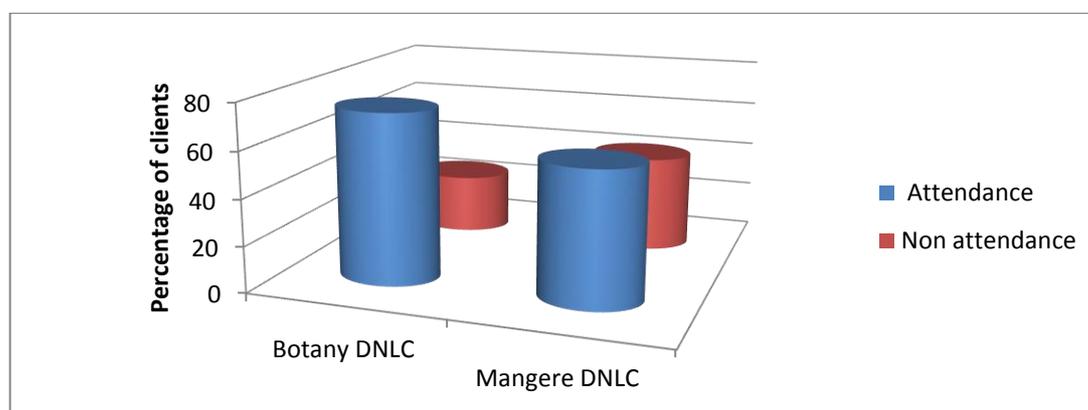


**Figure 8 Attendance rate of Botany and Mangere DNLCs**

As shown in table 4 to follow, there was an attendance contribution of 58% from Mangere DNLCs and 74% from Botany DNLCs. Amongst those who have defaulted at least one DNLC appointment, 42% were from Mangere and 26% from the Botany area, as demonstrated in figure 9. The p-value was found to be statistically significant ( $p\text{-value} = <0.0001$ ), which confirms that there was a significant difference in the attendance rates of appointments among patients in Botany DNLCs as compared to the Mangere DNLCs. Chi-square test or Fisher exact test was carried out to assess the association between each of the patients' demographic characteristics within each group. Two samples T test or Kruskal – Wallis test were used to test for significant difference in the continuous variables between the groups. A p-value of  $<0.05$  was considered statistically significant. The univariate logistic regression model confirmed a significant difference in the attendance rates between the two clinics. Those visiting Botany DNLCs are 2.01 times more likely to attend the offered appointments as compared to those in the Mangere clinics (95% CI; 1.45, 2.78).

**Table 4 Attendance rate among DNLCs in two regions of service provision (Botany and Mangere)**

Covariate	DNA N= 250 (35%) N (Row %)	Attended N=457 (65%) N (Row %)	Total N (Col %)	P-value
<b>DNLC Botany</b>	79(26)	220 (74)	299 (42)	<b>&lt;0.0001</b>
<b>DNLC Mangere</b>	171 (42)	237 (58)	408 (58)	



**Figure 9 Overall attendance rates among DNLCs in two areas of service provision from CMH**

### 4.3 Demographic characteristics of the study participants

The demographic characteristics were studied in relation to patients’ attendance and non-attendance in both regions of service provision. The following section represents ethnicity, gender, age and NZDI as potential variables that may influence the attendance and non-attendance rates as mentioned in Table 5. Based on the results,

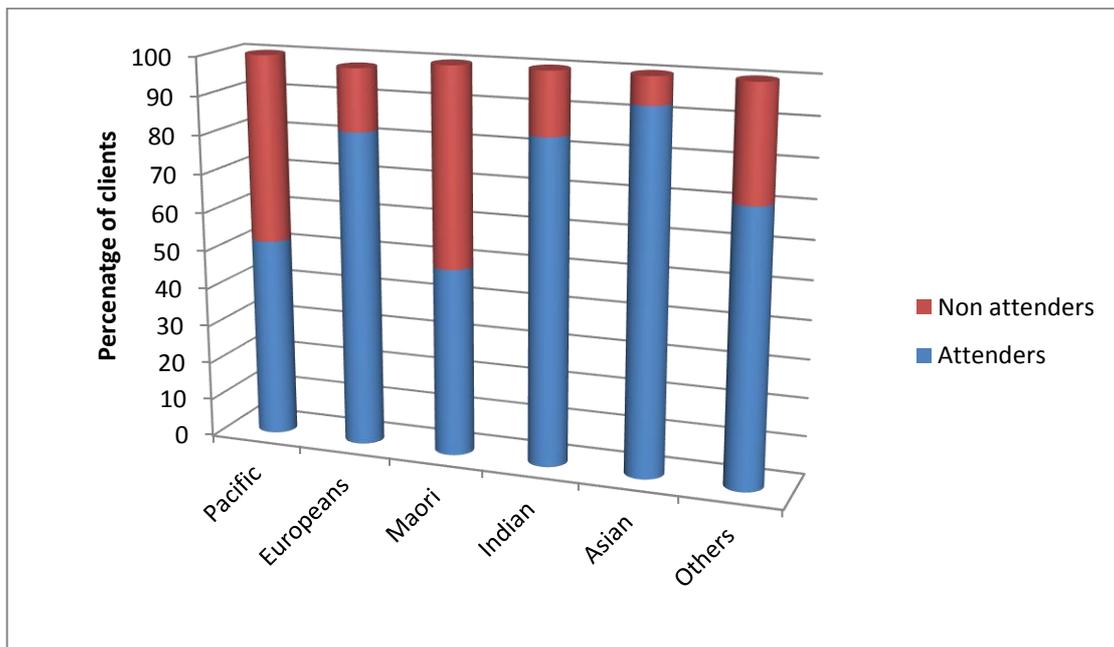
there were significant differences across ethnicity, age and NZDI for attendance and non-attendance with DNLCs.

**Table 5 The demographic characteristics of the study participants**

Covariate	Region/ Variables	DNA N=250 (35%) (Row %)	Attendance N=457 (65%) (Row %)	Total (Col %)	P-value
<b>Ethnicity; N (%)</b>	Asian	3 (7)	38 (93)	41 (6)	<0.0001
	European	24 (16)	129 (84)	153 (22)	
	Indian	12 (17)	59 (83)	71 (10)	
	Māori	36 (51)	34 (49)	70 (10)	
	Other	6 (29)	15 (71)	21 (2)	
	Pacific Islander	169 (48)	182 (52)	351 (50)	
<b>Sex; N (%)</b>	Female	128 (38)	207 (62)	335 (47)	0.13
	Male	122 (33)	250 (67)	372 (53)	
<b>Age (Years); mean, (SD)</b>		50 (14.1)	55 (15.9)		<0.0001
<b>NZ Deprivati on Index (NZDI); N (%)</b>	NZDI 1	10 (13)	65 (87)	75 (11)	<0.0001
	NZDI 2	17 (22)	62 (78)	79 (11)	
	NZDI 3	8 (13)	52 (87)	60 (8)	
	NZDI 4	26 (32)	55 (68)	81 (11)	
	NZDI 5	189 (46)	223 (54)	412 (58)	

The data was categorised on the basis of ethnic origin in relation to attendance and non-attendance. When the variant of ethnicity was studied in row percentage, it was found that the ethnic composition of CMHs' total stakeholders (including attenders and non-attenders) from both areas of service provision includes a proportion of

people from Pacific origin 50%, followed by Europeans 22%, Māori 10%, Indians 10%, Asians 6% and other ethnic groups as 2% only. 83% of European, 93% of Asian, 84% of Indian and 71% of others attended offered appointments as compared to Māori or Pacific Islanders (PI) who had attendance rates of 49% and 52% respectively. Ethnicity showed a statistically significant difference within different ethnic groups, which was found to be associated with patients' attendance with DNLCs. To test its significant association, a chi square test was applied to the two ethnic groups, which showed the highest non-attendance among Māori and PI. Chi square confirmed ethnicity as a significant factor for non-attendance in PI since the p-value was <0.001 as shown in table 11.

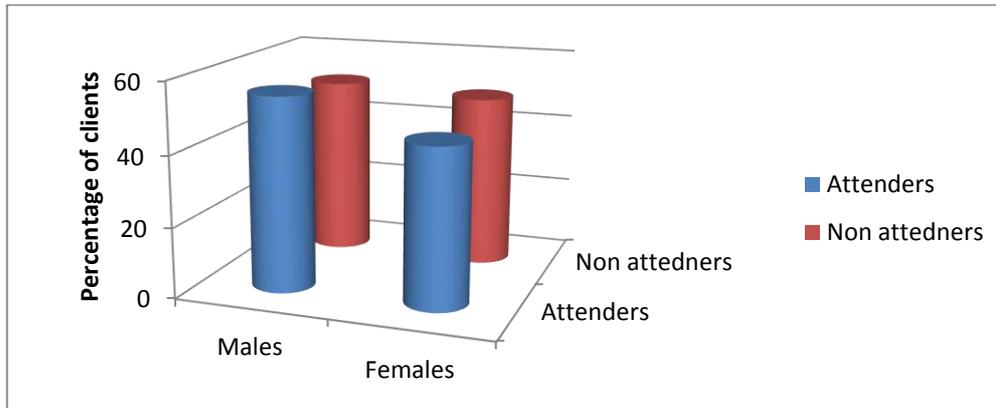


**Figure 10 Trend of Attendance presented by ethnicity as a variant**

#### 4.3.1 Gender

There were more males than females who attended the overall offered appointments, with a proportion of 55% of attendance as compared to 45% by females, as shown in

Figure 10. The chi-square was applied to study gender relation with attendance and non-attendance. Gender was statistically found to be a non-significant factor in its association with attendance to DNLCs.



**Figure 10 Males attends more offered appointments as compared to females**

#### 4.3.2 Age

Mean age of attendance was found to be 50 years with standard deviation of 14.1 years, as shown in Table 5. Age was found to be a statistically significant factor influencing patients’ attendance with DNLCs. In overall attendance, the patients who attended the offered appointments were 5 years older than those who did not attend the offered appointments.

#### 4.3.3 New Zealand Deprivation Index

The NZDI was clubbed into pairs of five deciles instead of ten. Table 5 shows that patients from the most deprived regions defaulted 46% of offered appointments. In comparison, those who fall into the least deprived geographical regions only defaulted 4% of the offered appointments, as shown in table 5. With the chi square application, NZDI was found to be a statistical significant factor, which may influence patients’

attendance with DNLCs. Other factors such as enrolment with PPC programme, number of hospital admissions and DM related complications were studied to check if there was any association with rates of attendance. Findings are presented in table 6.

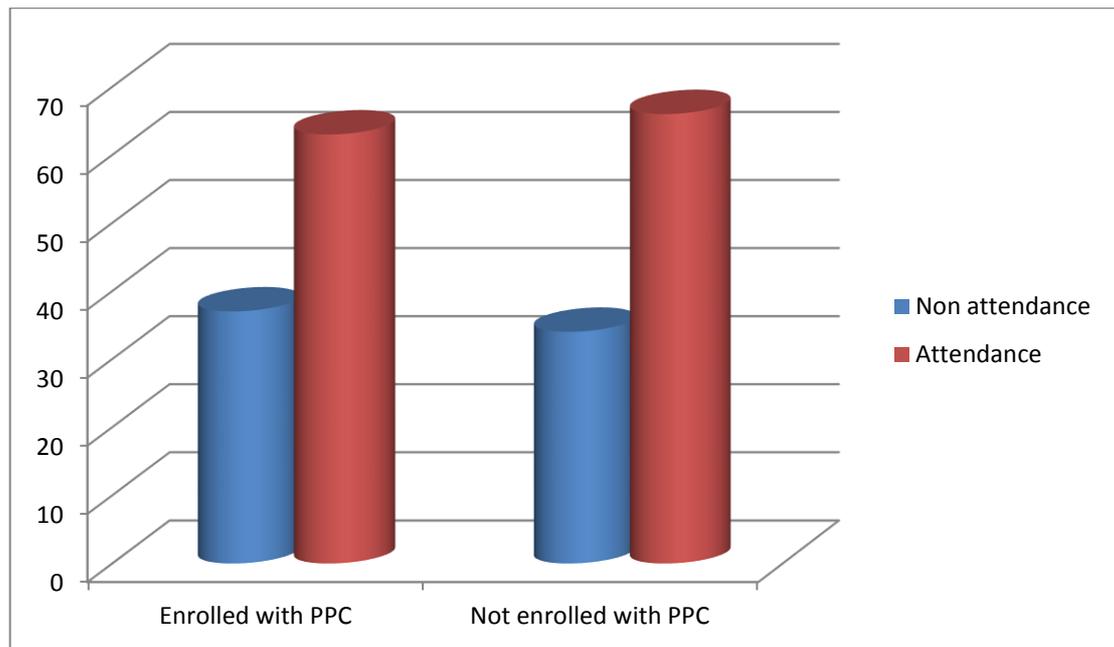
**Table 6 Other factors associated with rates of attendance**

<b>Covariate</b>	<b>Level</b>	<b>DNA N=250 (35%)  N (Row %)</b>	<b>Attendance N=457 (65%)  N (Row %)</b>	<b>Total</b>	<b>P-value</b>
<b>Shared care</b>	No	128 (34)	249 (66)	377 (53)	0.40
	Yes	122 (37)	208 (63)	330 (47)	
<b>Number of Hospital Admissions</b>	0	62 (29)	155 (71)	217 (31)	<0.0001
	1	66 (31)	144 (69)	210 (30)	
	2	32 (29)	79 (71)	111 (16)	
	3	32 (38)	53 (62)	85 (12)	
	4+	58 (69)	26 (31)	84 (12)	
<b>Acute complications</b>	0	173 (34)	333 (66)	506 (72)	0.033
	1	47 (33)	95 (67)	142 (20)	
	2+	30 (51)	29 (49)	59 (8)	
<b>Microvascular complications</b>	0	196 (35)	363 (65)	559 (79)	0.18
	1	47 (40)	70 (60)	117 (17)	
	2+	7 (23)	24 (77)	31 (4)	
<b>Macrovascular complications</b>	0	198 (35)	367 (65)	565 (80)	0.92
	1	44 (37)	75 (63)	119 (17)	
	2+	8 (35)	15 (65)	23 (3)	

#### **4.3.4 The PPC programme enrolment**

The research findings have shown that 53% of participants were not enrolled with PPC and 47% were enrolled with PPC with their GP practice as shown in figure 11.

Enrolment with the PPC programme has no statistical significance with patients' attendance with DNLCs.



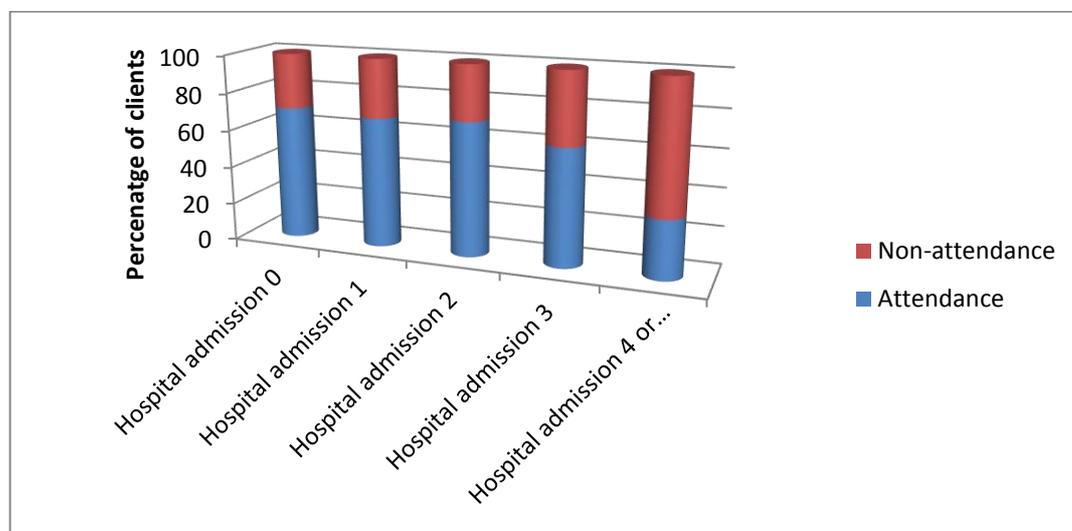
**Figure 11 Enrolment of participants with PPC**

#### **4.3.5 Hospital admissions**

Those who presented to hospital more than 4 times, had an association with a higher proportion of non-attendance to DNLCs as reflected in table 6, with a non-attendance rate of 69% and an attendance rate of 31%. Hence, attendance with DNLCs and hospital admission were found to be inversely proportional to each other and hospital admission was found to be a statistically significant factor as demonstrated in figure 12 and 13. Hospital admissions were further tested with chi square test as shown in table 7 and was again found to be significant with a p-value of <0.0001 as demonstrated by figure 12.

**Table 7 Chi square test to assess the difference in significance among number of hospital admissions**

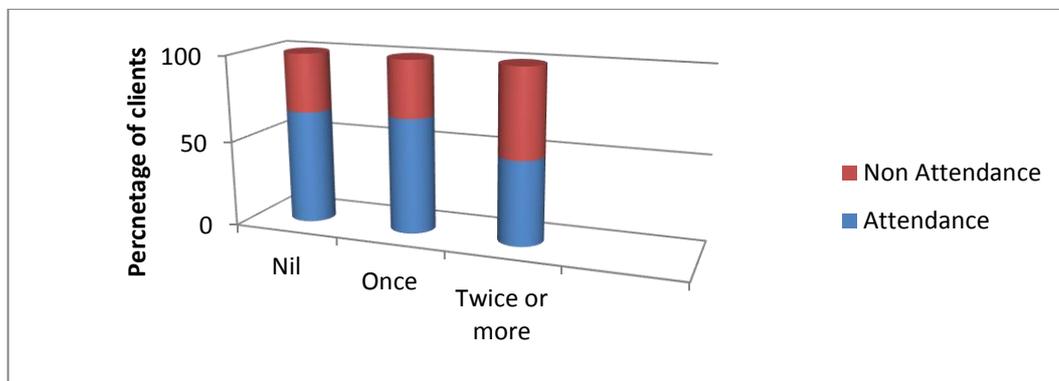
Number of Hospital Admission	DNA N=250 (35%) N (Row %)	Attendance N=457 (65%) N (Row %)	Chi square	P-value
0 to 3	110	276	49.39	<0.0001
4 or more	58	26		



**Figure 12 Overall relation of attendance with hospital admissions**

#### **4.3.6 DM related Complications**

The reason for admission and coded complications of DM were categorized into 3 sub-headings of acute, microvascular and macrovascular complications, as shown in Table 6. It was found that 66% of total patients who attended to DNLCs appointments had nil hospital admission with acute presentation of DM. Those who were admitted for an acute complication twice or more, had relatively lower attendance rates at 49% and relatively raised non-attendance rates of 51% as shown in figure 13.



**Figure 13: Hospital admission with acute complications and attendance rate**

In regards to microvascular and macrovascular complications, it was found that attendance rates were higher among those who had nil recorded microvascular and macrovascular complications, at 65% of the total proportion of patients with no complications. When chi-square test was applied on each complication variable, no significance was found. The number of hospital admissions and acute complications were found to be significantly associated with attendance rates (p-value <0.0001 and p-values 0.033 respectively), which was further confirmed by chi-square test.

#### **4.4 Comparison between two regions of service provision with logistic regression analysis**

Two regions of DNLC service provision in Mangere and Botany were compared in terms of the attendance outcome and adjusted for the risk factors and demographic variables. The comparison was made on demographic characteristics and other factors associated with attendance rates.

##### **4.4.1 Ethnicity**

Both areas of the service provision were compared among one another and the variant of ethnicity was examined. Comparison of ethnic groups showed the breakdown of the total number of stakeholders in Mangere are PI 71% followed by Māori 12%,

Europeans and Indian 7% each; Asians and others as 1% each. Whereas in Botany DNLCs, the total composition of stakeholders by ethnicity was Europeans 41%, PI 21%, Indian 14%, Asians 12%, Māori 6% and others 5%. Asians ranked as the highest attenders to DNLCs in Botany (92%) and Mangere (100%). This was followed by Europeans attending 93% in Mangere DNLCs and 82% in Botany DNLCs. Indians followed a similar trend, with an attendance of 82% in Mangere and 84% in Botany. The indigenous people of Māori origin showed an attendance rate of 48% in Mangere and 50% in Botany, which was followed by people of Pacific origin, with an attendance rate of 54% in Mangere and 44% in Botany. The people from other ethnicity have an attendance rate of 33% in Mangere and 87% in Botany as mentioned in table 8. Table 8 also confirms that rates of non-attendance remained higher among people of PI and Māori origin by 56% and 50% respectively in Botany DNLC and 46% and 52 % in Mangere DNLC respectively.

Table 10 shows the likelihood of attendance from different ethnic origins in reference to Europeans, both in the univariate and adjusted logistic regression models. It was found that in reference to Europeans, Māori and PI patients are 0.29 (71%) and 0.36 (64%) times less likely to attend their appointments respectively (Māori 95% CI; 0.13, 0.67 and PI 95% CI; 0.16, 0.82).

#### **4.4.2 Gender**

When the gender characteristic was compared between two areas of DNLC service provision, it was found that the total composition of our stakeholders was 50% males and 50% females in Mangere and 43% females and 57% males in Botany. Females in Botany DNLC attended 75% of appointments as compared to Mangere DNLCs where

only 53% of females attended all the offered appointments, a finding of statistical significance (p-value < 0.0001) as shown in Table 7. However, when the interaction was tested in a separate logistic regression model with gender and clinic, it was not found to be statistically significant (p-value=0.09).

#### ***4.4.3 New Zealand Deprivation Index***

As shown in Table 8, when the variant of NZDI was examined separately for both clinics, it was found that the total composition of our stakeholders (88%) are from the most deprived geographical region, NZDI scale 5. 8% of patients are from NZDI scale 4, 3% from NZDI scale 3, 1% from NZDI scale 2 and 0.25% represent a meagre composition of the least deprived geographical region from NZDI scale 1 in Mangere DNLCs. In Botany DNLCs, 25% were from NZDI scale 1 that is the least deprived geographical region, followed by 25% from NZDI scale 2 and 18% from NZDI scale 5 that is the most deprived, which was then followed by 17% from NZDI scale 4 and 16% from NZDI scale 3.

#### ***4.4.4 Attendance and NZDI***

The attendance rates varied from 100% in the least deprived regions, to 91% from NZDI code 2, 71% from NZDI code 3 and 55% among most patients from the most deprived regions in Mangere DNLC. Similar trends were seen among patients in the Botany DNLCs, where attendance rates were highest at 86% among least deprived areas, followed by 77% and 85% in NZDI codes 2 and 3 respectively, 66% in NZDI code 4 and 47% among those who lived in the most deprived region (NZDI code 5) for Botany. It was found that attendance rates are inversely proportional to the NZDI.

The unadjusted and adjusted logistic regression models confirmed the expression that patients living in the least deprived geographical regions are more likely to attend offered appointments, in comparison to those living in the most deprived geographical regions, as shown in table 10. In reference to patients from the least deprived regions, these patients are 4.4 times more likely to attend if coming from a least deprived geographical region (95% CI, 1.67, and 11.4).

#### ***4.4.5 The PPC programme***

It was noted that a proportion of 54% and 53% of our total stakeholders in Mangere and Botany were not enrolled with PPC. It was found that whether a patient is enrolled with PPC or not, tendency to attend DNLCs remains unaffected as mentioned in Table 9. PPC was found to be statistically non-significant.

The data was further examined to compare the other factors, which may influence patients' tendency towards attendance with DNLCs in two areas of DNLC service provision as mentioned below.

#### ***4.4.6 Hospital admissions***

It was noted that from Mangere, was 22% of total patients had nil hospital admissions, 31% had one hospital admission, and 47% had 2 or more hospital admissions.

Whereas in Botany DNLCs, 43% patients had no hospital admissions, 28% had one hospital admission and 29% had two or more hospital admissions. While comparing within each DNLC, it was noted that patients with higher attendance rates to DNLCs had no hospital admissions and patients with higher non-attendance rates had the highest number of hospital admissions. Table 7 shows those patients with no hospital

admissions attended 63% of offered appointments in Mangere and 78% in Botany DNLCs. Whereas, those who were admitted 4 or more times to hospital had the highest non-attendance rates among each group; 68% in Mangere and 72 % in Botany. This relation was found to be statistically significant ( $p < 0.0001$ ). Based on the adjusted results, those who had more than 4 hospital admissions were 0.18 times less likely to attend compared to those who had no admissions to hospital (95% CI 0.09, 0.37) as mentioned in the table 10.

The reasons for hospital admission and the coded DM related complications were explored for all patients in both clinic regions. It was found that 68% of patients in Mangere had nil acute reason for hospital presentation, 22% had one acute reason for hospital presentation and 10% had two or more acute hospital admissions as mentioned in table 9. In comparison to Botany, a similar trend was seen, where 76% had nil acute complications, 17% had one acute complication and 7% had two or more acute complications in Botany DNLCs. In regards to microvascular and macrovascular complications, similar trends were followed in both DNLCs as mentioned in table 9. It was noted that those patients who have attended their appointments, have reduced incidence of microvascular and macrovascular complications when compared with those who did not attend. Table 9 shows that in Botany DNLCs, those patients who had no microvascular and macrovascular complications, attenders were 73% and 72% respectively versus non-attenders who were 27% and 28% respectively. Similar expression was seen in Mangere DNLC, where those patients who had no microvascular and macrovascular complications, attenders were 85% and 83% respectively versus non-attenders had rates of 59% and

60% respectively. Mangere attenders had a 73% higher attendance rate to DNLCs and had no microvascular complications as shown in table 9.

**Table 8 Attendance rates between two regions of DNLC service provision for each covariate**

Covariate	Botany Rates of attendance		Mangere Rates of attendance		Total Number in Botany N	Total Number in Mangere N
	DNA N=79	A N=220	DNA N=171	A N=237		
<b>Ethnicity (N, %)</b>						
<b>Asian</b>	3 (8)	33 (92)	0 (0)	5 (100)	36 (12)	5 (1)
<b>European</b>	22 (18)	101 (82)	2 (7)	28 (93)	123 (41)	30 (7)
<b>Indian</b>	7 (16)	36 (84)	5 (18)	23 (82)	43 (14)	28 (7)
<b>Māori</b>	10 (50)	10 (50)	26 (52)	24 (48)	20 (7)	50 (12)
<b>Other</b>	2 (13)	13 (87)	4 (67)	2 (33)	15 (5)	6 (1)
<b>Pacific Islander</b>	35 (56)	27 (44)	134 (46)	155 (54)	62 (21)	289 (71)
<b>Gender (N, %)</b>						
<b>F</b>	32 (25)	98 (75)	96 (47)	109 (53)	130 (43)	205 (50)
<b>M</b>	47 (28)	122 (72)	75 (37)	128 (63)	169 (57)	203 (50)
<b>NZDI (N, %)</b>						
<b>1 (Least)</b>	10 (14)	64 (86)	0 (0)	1 (100)	74 (25)	1 (0)
<b>2</b>	17 (23)	57 (77)	0 (0)	5 (100)	74 (25)	5 (1)
<b>3</b>	7 (15)	41 (85)	1 (8)	11 (92)	48 (16)	12 (3)
<b>4</b>	17 (34)	33 (66)	9 (29)	22 (71)	50 (17)	31 (8)
<b>5 (Most)</b>	28 (53)	25 (47)	161 (45)	198 (55)	53 (18)	359 (88)

Table 9 Other factors associated with attendance of patients

Covariate	Botany Rates of attendance		Mangere Rates of attendance		Total Number in Botany N	Total Number in Mangere N
	DNA N=79	A N=220	DNA N=171	A N=237		
<b>PPC programme</b>						
<b>No</b>	39 (25)	118 (75)	89 (40)	131 (60)	157 (53)	220 (54)
<b>Yes</b>	40 (28)	102 (72)	82 (44)	106 (56)	142 (47)	188 (46)
<b>Hospital Admissions</b>						
<b>0</b>	29 (22)	100 (78)	33 (38)	55 (63)	129 (43)	88 (22)
<b>1</b>	21 (25)	64 (75)	45 (36)	80 (64)	85 (28)	125 (31)
<b>2</b>	10 (22)	35 (78)	22 (33)	44 (67)	45 (15)	66 (16)
<b>3</b>	6 (27)	16 (73)	26 (41)	37 (59)	22 (7)	63 (15)
<b>4+</b>	13 (72)	5 (28)	45 (68)	21 (32)	18 (7)	66 (16)
<b>Acute</b>						
<b>0</b>	61 (27)	167 (73)	112 (40)	166 (60)	228 (76)	278 (68)
<b>1</b>	11 (22)	40 (78)	36 (40)	55 (60)	51 (17)	91 (22)
<b>2+</b>	7 (35)	13 (65)	23 (59)	16 (41)	20 (7)	39 (10)
<b>Microvascular</b>						
<b>0</b>	69 (27)	184 (73)	127 (42)	179 (59)	253 (85)	306 (75)
<b>1</b>	10 (23)	33 (77)	37 (50)	37 (50)	43 (14)	74 (18)
<b>2+</b>	0 (0)	3 (100)	7 (25)	21 (75)	3 (1)	28 (7)
<b>Macrovascular</b>						
<b>0</b>	70 (28)	178 (72)	128 (40)	189 (60)	248 (83)	317 (78)
<b>1</b>	7 (16)	36 (84)	37 (49)	39 (51)	43 (14)	76 (19)
<b>2+</b>	2 (25)	6 (75)	6 (40)	9 (60)	8 (3)	15 (4)

**Table 10** Odd ratios with 95% Confidence interval from the unadjusted and adjusted logistic regression model showing the likelihood of attendance for Botany and Mangere DNLCs

Covariate	Level	Unadjusted Odds ratio (95% CI)	P-values Unadjusted	Adjusted Odds ratio (95% CI)*	P-values* Adjusted
<b>Clinic</b>	Botany	2.01 (1.45 ,2.78)	<0.0001	1.38 (0.28 ,6.7)	0.69
	Mangere	Reference		Reference	
<b>Age</b>	per unit (year) increase	1.02 (1.01 ,1.03)	<0.0001	1.03 (1.01 ,1.04)	0.0002
<b>Ethnicity</b>	Asian	2.36 (0.67 ,8.25)	<0.0001	1.23 (0.17 ,8.69)	0.0016
	Indian	0.92 (0.43 ,1.95)		1.29 (0.45 ,3.67)	
	Māori	0.18 (0.09 ,0.33)		0.29 (0.13 ,0.67)	
	Other	0.47 (0.16 ,1.32)		0.39 (0.1 ,1.54)	
	Pacific Islander	0.2 (0.12 ,0.33)		0.36 (0.16 ,0.82)	
	European	Reference		Reference	
<b>SEX</b>	M	1.27 (0.93 ,1.73)	0.13	1.05 (0.73 ,1.51)	0.79
	F	Reference		Reference	
<b>NZDI</b>	1	5.51 (2.75 ,11.02)	<0.0001	4.35 (1.67 ,11.36)	0.0098
	2	3.09 (1.75 ,5.47)		3.18 (1.39 ,7.28)	
	3	5.51 (2.55 ,11.88)		3.3 (1.32 ,8.27)	
	4	1.79 (1.08 ,2.97)		1.53 (0.8 ,2.93)	
	5	Reference		Reference	
<b>PPC programme</b>	Yes	0.88 (0.64 ,1.19)	0.40	0.87 (0.6 ,1.25)	0.45
	No			Reference	
<b>Hospital Admissions</b>	1	0.87 (0.58 ,1.32)	<0.0001	1.09 (0.65 ,1.82)	<0.0001
	2	0.99 (0.6 ,1.64)		1.28 (0.7 ,2.35)	
	3	0.66 (0.39 ,1.12)		0.91 (0.49 ,1.71)	
	4+	0.18 (0.1 ,0.31)		0.18 (0.09 ,0.37)	
	0	Reference		Reference	
<b>Acute</b>	1	1.05 (0.71 ,1.56)	0.04	1.34 (0.7 ,2.55)	0.24
	2+	0.5 (0.29 ,0.86)		0.72 (0.31 ,1.65)	
	0	Reference		Reference	
<b>Microvascular</b>	1	0.8 (0.54 ,1.21)	0.19	1.15 (0.62 ,2.15)	0.074
	2+	1.85 (0.78 ,4.37)		3.21 (1.17 ,8.77)	
	0	Reference		Reference	
<b>Macrovascular</b>	1	0.92 (0.61 ,1.39)	0.92	0.86 (0.4 ,1.85)	0.93
	2+	1.01 (0.42 ,2.43)		0.95 (0.29 ,3.11)	
	0	Reference		Reference	

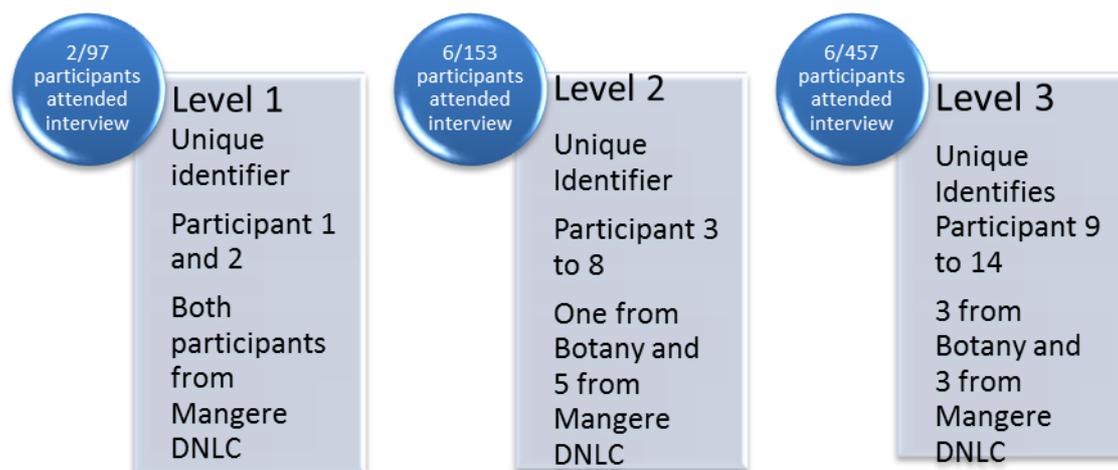
\* P-values from the full-adjusted model with the significant interaction terms (\*\*).

**Table 11 Chi square test to assess the difference in significance among ethnicity characteristics**

Ethnicity	DNA N=250 (35%) (Row %)	Attendance N=457 (65%) (Row %)	Chi Square	p-value
<b>Māori</b>	36	34	8.78	0.003
<b>Non-Māori</b>	214	423		
<b>Pacific Islander</b>	169	182		
<b>Non- PI</b>	81	239	37.34	<0.001

#### 4.5 Attendance under three levels of attendance - incidental finding of gaps in administration system

As explained in the previous chapter, the data from both regions was further categorised into three subgroups to examine for patterns of attendance, in relation to type of appointments as shown in figure 14.

**Figure 14 Three subgroups representing number and level of attendance in both regions**

These three levels were examined for demographic characteristics and other factors, which may relate to patients' attendance with DNLCs. As shown in table 10,

attendance rates were studied at three different levels and it was noted that Asians, Europeans and Indians ranked higher for their attendance in level 3, with a proportion of 93%, 84 % and 83% respectively, which was followed by other ethnic group 71 %, PI 52% and Māori 49%. Those ethnic groups with higher attendance rates showed twice the more likelihood to engage with DNLCs. Those ethnic groups, which tend not to attend the offered appointments, become the area of interest. It was also noted that patients with Māori and Pacific origin ranked the highest for non-attendance with a proportion of 17% and 19% in level 1 and 34% and 29% for level 2. Ethnicity was found to be a statistically significant co-variant for attendance in these three groups ( $p < 0.0001$ ) as mentioned in table 11.

Age is another significant factor, as patients more likely to attend are 4-5 years older than those who do not attend. A similar expression of NZDI was noted over the 3 levels as observed previously. Patients from the least deprived regions attend more appointments. Those who attended the most appointments had lesser hospital admissions, the results remained statistically significant. Gender, enrolment with PPC and DM related complications remained non-significant variants for attendance at these three levels as mentioned in table 12.

**Table 12 Sub categorisation of attendance rates into three sub groups and logistic regression table**

Region/Variables	Level 1 DNA N=97 (13%)	Level 2 Attended FSA, DNA F/up N=153 (22%)	Level 3 Attended all N=457 (65%)	P- value*	P- value**
<b>Clinic n (%)</b> Botany	41 (14)	38 (13)	220 (74)	<.0001	0.0039
Mangere	56 (14)	115 (28)	237 (58)		
<b>Age; mean (SD)</b>	48 (15.2)	52 (13.1)	55 (15.9)	<.0001	0.03
<b>Ethnicity (n, %)</b> Asian	0 (0)	3 (7)	38 (93)	<.0001	0.75
European	9 (6)	15 (10)	129 (84)		
Indian	6 (8)	6 (8)	59 (83)		
Māori	12 (17)	24 (34)	34 (49)		
Other	2 (10)	4 (19)	15 (71)		
Pacific Islander	68 (19)	101 (29)	182 (52)		
<b>Gender (n, %)</b> F	46 (14)	82 (24)	207 (62)	0.205	0.34
M	51 (14)	71 (19)	250 (67)		
<b>NZDI (n, %)</b> 1 (Least)	1 (1)	9 (12)	65 (87)	<.0001	0.11*
2	10 (13)	7 (9)	62 (78)		
3	2 (3)	6 (10)	52 (87)		
4	12 (15)	14 (17)	55 (68)		
5 (Most)	72 (17)	117 (28)	223 (54)		
<b>Shared care</b> No	55 (15)	73 (19)	249 (66)	0.269	0.17
Yes	42 (13)	80 (24)	208 (63)		
<b>Hospital Admissions</b> 0	24 (11)	38 (18)	155 (71)	<.0001	<0.0001
1	64 (30)	2 (1)	144 (69)		
2	9 (8)	23 (21)	79 (71)		
3	0 (0)	32 (38)	53 (62)		
4+	0 (0)	58 (69)	26 (31)		
<b>Acute Complications</b> 0	69 (14)	104 (21)	333 (66)	0.13	0.87
1	17 (12)	30 (21)	95 (67)		
2+	11 (19)	19 (32)	29 (49)		
<b>Microvascular</b> 0	84 (15)	112 (20)	363 (65)	0.034	0.013*
1	13 (11)	34 (29)	70 (60)		
2+	0 (0)	7 (23)	24 (77)		
<b>Macrovascular</b> 0	79 (14)	119 (21)	367 (65)	0.80*	0.50*
1	14 (12)	30 (25)	75 (63)		
2+	4 (17)	4 (17)	15 (65)		

The parametric p-value is calculated by ANOVA for numerical covariates and chi-square test for categorical covariates. \* Fisher exact test used. \*\*Comparing the two groups under non-attendance

#### **4.6 Summary of Quantitative findings**

The purpose of this retrospective audit was to confirm attendance rates and any causative relationships of demographic features with attendance and non-attendance. This audit has confirmed that total uptake of the DNLC service was shown as 65% in both regions of the service provision. The study reveals that the highest non-attendance rate was found in the Mangere DNLCs as compared to Botany DNLCs. This study has also confirmed the statistically significant difference between demographic features of the population living in the Mangere region versus Botany region, which confirmed that geography matters for patients' engagement. This study has shown significant variations in attendance, especially for age, gender, ethnicity and NZDI. People, who tend to attend their appointment, were found to be 5 years older than those who do not tend to attend, with a mean age of 50 years. This research has also confirmed that NZDI plays an important role as a social determinant for the uptake of health-care provision. This study has revealed that the attendance with a DNLC is inversely proportionate with NZDI. Higher attendance was seen among people from the lower NZDI decile, which represents the least deprived population.

#### **4.7 Conclusion**

This chapter has presented the findings of quantitative research methods. The research findings have confirmed the extent of attendance and non-attendance rates. The audit has also confirmed the causative factors associated with attendance and non-attendance. Those identified causative factors, which seem to be associated with attendance and non-attendance, will be further explored in the qualitative research section will be well presented in the proceeding chapter.

## **Chapter 5 Qualitative results**

### **5.1 Introduction**

This chapter will report qualitative research results in three main sections. The first section, will present demographic information of participants, linking this to attendance and non-attendance with DNLCs. The second section will highlight the psychological, social and economic factors for their influence on attendance with DNLCs. This will also highlight patients' perceived barriers and facilitators, which will provide in-depth understanding of findings in order to answer the research question. The third section will highlight participants' feedback on service provision, referral process and administrative aspects, which have influenced their decision making for the uptake of appointments and influence upon their engagement with care providers. The researcher gained rich data, which was organised by emerging themes. Direct quotes will be used to present the phenomenological expression of the research findings. Tables and graphs will be utilized to aid the interpretation of findings.

### **5.2 Demographic Data**

#### **5.2.1 Age and gender**

As mentioned in table 13, Individual identification will be kept confidential, by applying individual numbers to participants to label the quotes. There were only 2 participants from level 1, which represents those patients who did not attend any booked appointments. One was male aged 28 years and the other was female aged 29 years. Participants in level 2 refer to those participants who attended FSA but did not attend follow up appointments, which included 4 males and 2 females, with an age range of 27 to 71 years. Participants in level 3 refer to those participants who have always attended their booked appointments, which included all males (7) with an age

range of 45 to 82 years. A noticeable variation was observed for age in each level of attendance. An association between female gender and non-attendance to appointments including FSA and/or follow up was revealed. It has also revealed that level 3 had nil female participants, as compared to the other two levels.

**Table 13 Age, Gender and unique identifier of participants in three levels**

Region	Level 1 (Unique identifier Participant 1-2)	Level 2 (Unique identifier participant 3-8)	Level 3 (Unique identifier participant 9-14)
DNLC1 (Mangere)	28M, 29F	27F, 58M, 48F, 53 M,	82M, 45M, 60M, 58 M
DNLC 2 (Botany)	Nil	52M, 71M	64M, 61 M, 58M

### **5.2.2 Duration of DM**

There was an obvious difference for duration of DM between the three levels. In level 1, the duration varied from a few months to 13 years. Among level 2 participants, it varied from 3 years to 23 years. Whereas level 3 participants had a duration range of 27 years to 35 years.

### **5.2.3 Country of birth and migration**

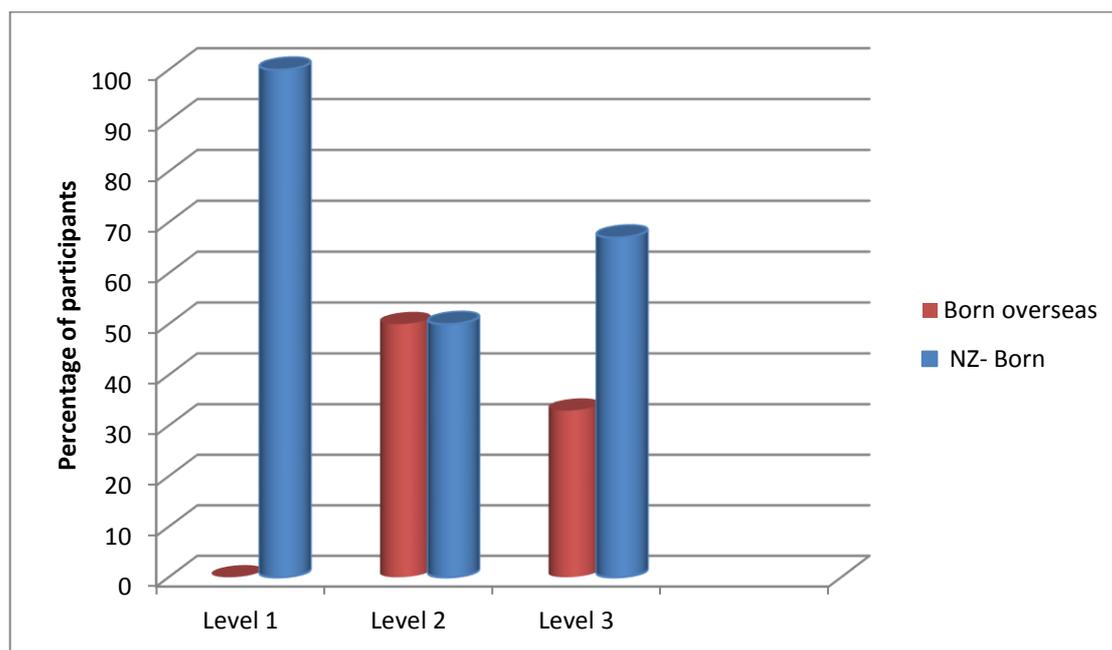
Considering the fact that NZ is a multi-ethnic country and CMH's stakeholders have diverse ethnic backgrounds. Therefore, it was considered vital to determine the country of origin (as mentioned in figure 15), migration and its perceived influence in relation to patients' attendance with DNLCs. Among level 1, both participants were born in NZ. Half of participants from level 2 and four out of six participants in level 3 were born in NZ. The remaining three participants from level 2 and two participants from level 3 migrated from; Tonga, Niue, Fiji and Asia. Migrated participants responded that they only developed DM after migration to NZ, as proven by participants' reflection on their immigration medical screening. They highlighted three factors contributing for DM development post migration which included; readily available and intake of fast food, sedentary lifestyle, and vigilant screening for DM in NZ as compared to their home country.

*"I came to NZ in 2000 and after coming to NZ I got diabetes. I just checked before I came here (in NZ) from the islands and it was negative."* *Participant 7*

*"Yes, migrated in 1984. Diabetes came after migration, during year 2001. I didn't had diabetes in Tonga."* *Participant 8*

*"Yes, at back home in China, Here is better, If I could have been back home, I don't think Doctors would have catch DM earlier than here."* *Participant 14*

In relation to attendance rates, it was noted that participants, who have migrated from overseas are more likely to attend as compared to those born in NZ, as reflected in figure 15.



**Figure 15 Country of birth of participants**

#### ***5.2.4 Employment and Education Status***

As mentioned in tables 14 and 15, the education status and employment status depicts that level 3 participants have higher academic qualifications which indicates their higher ability to understand the need to manage their long term condition, as compared to level 1 and level 2 participants. Secondly level 3 participants were retired or were in skilled or stable professional jobs, as compared to those who defaulted appointments. It was further confirmed, that taking leave from work wasn't expressed as a barrier by level 3 participants, whereas it was perceived as a barrier by patients who did not attend their appointments in level 1.

**Table 14 Employment status of participants**

Region	Employment status Level 1	Employment status Level 2	Employment status Level 3
DNLC 1	Commercial painter on casual basis.  Not working	Looking for - WINZ benefit.  Working as HCA.	Retired Electrician.  Civil engineer  Unemployed on sickness benefit
DNLC 2	Nil participant	Not working.  On sickness benefit.  Retired, working as local board member.  Folk lifter.	Multiple business owners. Semi-retired  Retired.  Mechanical engineer

**Table 15 Education status of participants**

Region	Education Status Level 1	Education Status Level 2	Education Status Level 3
DNLC 1	National certificate  Year 13, form 7	Completed year 11 have completed employment programme at MIT.  Completed 3 <sup>rd</sup> form.	Certificate.  Masters.  5 <sup>th</sup> Form.
DNLC 2	Nil participant	Year 3.  Form 3 and tertiary degree in theology.  Year 5.  Year 10.	Graduation.  Senior secondary.  Graduation

Thus, section one has highlighted the demographic features and its association with attendance and non-attendance with DNLCs. The next section will highlight the

thematic analysis of participants' expression for the reasons associated with their attendance and non-attendance with DNLCs.

### **5.3 Psycho-socio-economic factors**

This section will highlight participants' experiences of living with DM, their views on DM self-management and perceptions about the support that they receive for their self-management. Most of the research participants expressed the change in their lifestyles for DM self-management is associated with socio-economic factors. Thus, these factors consequently influence their decision whether to attend appointments or not. Some participants highlighted an interesting inter-relation, between social practices and their influence DM Self-management and vice versa. Others shared their perceived barriers and facilitators as successes or challenges to attend the appointments. The data was classified under three main overlapping factors including psychological, social and economic factors as discussed below.

#### ***5.3.1 Psychological Factors***

##### ***Health Literacy, Acceptance, Lived experience of DM and Motivation***

Both participants of the level 1, expressed understanding DM as a long-term condition, which delays one's ability to heal if any injury occurs and requires ongoing self-care with a purposive effort to control DM. Participants expressed DM as an additional commitment on top of other commitments for survival. One participant highlighted that DM is literally not a disease, as it only becomes a problem once it is un-controlled. The other participant rather emphasised, that DM is a problem of mind and self-control. Both responders expressed similar feelings, while highlighting their financial in-ability to manage this disease continuously by eating healthy food.

Participants verbalised lack of acceptance of diagnosis, self-trust and self-motivation in managing their DM. Both participants expressed their lived experience of DM related acute complications.

*“Ongoing disease takes place if you don’t take care of yourself, just like rust to a car. I am not used to taking medications, so it’s just that adapting to it.. Maintaining it.. And trying to keep up with everything else in the life.”* Participant 1

*“I don’t think it’s a disease. I know people can die from it if it’s uncontrolled but it’s not a disease. For Me it’s to get myself to believe and to actually do what I am doing to control it and to control the bad effects of diabetes.”* Participant 2

All of level 2 participants also expressed their understanding of DM as a long-term disease, but expressed a more clear understanding of the risk of developing DM related complications, as a consequence of hyperglycaemia due to uncontrolled DM. These participants had lived experience of DM related chronic complications; partial vision loss, pain and sensations of burning feet when having hyperglycaemia and expressed sexual frustration due to erectile dysfunction. The experience of sweating and body shakes due to hypoglycaemia was also mentioned by level 2 participants.

*“Even at the middle of night; I feel I get hypo you know. I can’t even get up. I sit on the ground and eat it (jelly beans). I shake that much that I can even fall; I can see I am falling over. I can feel it when it’s coming. I don’t get hypos often, it only happens when I don’t eat or I have dysentery. I keep jellybeans with me.”* Participant 3

However, three participants of level 2 did not verbalise any internalization or acceptance of DM. The other three participants clearly verbalised that they have accepted DM and they understood the need to manage it by undertaking care as advised. Three participants highlighted a feeling of dependence upon medication to stay alive. Two participants highlighted the frightening; disempowering and limiting lived experience of hypoglycaemia. Participants perceived hypoglycaemia as restrictive and limiting their ability to cook independently and drive safely on the roads.

*“If I get a hypo I get into trouble. If I get hypo that means I can’t cook or I can’t take insulin before I drive or I don’t drive after 4 o clock as I have taken my insulin by then. So, it affects my ability of concentration and co-ordination.” Participant 3*

Among level 3 participants, four participants expressed that DM is an ongoing disease. The remaining two participants expressed that DM is a ‘silent killer.’ All participants expressed acceptance of DM by making good lifestyle adjustments such as; eating a more balanced diet, making their life more organised, being conscious of DM as part of their everyday life, especially while making food choices, and the need to test glucose levels. Three participants clearly described the pathophysiology of T1DM and T2DM in simple words. They also reflected on their need for insulin replacement with self-injections of insulin. All of these participants expressed acceptance of their diagnosis of DM and have also experienced DM related complications.

*“Pancreas reduces the amount of insulin and there is resistance in uptake of insulin by cells in type 2 DM.”*

*Participant 12*

*“It’s a silent killer, you can get diabetes and can think it’s not going to do any harm to you but no anything can happen. I certainly know what diabetes does to the body.”*

*Participant 10*

*“My pancreas is no longer producing insulin, so I have to inject. So, I have manual control instead of a person has an automatic control, just like a car.”* Participant 13

Three participants in level 3 also expressed a feeling of restrictive lifestyle including; label reading, checking and matching carbohydrate content in meals with their insulin dose, portion size and glucose testing. One participant responded that attending the appointments helps people to stay positive and motivated, which ultimately help people to recover or manage their DM well and live a longer life.

Finally, it was evident that level 3, who attended all their appointments, had higher health literacy about DM and had adapted to the details of self-management adjustments, as compared to those from levels 1 and 2. Secondly, the acceptance of disease appeared higher among level 3 as compared to participants of levels 1 and 2. Interestingly, all the participants expressed their lived experience of complications, but this knowledge itself does not seem to impress their decision making, to attend or not attend the appointments.

### **Motivation**

Both participants of level 1 reported lack of motivation. One responded that he was motivated in the beginning when first diagnosed with DM to know all about DM and self-care. However, the participant's need to learn wasn't served by primary and secondary care providers immediately upon diagnosis. This participant was referred by his GP to consult with a DNS, in regards to DM education and resources. The participant was informed about the physical address of the proposed DNLC by their GP. This participant decided to walk into the DNLC for a consultation with a DNS. But the receptionist at DNLC advised the patient that he would need to wait until he received an appointment letter. The participant found this response quite unhelpful. This participant raised the concern that he was available as he had taken time off from work to recover from the acute symptoms of DM. The appointment came weeks later when the symptoms had improved and the participant had resumed his usual responsibilities and commitments of life. The participant was unimpressed with his first experience of CMH service and decided not to disrupt his work again, for an appointment offered by CMH.

*“I rather work than attend, I came before but I was advised to wait. By the time, I received the letter; I was very full on with work. I was newly diagnosed so was trying to catch up with DNS, also because I had 2 weeks off. But I had to wait; I should not have to wait.”*

*Participant 1*

The other respondent talked about her ability to manage DM really well when she was pregnant. This participant expressed higher motivation as she knew she would be

rewarded with a baby for doing so. However since delivering the baby, motivation had dropped.

*“I guess finding that I am pregnant was major news for me. As I knew it took my husband and me so long to get me pregnant. So, I guess, someone growing in me was the biggest motivation to control my diabetes.”*

*Participant 2*

The participants of level 2 expressed their motivation and mind-set for self-responsibility as a facilitator, which they believe helps them to make and maintain lifestyle changes. In level 3, participants stated that self-responsibility, self-motivation and readiness, appropriate referrals made by the GP to consult with the DNS and guidance from the DNS, were facilitators for self-management of DM.

Thus, lack of motivation was perceived as a barrier for attendance by level 1.

Motivation to self-manage was considered as an enabler, to attend the appointments by level 2 and level 3 participants.

### ***Participants’ perceptions about support with DM self-management***

Among level 1, one participant responded that family members and a social network like church members to aid the management. This participant also had health professionals mainly the GP, who explained information to enhance understanding of ways to manage.

*“I would say my partner, my family, my church, the constant reminding. Just for them to start a question about it. The nurses the doctors, they just break it down for me how the diabetes works.”*

*Participant 1*

Whereas the other participant highlighted that self-management is about a person’s own self-acceptance of the disease, self-readiness, self-motivation and self-determination to self-control the glucose levels.

*“My husband tries to tell me about diet, he actually tries to push me to eat more vegetables but it doesn’t help me, I think it’s up to me. I know he is trying to help me but it’s up to me whether I want to follow or not. Big No, No... For talking to a family, church and even same ethnic group. I feel more comfortable talking to outsiders about my condition.”*

*Participant 2*

Level 2 participants expressed that family members are supportive, by making changes to their family meals such as; cessation of additive sugar in their food, encouragement to buy healthy food and giving reminders about medication and self-care. All of these participants received support from a DNS. Participants explained that the DNS gives them advice; on the portion size of food, shares resources like books and pamphlets with them, suggests to them different sources of starch, reminds them about healthy food choices, suggests means of remembering self-cares and makes appropriate referrals to other relevant health professionals when required. The participants also reflected, that they liked the way DNSs make pictorial or graphical presentation of their laboratory results to enhance understanding. The participants recognised and acknowledged the use of a unique sense of humour by DNSs,

preserving patients' status and discussing sensitive topics whilst considering patients' strengths and weaknesses of self-management, in a beneficial manner to enhance their therapeutic relationship with the DNS.

*“My mum, she gives me non-sugar stuffs; she does meals, with no or less sugar in it you know. DNS gave me book with what has high in sugar and what don't, they educated me. I didn't know as GP doesn't have anything to do with it. He just keep saying that your numbers are high you know.”*

*Participant 3*

*“My partner encourages me to eat the right food, keep up with medications. Dr. and Diabetes Nurse, they encourage me to eat the right food”*

*Participant 5*

Participants also verbalised that they also received support from their GP and DM doctors. There was an expression of dissatisfaction with the support they received from their GP. One participant rationalised this, by saying that his GP doesn't give sufficient information on lifestyle changes, especially dietary changes. Another participant also expressed that his GP is more focussed on the numbers of laboratory results instead of dealing with him as a whole person.

*“In regards to education, DNS did really - really well. In Manukau Super Clinic, the Doctors (Dr) just said that don't eat pies, and stuffs and that was harder. That was Diabetes Dr. He just gave me chance by saying don't eat this and that. They don't tell you enough. So Drs didn't really explain well. GP is definitely more focussed on laboratory results and numbers instead of me as a person”*

*Participant 3*

Thus, level 2 participants praised for the support that they received from their family members and DNS, which act as enablers for attendance. One participant expressed that DM self-care remains self-responsibility, whilst receiving support from family members and a DNS.

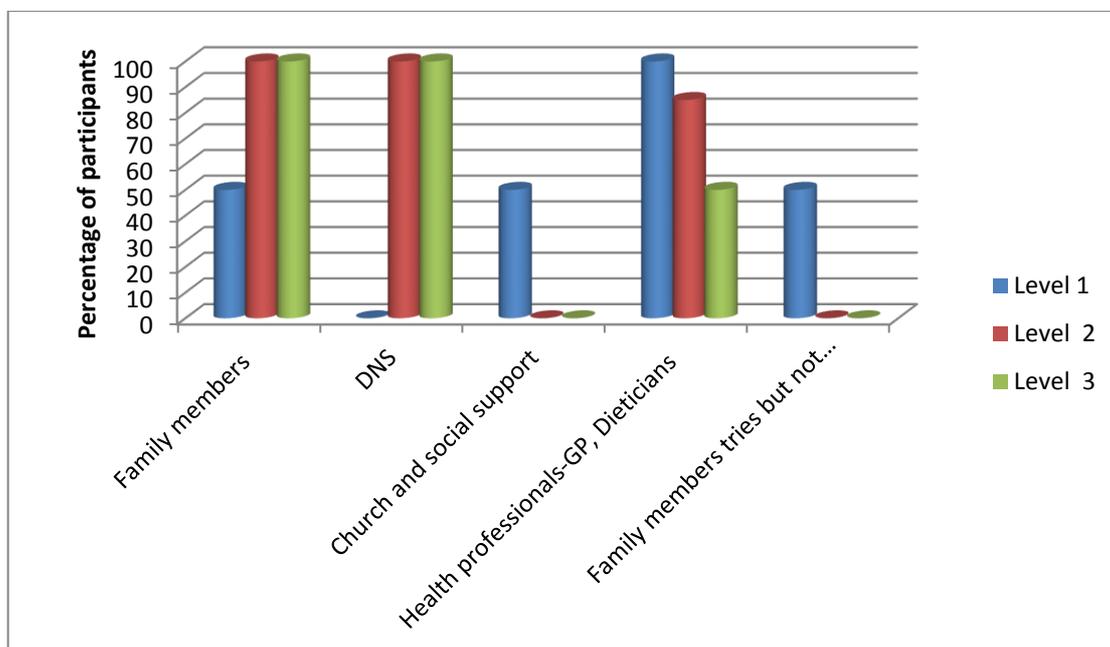
Among level 3 participants, all participants expressed receiving support from family members and a DNS. They rationalised their responses by highlighting, that their partner cooks healthy food for them and also helps them by giving reminders about self-management in their everyday life. Participants highlighted, that their children also remind them about the daily self-management activities from time to time. Participants highlighted the importance of education that they received from DNS consultations and their appropriate referrals to a dietician and group education sessions. Three participants reported getting support from their GP but there was nil response from participants, for receiving support from PNs.

*“Health Professional, Diabetes Nurse and family – my wife she make sure I take my injections and my pills for diabetes.”*

*Participant 10*

*“Health professional, my wife and children. When I was diagnosed, I went to MSC, DNS gave a group discussion, and from there I start changing my life.”*

*Participant 11*



**Figure 16 Participants' perception about support with DM self-management**

In summary, those participants who received and accepted support from family members tend to attend their appointments as compared to others. Support from DNSs was perceived by levels 2 and 3 participants as an enhancer to attend and engage, whereas level 1 missed out on those supportive measures, since they did not attend any appointments, as shown in Figure 16.

### ***Role of early interventions and influence on patient engagement***

#### **Emotional state of participants on diagnosis of DM and initial advice on management upon diagnosis**

Participants from all three levels were asked to comment on the initial emotions upon hearing the diagnosis of DM. They were also asked for their perceptions about the initial advice that they received on diagnosis of DM for self-management. The role of initial advice was explored in relation to participants' attendance and non-attendance.

Both participants from level 1 expressed their experience of negative emotions by sharing their thoughts upon hearing the diagnosis as those of; shock, shame, denial, hard to accept it, wish to ignore it, blame the genes. Below are some quotes from patients:

*“I was so young. I didn’t know anyone of my age had diabetes. I always thought it was something that old people get. I didn’t want to know about it. I just put a barrier on. May be that’s why till now it is uncontrolled you know I just didn’t want to know about it, don’t want to think about it at all.”*

*Participant 2*

*“Yeah... I was gutted, felt like I got it too young. I was shocked and ashamed and Ahhh I tried to deny it, but it was there like your mind still feels healthy but your body doesn’t... So being a deny with myself.”*

*Participant 1*

Participants expressed that the diagnosis was declared by their GP to them. One participant expressed that the GP wasn’t sure as to which type of DM and subsequent treatment options as mentioned in the quote below.

*“At first doctor thought I was type 2 but the symptoms I had was like type 1, but they didn’t know if I should have at least 2 tablets in the morning or one tablet a day with insulin.”*

*Participant 1*

The other participant expressed that they were immediately referred to a dietician to reduce their sugar intake and were forced to do exercise.

*“I was refereed to Dietician to cut my sugar down and put up with more exercise.”*

*Participant 2*

Thus, the un-certainty in establishment of the diagnosis and subsequent management plan wasn't perceived as a positive factor by the participant, which consequently effected engagement. The referral to a dietician was also not perceived as a positive option. It was rather perceived restrictive by the participant. Thus, these participants expressed the experience of negative emotions upon diagnosis, an expression of unsurity of management and perception that diet would be restrictive.

Among level 2, all participants received the confirmation of diagnosis from their GP. Four out of six participants expressed feelings of negative emotions including feeling; disturbed, overwhelmed, guilty, shocked and blamed their genes. Participant expressions were as follows:

*“So, I was already going through the survivor's guilt, it took me couple of years to get over that and on top of that Diabetes came. I was overwhelmed, had guilt and shock of Diabetes.”*

*Participant 3*

*“Serious, Shock. Didn't think I'll get it but my dad had it so it passed down to me and I got it, because I was eating healthy.”*

*Participant 4*

The other two participants expressed that they didn't worry about DM and did not experience any negative emotions, as they had other important things happening in their life, which were their priority at that time.

*“I didn’t have any feelings. I wasn’t really shocked. I thought I have this condition and it will be fixed up. I had full confidence in Middlemore. I personally think I had more important things in my life to manage than Diabetes.”* Participant 6

*“I didn’t care about what Doctor told me. Because at that time I was looking after for my son’s sickness. I didn’t look after myself. Now, Diabetes is going bad. Now, I realize that I look after myself and take my medication”* Participant 7

In regards to advice upon initial diagnosis, two participants were immediately referred to hospital and a speciality clinic. Four out of six participants commented, that they were advised to undertake changes in diet, but without specific details regarding how to follow the advice. Thus, the advice that they received did not provide the specific information to promote self-management of DM.

Among participants from level 3, four participants expressed an experience of negative emotions upon hearing the diagnosis including; guilt, self-blame, sadness, tearfulness, shock, worry, stress and fear of death. Two participants expressed no emotional disturbance upon hearing the diagnosis, these participants rather expressed, that they had other priorities in life to manage instead of DM. However, there was some reflection from participants about their priority based decisions at that time of diagnosis, as mentioned in the following quote

*“Back then, I thought I am fit enough and nothing will happen to me. But after experiencing amputation and dialysis, now I think how wrong I was.”*

*Participant 10*

*“Initially, I was a bit frightened when I thought it will reduce my life span by few years. It is not impacting that hard way on my life as I first thought.. Yes, learning the skills from DNS gave me the confidence to deal with it by my own; it’s nothing to be afraid of.”*

*Participant 12*

*“I thought I am going to die and my life will be terrible. I was guilty as it has happened due to my laziness. I was shocked but still tried to follow instructions. But no, not anymore.”*

*Participant 14*

Interestingly, among those four responders, although there was variation in emotions experienced, all of these participants expressed fear of death due to DM. Five out of six participants expressed readiness and were motivated to learn how to make adjustments in their life to live well with DM. The reason for motivation was highlighted, as a wish to stay alive to be around for family and children. This was also found to be a valid reason behind the emotion of worry, illustrated by other participants of the study. Participants from this group praised the support that they received from their health professionals and family members, which acted as an enabler for them to accept this new diagnosis.

The GP declared the diagnosis to these participants. Half of level 3 participants expressed that they were given advice on food and lifestyle changes, but that information wasn’t sufficient to make those changes to manage their DM.

*“Doctor just explained but it wasn’t enough. He said first reduce your weight. STOP sugar content food. DO MORE exercise. Keep positive mind/positive thinking and take NO stress. He said all this on his fingertips. You know Drs don’t have too much time, only in several minutes he said all that you know”.* Participant 14

Though this participant expressed the given advice wasn’t sufficient. However, positive words worked to promote engagement with the DNS. This participant managed to put his DM into remission, self-managing with lifestyle modifiers only after cessation of medications. The remaining three participants responded that they were not given any initial verbal advice on lifestyle changes. One participant reported not receiving any verbal advice, but a pamphlet was given to read which was difficult to understand mainly regarding the link between carbohydrates and blood glucose levels. Another participant reported that the only memory he could recall, was when the doctor said the following as quoted

*“I can only remember Dr. Saying that in 20-30 years’ time you can go blind and lose your limb because of diabetes. But he didn’t say anything about what I had to do like eating properly”* Participant 13

Sadly, this participant had an amputation and end stage renal failure after 25 year duration of having DM.

Two participants were referred to hospital and DNLCs. Those participants co-related this referral to a thought, that GPs often don’t have that much time to explain these basic things to patients, because they are busy and have more patients to see in their waiting rooms; and doctors were not fully equipped to initiate insulin therapy, hence

referred the participant to hospital. There was an expression of distress and disruption to their business and family life upon going to hospital.

Conclusively, all the participants from the three levels reported experiences of negative emotions, distinct acceptance of diagnosis and insufficient advice on self-management of DM. Participants also expressed, that they had different priorities of life upon the diagnosis and that was the reason behind their lack of motivation to self-manage. Thus, there was a variation in self-motivation among participants while experiencing those negative emotions. Interestingly, level 3 participants who attended all appointments expressed their reflections upon self-actualisation of being unaware at the time diagnosis, of the real problems that DM can really cause with its complications. Their thoughts of non-acceptance of diagnosis were converted to acceptance of diagnosis, expressed as the undertaking of self-motivation due to a fear of death and wishing to stay alive for their families. Thus, those participants who experienced self-motivation and self-realization of DM and its progressive nature seem to attend their appointments as compared to those who have not self-actualise the consequences of DM just yet. Therefore, the role of initial advice remains crucial to enhance patients' engagement with health professionals, to gain self-management skills.

### ***Participants views on current ways of learning about DM***

#### ***In-effective learning from health education***

A level 1 participant expressed that DM is a problem of mind, self-motivation and self-control as mentioned in figure 17. This participant expressed her feelings around in-effective learning from health education, which is given by health professionals,

and felt that support was unrelated to self-motivation. The participant also stated that when patients are not ready to listen and self-manage, then those support factors have no impact.

*“The same thing that I have always heard. What diabetes is, what it does to me, how to control, manage, things I can do to like change. Yes, these things that I have always heard in diabetes clinic.”*

*Participant 2*

*“I think, at the end of the day it’s not your job or GP’s job to push us. It’s more about us, whether I get myself to do it or not. It comes down to self and self-management. So, you can tell us, at the end of the day, it’s up to the person.”*

*Participant 2*

Among level 2 participants, availability of food that the family eats, was identified as a barrier to self-control, which hinders concordance to the advice given by health professionals, rendering the advice in-effective as mentioned below

*“Everything I can hear, doctor, diabetes nurse can tell me everything but for me I can’t do what they say. Sometimes I do but sometimes I can’t. It’s like I better eat this that not supposed to eat. Because, it’s like due to culture and having more food at home. Because my family brings food that’s why I can’t stop. Plus if I cook, it’s only me who eat more.”*

*Participant 7*

*Effective learning from others experiences*

Interestingly, half of level 2 participants expressed a fear of complications. Out of those three participants, two highlighted their experience of learning by observing others, who had experience of loss due to DM related complications.

*“Losing legs and eyesight makes it serious, because it is scary to see that people can lose body parts just by not taking care of themselves.”* *Participant 4*

One participant expressed that he had a physical tour organised by service providers in some other branch. Another participant said he watched a programme on television. These visual learning aided them, to see live examples of those people who have undergone amputations, dialysis and gone blind due to poor control of DM. These participants expressed this as an eye-opening event for them. They were able to visualise themselves in the same stage if they continued to ignore their DM and self-management. Participants said those events really enhanced their motivation to self-manage and control their DM by engaging with health professionals, to avoid such injurious consequences.

*“The xyz team took me around and showed me, which really scared me that people had their legs taken off because they didn’t listen. They carried on eating sugar and drinking. So their kidneys became bad, they had to go through dialysis and they had to lose their legs”* *Participant 7*

The lead researcher asked “what do you think was that a positive or negative experience for you?”

*“Oh, definitely, scare them; scare them to get them straight right. It did to me. It’s the real world, the reality. It made me come straight you know. Because when you are first told to make changes then you don’t know as you are not educated about it, you only know what you know, so you don’t know the reality until you show them that this is what going to happen to them if they don’t control.”* Participant 7

*This programme on television about Middlemore showed a guy who was blind because he didn’t take notice of the fact that he has Diabetes. You can’t play with health professionals. If you have diabetes, it comes to personal responsibility, it’s very important. Yes, I would support that programme, I think it’s a very good example to learn to co-operate with health professionals.* Participant 6

Another two participants in level 3 reflected that although people cannot feel any symptoms, but internally DM is harming them.

*“It’s a silent killer, one can think it’s not going to do any harm to you but no anything can happen.”* Participant 10

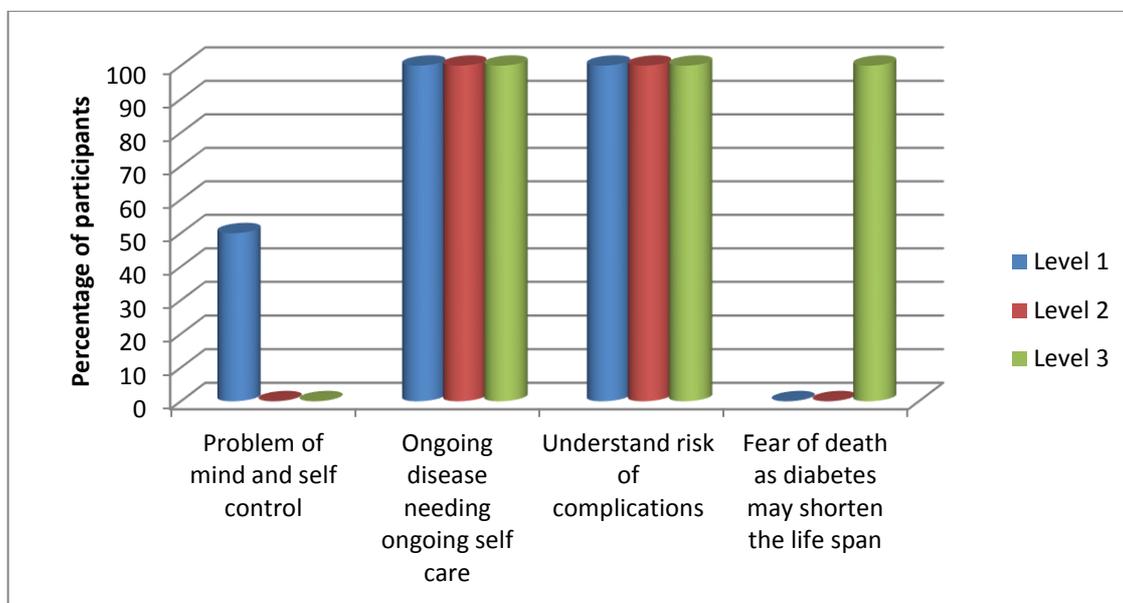
There was one participant in level 3, who has experienced the severe complications of DM in his life and impressed the wish to be a live example for people who have DM. This participant highlighted his learning from life, when he did not self-manage his DM in the beginning, as he did not realize back then that DM complications could be real. Since this participant has experienced multiple complications including; bilateral below knee amputation rendering him wheelchair bound, undergoing haemodialysis 3

times a week and having poor vision; he expressed that there is a need to commence visual tours or sessions, so that people can gain inspiration from live examples of people who have experienced those complications.

*“Back then, I thought I am fit enough and nothing will happen to me. But how wrong I was... Well, when I first lost my limbs, I wanted to get in to may be not a course but a place to spread a message that this is what happens when you don’t listen to your diabetes health professionals,*

*Participant 10*

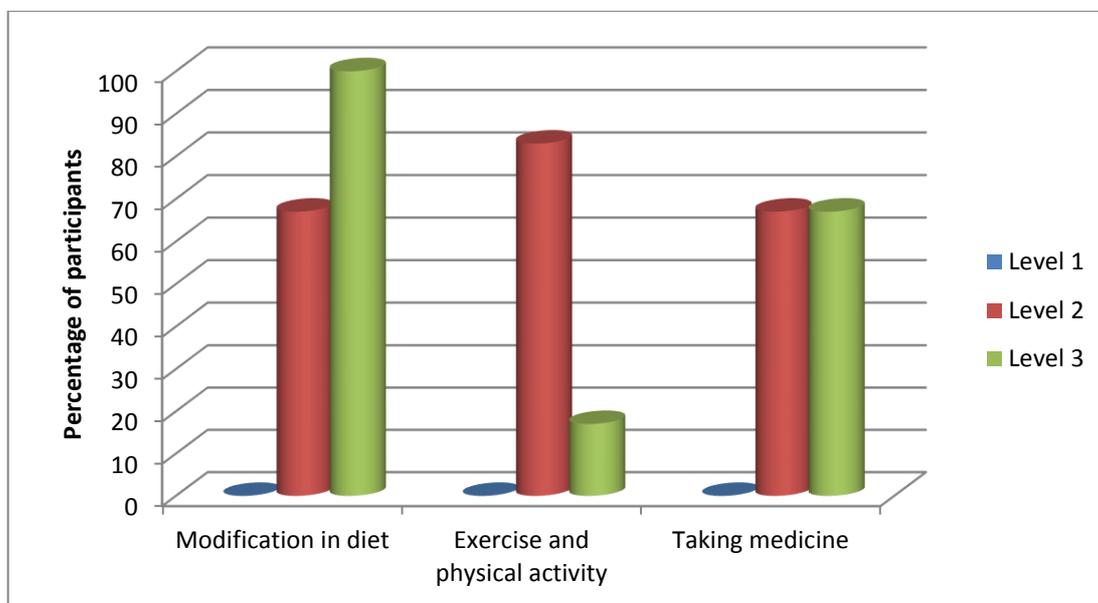
Thus, levels 1 and 2 participants expressed that current ways of creating awareness about DM are not effective enough to raise self-motivation and self-control on carbohydrate portion size, which was perceived as a hindrance to follow the advice of health professionals. Levels 2 and 3 participants who are partial attenders and always attenders, expressed their views that learning from real life examples may make people living with DM self-realise and self-actualise about the reality of the progressive nature of DM. This in turn may raise people’s self-motivation, which will indirectly help them self-control and engage better by active listening with the care providers.



**Figure 17 Participants understanding and their insights towards DM**

### ***Readiness to make change encourages attendance***

Participants expressed their views about changes they have made to their lifestyle to manage DM. These responses have highlighted that participants' readiness to make changes, encourages attendance with DNLCs. These factors will be discussed under the following themes of modification with diet, role of exercise and physical activity; and taking medications as mentioned in Figure 18.



**Figure 18 Readiness to make lifestyle changes enhances attendance**

### ***Modification with diet***

Level 1 participants said that they have not made any changes to their lifestyle.

Despite of making no conscious changes to their life, still they are more aware and cautious about healthy and unhealthy food choices.

*“Too expensive to buy healthy food”*

*Participant 1*

*“Like the cost of food is a barrier”*

*Participant 2*

Among level 2 responders, four participants expressed that they have made changes to their diet to manage their DM. Those changes include eating more organic food including vegetables and fruits, choosing fruits wisely, reducing the intake and size of bananas, reducing portion size generally, and avoiding sugar and processed foods especially sources of starch. These participants also expressed, that it took them about 6 months to adapt to these changes and it wasn’t an easy transition for them. Two participants expressed no change in lifestyle due to DM. One out of those two

expressed, that it is a struggle to make lifestyle changes due to cultural barriers, especially in controlling portion size.

All participants in level 3 expressed that they have made changes in dietary habits. They also expressed their willingness and motivation to make these changes, despite these changes being out of their comfort zone. Among all participants, two participants expressed they are still finding this modification challenging especially their struggle with controlling food portion size and that living alone makes self-care further difficult. One participant said he cooks only for himself, it becomes hard to control the portion size, because food ingredients are not available in small packs; hence he either ends up wasting food or eating more than what he needs. Whereas two participants highlighted their pre-existing good habits of eating healthy and eating un-processed food items with minimal sugar content. These participants reflected that continuing these pre-existing habits made their transition easier.

Consequently, existing healthy eating habits and modification in diet was a facilitator to attend the appointments.

### ***Exercise and physical activity***

Among Level 1, both participants expressed no formal change in their life in regards to commencing exercise and physical activity for management of DM. One respondent talked about physical activities that they normally do at work. The other respondent stated that lack of energy was a barrier to physical activity. On the other hand, five participants expressed that they have added exercise, mainly walking, since their diagnosis in level 2. One participant reported nil change since the diagnosis of

DM. Among level 3, most participants expressed their ability to make such adjustments as a part of their life since being diagnosed with DM.

Thus, those participants who have made exercise and changes in physical activity seem to attend the appointments as compared to those who haven't made any such lifestyle adjustments.

### ***Medications***

Among level 1, participants expressed varied response in relation to taking medications. One responder said that if he ate healthy then he didn't need to take medicines. The other participant confirmed that she is not taking any medications to manage her DM, despite being aware that her DM is uncontrolled. Whereas, in level 2, four participants responded that taking medication is a change in their life that has occurred due to DM. Participants' appeared to be happy and thankful for medications, which enabled them to manage their DM. Among level 3, four participants' expressed that taking medication was a change in their life. Accordingly, higher medication adherence is associated with patients' tendency to attend the DNLC appointments.

### **5.4 Perceived barriers and facilitators to attendance**

To explore the associated factors with attendance and non-attendance, all the participants were asked for their views on barriers and facilitators in regards to their attendance or non-attendance with DNLCs. All participants were also asked for the views on potential preconceived barriers that the researcher thought might potentially interfere with patients' ability to attend.

#### **5.4.1 Level 1 participants**

Both participants expressed psychological factors with relevant reasons behind their responses as mentioned earlier under the section of motivation. They also raised socio-economic factors as mentioned below

#### ***Social Factors***

These participants expressed social factors and their influence upon their decision making was observed. Both participants expressed the influence of peers, who do not manage their DM and highlighted that surroundings matter to them. One participant expressed the realisation of this challenge in regards to the need to change.

Participants said that since they were young, they have been eating what their family eats, which is carbohydrate rich food and large amounts of meat. Since developing DM, these participants are expected to change their eating habits. These participants reported their effort to change, but this change doesn't endure because at the end of the day, the family want to eat the way they have always eaten. Both participants expressed that inability to make change was one of the barriers to attendance, as people are scared of being judged and perceived it as failures they felt scared to attend.

*“I think it has got to be with whom you interact and area you live, no vegetarian shops in the area so then you have to go out, taking time to drive, and financially you are able to do this or not.*

*Participant 1*

These participants also confirmed that family commitments influence participants' ability to attend the appointments, since the participants preferred to continue with the

roles towards their families instead of attending the appointments. One participant was the main earner for his dependants, thus preferred to go to work. The other participant was a mother, whose dependent child was unwell, hence her priority was to nurse the child thus she was unable to attend.

### ***Economic factors***

The level 1 participant expressed the challenge of economic factors as barriers to attend. Participants highlighted that eating healthy food is expensive and unavailable in the area where they live. Participants reported the geographical concerns which influence their ability to purchase unhealthy food options, when healthy options are not readily available in the nearby markets. It then becomes a choice between driving around to buy healthy food, which again costs in petrol, versus purchasing what is more readily available but perhaps not as healthy. The financial impact of travelling for such purchases interferes in such decision-making.

*“I think it is just ahhh it has got to be with who you interact with hmmm your area to , no vegetarian shops in the area so then you have to go out, taking time to drive ,and financially you are able to do this or not.”*

*Participant 1*

These participants elaborated their thoughts, by sharing their experiences when they have tried to eat healthy choices, but lost motivation to maintain such habits over time, due to their inability to afford such foods. In addition, these participants further highlighted their responsibility to provide food for their family members is their first priority, instead of attending appointments for their own health. One participant responded that taking leave from work for the appointment wasn't thought to be a

wise option, considering two weeks of sick leave was taken recently due to acute complications of DM. This participant also expressed his tendency to avoid consulting with his GP, even for acute problems related to DM, for example an infected boil, due to fear of hospitalisation which will affect the family financially due to unpaid time off from work.

*“Like I had a boil on my foot but I was scared to go to the doctors, because I knew they will send me to hospital. Because I’m a painter and if I stay I will not get paid so I am the provider for the family so I put them first before me.”* Participant 1

One participant stated, that the day of week also matters, with better financial affordability from midweek onwards. Since she receives social welfare financial support on Wednesday mornings; hence days after Wednesday are more affordable.

#### **5.4.2 Level 2 participants**

Half of these participants expressed psychological, economic and social factors as enablers and barriers for attendance. Level 2 participants also expressed, that the availability of food rich in carbohydrates in the fridge at home and in nearby shops or the market, compels them to eat that food, thus they find it really challenging to switch from the food that they have always eaten to the suggested meals by health professionals, which have a lot of salad. Though participants did not raise this concern as a precipitating factor for non-attendance, it was a connecting factor with non-attendance, when participants were unable to follow DNSs’ advice.

*“Like whatever in the fridge is normally like the pacific island food like taro and beef. So trying to adjust, bringing in the salad was like Oh... you are eating salad (from other family members). So, it’s more kind of the expectation of food that your peers. I think its culture, being brought up with that culture and with that food around us since when I was a baby.”* Participant 2

*“Because, it’s due to culture and more food at home. Because my family brings food, I can’t stop plus if I cook, it’s only me who eat more.”* Participant 7

Another two participants expressed social factors as barriers. One participant expressed that he did not attend the appointment when his father was seriously unwell. This participant also expressed that during that time, he also had issues with his teeth, and hence he wasn’t eating as healthy as normally he would have, while following suggestions about food from the DNS. Thus, this affected his decision making to attend the appointment as mentioned in figure 19.

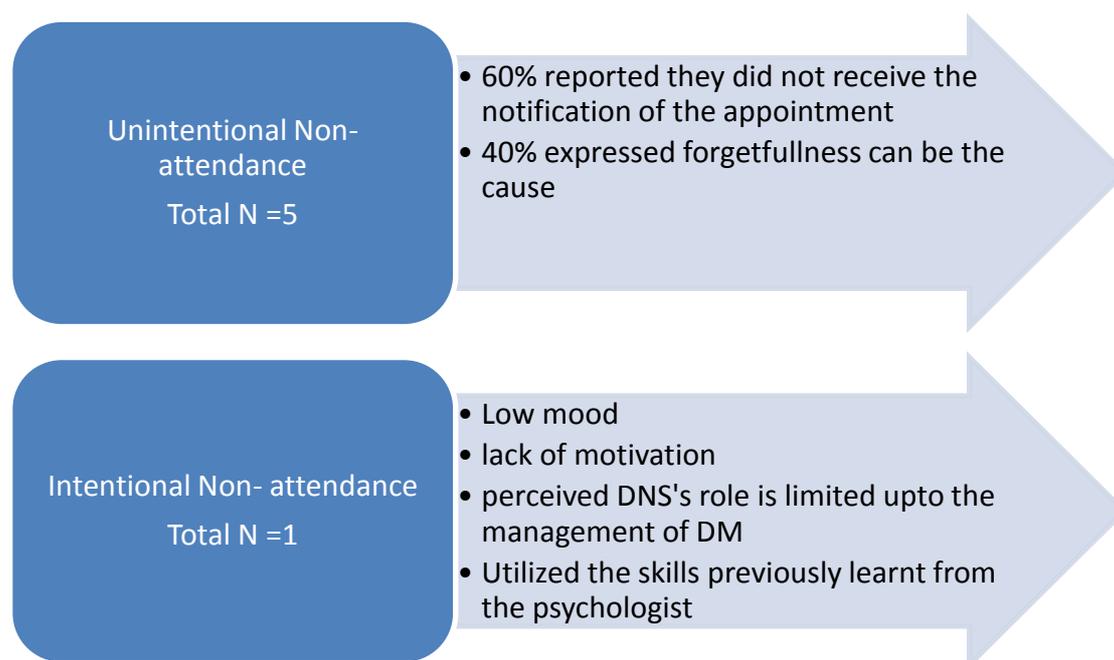
*“I was stressed as my dad was sick and me being sick. I knew myself that my numbers are high and what DNS going to do about this. I was frustrated I was so sick, no teeth and couldn’t eat anything properly, so it was overwhelming.”* Participant 3

Level 2 participants also emphasised on enablers as feeling of motivation and empowerment after meeting with a DNS. The DNS gives them a positive sense of belongingness and they appreciate the professional consultation of one- to-one, which was perceived as an enabler to attend.

*“My Diabetes Nurse, I always see her every 3 months. She helps me a lot. She tell me the right things but it’s my choice to do or don’t.”* Participant 3

*“I think I have been very well treated. I am also a person, I love people. You all are nice people. If I get an opportunity to empower, I enjoy that. Once, I leave from here, I feel empowered “* Participant 6

Four participants highlighted that the personal interaction with a DNS, makes them feel connected to a professional which enhances their DM self- management. These participants expressed a feeling of satisfaction at being assessed and getting confirmation of their progress. Three participants stated that they like to meet with the DNS, but it still comes to their self-responsibility to follow the advice from the DNS or not.



**Figure 19 Barriers for non-attendance verbalised by Level 2 participants**

In regards to non-attendance by level 2 patients, five participants were not aware that they did not attend their follow up appointment. Four out of those five participants adamantly expressed no knowledge of being informed about the offered appointment via letter, and therefore they did not attend appointment. Among these four participants, two raised the concern that they received a call from the clinic receptionist, who told them that they were supposed to attend their appointment, but the notice was too late to reach the clinic in time. These participants expressed feelings of frustration and disappointment at not being able to go through the consultation with their DNS because letter came after the actual appointment. Another two participants said they wanted to attend their appointments but they often forget things and it wasn't a surprise to them that they did not attend. The participants were then advised the dates of appointments they had missed. The participants tried to think of their life circumstances at that time and expressed mixed responses by saying they always want to attend appointments, however they expressed some hindrance about attending when they know they are unable to manage DM as suggested by the DNS. These participants felt fear of having high glucose levels in the blood results and were afraid of what the blood results will be.

A participant expressed his intentional non-attendance in level 2. This participant expressed his feelings of low mood, lack of motivation, fear of being judged by the DNS for high blood glucose levels and under-estimated the role of the DNS in his circumstances. This participant expressed his situation at that time, when he had toothache and struggled to eat healthy food and he didn't expect that his DNS could help him with this problem. He also experienced low mood and lack of motivation

and felt being in a difficult patch of his life. He preferred not to attend the appointment, where he thought the DNS won't be able to help him. He instead preferred to utilize the skills that he learnt from psychologists and psychiatrists. He expressed being successful in recovery from that rough patch of his life. There was also an expression of feeling overwhelmed, due to multiple appointments from different specialty departments.

### ***5.4.3 Level 3 participants***

These participants verbalised the reasons for their attendance with all appointments as enablers. All of these participants reported being motivated and supported by the DNS, to gain confidence in their self-management. They expressed that attending DNS appointments gives them opportunity to learn more about DM self-management. These participants further verbalised, that they like to receive feedback and a confirmation from the DNS about whether they are managing their DM satisfactorily or not. One participant verbalised, that prior to meeting with the DNS, he tried to self-learn about DM and management skills, but he became overwhelmed with contradictory advice available in books and on the Internet. This participant verbalised that he felt an information deluge and didn't know what to do. The DNS confirmed the advice on lifestyle changes and medications, which enabled participants to manage their DM satisfactorily.

Level 3 participants also expressed social factors as enablers such as involvement of family, especially when family reminds and helps them to eat healthy by buying healthy food items. One participant expressed that he lives alone which makes self-management challenging, especially in regards to control of portion size. This

participant expressed that he does not like to waste food, but buying small packs are often dearer than buying in bulk. This participant expressed that the after effect of attending the appointment is very positive, which re-enforced him to self-manage DM. Thus, attending the appointment itself was perceived as an enabler to attend the next appointment.

*“It’s a positive after effect you get after the appointment”* Participant 9

*“It’s just my cooking and portion size. Like when I can buy baked beans for 99 cents a can then why should I buy half a can which is costly than full can. I accept their advice, but it’s just the portion size that I struggle with.”* Participant 9

#### **Summary of Section 5.4**

In conclusion, socio-economic factors were perceived as barriers to attend by participants of level 1 and level 2. Simultaneously, DNS consultation and support from family members was perceived as an enabler to attend the appointments by level 2 and 3 participants, since it promotes positive re-enforcement to self-manage.

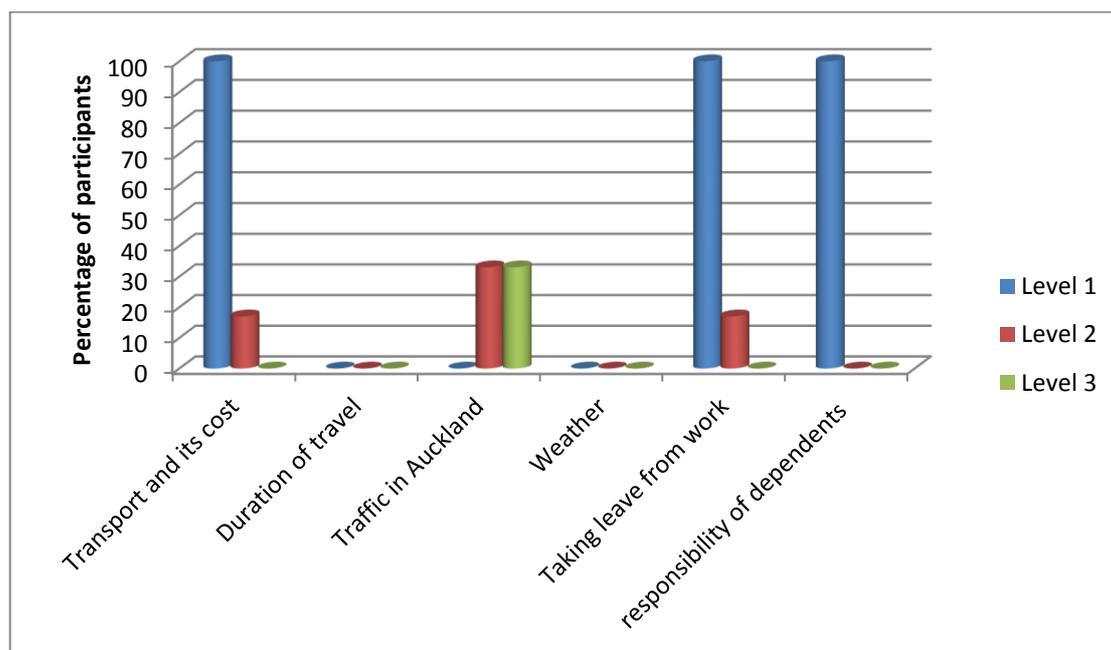
#### **5.5 Participants’ response for potential pre-conceived barriers**

As mentioned in figure 20, both participants in level 1 positively identified transport and its cost of travel as a significant financial barrier to attendance. They also confirmed that variation in weather, duration of travel, traffic and previous experience with a DNS has no association with their non-attendance. Whereas in Level 3, all participants expressed that transport and its cost is not a barrier to attend the appointments as they live nearby to the clinic. However, two participants expressed

that time of day matters for the traffic, because although they live nearby, traffic is a significant factor in rush hour. Similar responses were received from level 2 participants for pre-conceived barriers to attendance.

Level 1 participants highlighted family commitments such as earning for their dependants, their childcare and taking leave was a barrier to attend. Whereas level 3 participants, expressed that childcare is not a barrier to attend. Participants reported that employment and changing weather had no effect on their ability to attend the appointments.

Both participants in level 1 confirmed that previous experience with the DNS has no association with their non-attendance. A similar response was given by level 2 and level 3, that previous experience with the DNS was very satisfactory, which was an enabler for participants to attend all of their appointments.



**Figure 20** Participants responses for pre-conceived barriers

## **5.6 Diabetes Service Provision**

### ***5.6.1 Feedback on service provision – Level 1***

Participants were asked to express their feedback on service provision and to give recommendations to enhance their engagement. Level 1 participants disclosed the following themes; need for easier access to service, need for friendly frontline face of service, being heard and listened to is important, fear of being judged especially by health professionals of same ethnic group, current awareness is not helpful. These themes are summarised in Figure 21.

#### ***Need for easier access to service***

One of the participants expressed the need for easier access to the service, for those who are newly diagnosed and are younger in age. This participant had struggled to get access in a timely manner that suited him. Another viewpoint was that although older people need more care and attention; health professionals must remember the needs of younger adults also.

*“Just got to be open minded. Not only older people with diabetes, there are young ones too, so you can’t forget the young ones and you can’t neglect the young ones.*

*More access to information to newly diagnosed.”*

*Participant 1*

#### ***Need for friendly frontline face of Service***

Both participants suggested, that the front-line staff who interact with patients in the beginning, have an impact on patients’ engagement. Thus, both participants identified that their previous experience, which was with a non-clinical person, wasn’t perceived to be friendly by them, which inhibited attendance. Thus, the front-line staff needs to

be more friendly and co-operative with patients. One participant verbalised that her dependent child was admitted to the hospital and reported feeling coerced to attend the appointment when telephoned with a reminder. This participant expressed that attending this appointment was nowhere on her priority list and to finish the conversation, the participant agreed to call back once she was ready to attend. The researcher further explored this response and then found the following answers

*“The person was trying to push me to get in for the appointment, but I told her that the baby is sick, and I shall call back but I didn’t call back.”*      *Participant 2*

*“Having second thoughts on the behaviour shown when asked to wait for the appointment. Did not meet my expectation.”*      *Participant 1*

### ***Being heard and listened to is important***

Both participants expressed that being heard is important. Instead of health professionals going on with the topic around DM and its management, listening to the patients are most important and sometimes missing. Health professionals talk about the same things around DM. One participant expressed her feelings of frustration at having to listen to the same lesson repeatedly.

*“It’s about being heard. Like how you are sitting here, listening to me, instead of saying do this this.”*      *Participant 2*

***Fear of being judged especially by health professionals of same ethnic group***

One participant also expressed, that when she come to attend such appointments, she is in a position where she has not been able to manage her condition well. She feels uncomfortable while being interrogated by health professionals, when questioned about why she is unable to manage her DM. The discomfort further increases, when the health professionals are from her ethnic group. The participant expressed feeling uncomfortable consulting with GPs of her own ethnic group. The participant expressed a fear of being judged by the health professional from the same ethnic group, because they know the cultural background. Thus researcher asked - Is there a fear that you will get judged?

*“Not really a fear. Its, I guess about being uncomfortable as I know that I have got it, not been doing well. GP talking to me about it, so, It’s more like you have been questioned or you feel interrogated or around all that lines.”* Participant 2

*“I guess, my GP has Samoan doctors and it’s like myself being Samoan, and another person also Samoan, I feel uncomfortable speaking to another Samoan, who is telling I have got this and that. So, that is another factor.”* Participant 2

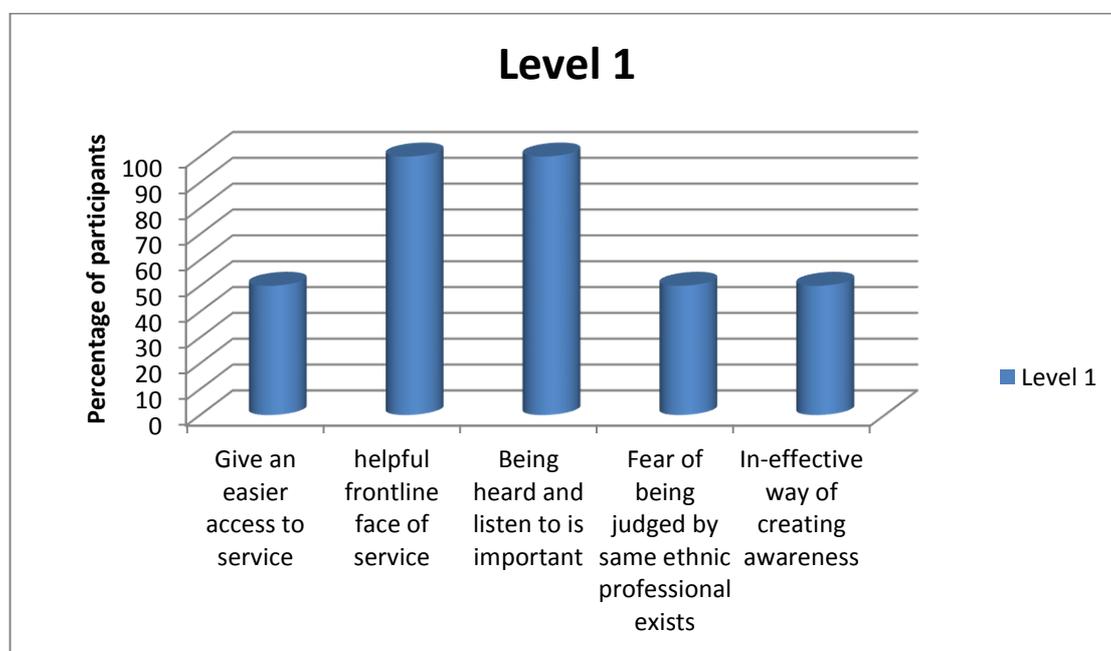
Researcher further asked - So, You think if diabetes nurse is not from same ethnic group you will open up more?

*Yes, exactly, I shall open up more and shall be more comfortable to speak with like you. Instead of you if I was doing an interview with a Samoan person, I could not*

*opened up as much as with you. Because you know there is always a cultural, background so you feel uncomfortable.”* *Participant 2*

**Current way of creating awareness**

One participant expressed, that the existing way of creating awareness about DM and its management is not effective. This participant felt that giving health education does not raise people’s self-motivation to engage. Thus, the current approach to DM management was a reason for non-engagement with the service provision.



**Figure 21 Feedback from Level 1 participants**

**5.6.2 Feedback on service provision**

The following information is regarding feedback from participants on service provision and around quality improvement, which was mainly expressed by levels 2 and 3 participants as mentioned in figure 22. Those facilitators were themed under the

following headings; motivation and empowerment, raising health literacy, seeking confirmation and guidance is important and perceived individualised care.

### ***Motivation and empowerment***

Opposing to level 1, all participants from levels 2 and 3, expressed feelings of motivation and empowerment, after meeting with a DNS. Participants expressed the benefits of attending the clinic, as they learned better ways to manage their DM, gained literacy on healthy food choices and were reminded to practice their self-management skills. Participants expressed that the DNS enables them to control their DM, by suggesting changes with lifestyle and helps them understand their laboratory results in an easy manner. These participants expressed that they were well encouraged by the DNS and they felt empowered with different tools and health literacy, which enabled them to feel confident to manage this condition independently. Participants expressed their gratefulness towards the service and DNS, for supporting them to gain clear insight and further motivating them to manage their disease. They also expressed that the service format is great and all patients with DM should utilize this service to enable them manage their DM well.

### ***Raising Health literacy***

Level 2 participants expressed their receptiveness around the advice given by DNSs, for food choices and portion size. All participants confirmed that DNSs increased their health literacy in level 2. Similar expression was seen from all level 3 participants, that the DNS enhanced their learning and their health literacy to manage their own condition. Participants rationalised their response, by expressing their advanced abilities including carbohydrate counting, self-glucose testing,

carbohydrates oriented to insulin dose titration, identification and management of hypoglycaemia and hyperglycaemia. The participants also confirmed that prior to seeing the DNS; they struggled to learn management skills due to vast amount of contradictory information available. Participants expressed difficulty in deciding what information to follow.

***Seeking confirmation and guidance is important***

Levels 2 and 3 participants confirmed that it is important for them to seek ongoing confirmation as to whether they are managing their DM well or not. As DM fluctuates, consequently the need for guidance to manage also changes over time. Participants expressed that living with DM requires an ongoing support system in place. Participants expressed great trust and confidence in the service provision and highlighted the importance of the inter-personal-professional relationship with the DNS. Participants acknowledged the respect they feel towards the professional approach by the DNS. Participants also expressed their feelings of personal belongingness with the DNS. Participants expressed that the DNS guides them with ways to overcome the self-management challenges and assists them to achieve success. These participants expressed the need for guidance throughout the lifetime. These participants also expressed how the sense of humour of a DNS can make them feel connected with the DNS. Participants also highlighted those times when they were unable to manage their DM as well as they could have, and they were prepared to face the gesture of disappointment from the DNS. However, participants further expressed this to motivate them, as they don't want to disappoint their DNS, who is working closely with them to manage their DM.

These participants also confirmed that the DNS can assess their blood results and explain them in a creative way, for example using graphical presentation to make information easy to understand. They also confirmed that the DNS checks their feet, eyes, and abdominal site for the injections and makes appropriate recommendations and referrals to green prescription, retinal screening, and podiatrist etc. if indicated. Participants appreciated that the DNS gives them suggestions instead of instructions. They also confirmed that these checks give them confirmation about whether they are on the right track and they utilize the DNS's advice and guidance to manage their DM well.

### ***Perceived individualised care***

In level 2, four out of six participants expressed that they are fully satisfied with the service they have received. These four participants verbalised that the DNS's advice is practical for them as an individual to follow. Conversely, two participants raised concerns that although the DNS gives culturally sensitive advice by advising to adjust the portion size of the same traditional food, still participants find it challenging to follow. Participants from level 3 expressed their perception, that the DNS provides them individualised care, instead of generalised care. Participants were able to realize, that the care provided by the DNS to them, was mainly based on; their own individual health, their capillary blood glucose levels and their life circumstances which was also as reflected by appropriate recommendations and referrals.

Half of level 3 participants expressed, that despite feeling motivated and receiving the guidance from a DNS, there is some impact of internal readiness and their own internal motivation that enables them to follow the guidance or not. Thus, all the

participants of this group were asked to express if the advice given by DNSs matches their life, considering their beliefs, values and culture. All these participants confirmed that the advice given was sensitive to their individual life.

### ***5.6.3. Perception of limitations of DNS role***

Among level 2, a participant verbalised his perception of the limitations of the DNS role, as being more focused towards healthy eating and promoting DM management only. They perceived that when they have other health problems; the DNS can't do much to help them control their DM. They expressed their hesitation to seek help from DNSs when they were low in mood and lacking motivation.

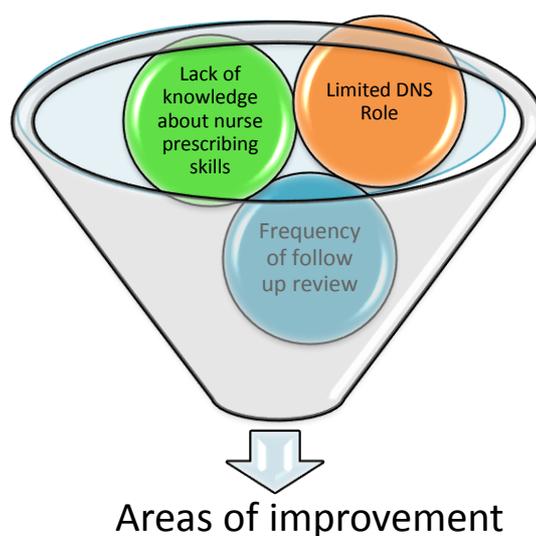
Level 3 participants appreciated the effort and input from the DNS, however participants expressed their feeling of limitation when the DNS only specialises in DM and cannot manage other health conditions. Participants expressed that the DNS has higher knowledge than a GP, to help patients' self- manage their DM. The DNS can adjust patients' insulin doses and often GPs are happy to agree with those recommendations. However, the participants still have to consult with their GP for their other medical, psychological and pharmacological needs. While addressing the above factors, participants highlighted the existence of specialty skills that they did not know existed prior to seeing a DNS, for example different types of insulin and different sizes of needles.

There was a participant in level 3, who expressed that there is a point of saturation, when the DNS has given maximum input and participants feel saturated and well empowered with the information to manage their DM. These participants expressed

that although there is still a need to monitor, education needs can be acknowledged by group education instead of one-to-one consultation. These participants informed that they had been visiting their DNS and there was a stage during the consultation where the DNS did not need to make a change with the management or education.

#### **5.6.4 Frequency of consultation with DNS**

All of the participants in level 3 expressed their need to have consultations more frequently than currently offered. Participants expressed that frequent consultation motivates them more to stay engaged with their DM self-management, as it gives them an opportunity for feedback and re-enforcement. They also linked this need with the professional relationship with the DNS. By having frequent appointments, patients get an opportunity to seek guidance and report back challenges in a timely manner.



**Figure 22 Feedback on areas of improvement by levels 2 and 3 participants**

#### ***Nurse prescribing skills***

Level 2 participants were asked for their experience of DM nurse prescribing skills.

All participants experienced insulin dose titration by a DNS. There was no expression

of experience with prescribing skills for any medications including insulin, by any of the participants. Among level 3 participants, all participants expressed their satisfactory experience of medication dose adjustments by DNSs. Only one participant experienced DNSs' prescribing skills. Five out of six participants were unaware that the DNS may be able to prescribe medications for them. Thus, the participants from levels 2 and 3 were asked for their views on the DNS prescribing DM medications for them, after gaining valid competence. These participants expressed that this would be a welcome change, as it would add convenience and will save time and money that they spend consulting the GP. It appears that creating awareness among our stakeholders about nurse prescribing skills may influence patient decision making in regards to attendance with DNLCs.

### **5.7 Management of referrals to diabetes service, administrative roles and its influence on patients' expectations – all three levels**

Considering the above-mentioned research findings, it was considered important to explore patients' viewpoints and understanding of the referral process, their experience of correspondence and their experience with administration staff (front-line staff and scheduling team). It was also considered vital to explore the referral process and its relevant influence on participants' expectations from CMH service and to further assure whether CMH service has met those expectations or not.

#### ***5.7.1 Correspondence for invitation of appointment***

In accordance with CMH guidelines, all patients who are referred to CMH outpatient clinics are initially contacted by a scheduler. The scheduler negotiates the date and time of the appointment, to ensure it is suitable to attend. The scheduler posts a letter confirming the appointment details and includes a laboratory form. However, if the

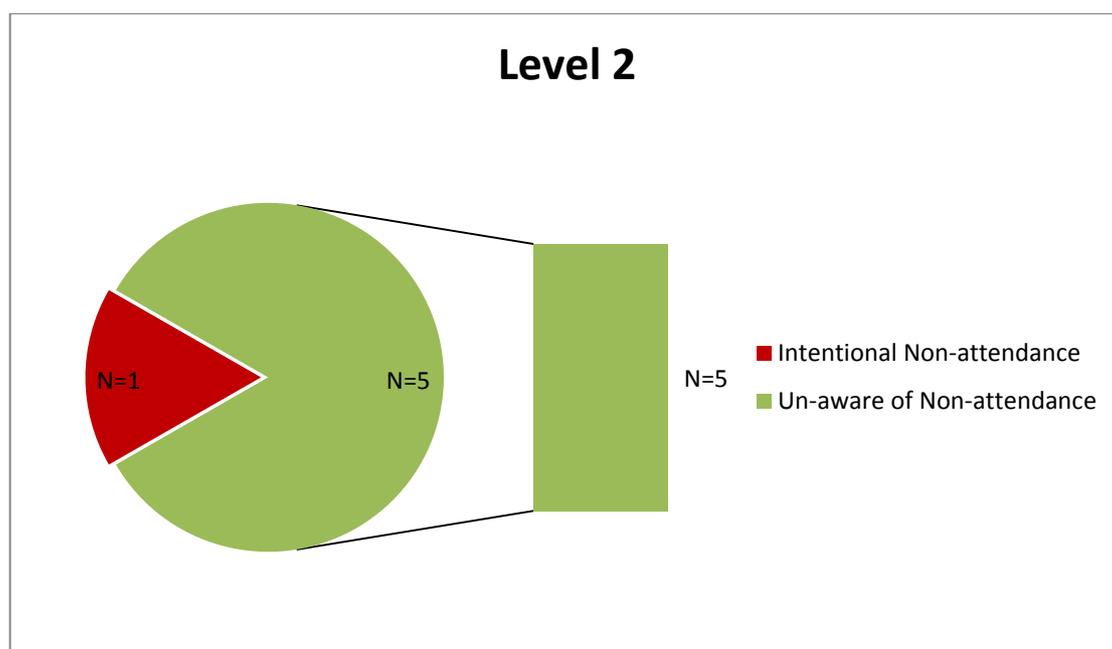
patient does not answer the phone, then a letter called Patient to Contact (PTC) is posted to the patient, inviting the patient to contact the scheduler in a given time frame. If there is no response from the patient, then the patient's referrer, mainly the GP, gets notified that the service was unable to contact the patient, hence CMH is leaving the care with primary care. The referrer is encouraged to re-refer when the patient is ready to engage.

Among Level 1 participants, one participant said they received a letter with the details of the appointment, but confirmed that there was no telephonic discussion to arrange a date and time. The other participant was also unable to remember any phone call or letter to discuss appointment arrangements. Both participants were able to remember a call that they both received a day prior to the appointment, to remind them about the appointment. This is when the participants felt a bit forced to attend the appointment, which they viewed negatively.

As mentioned in figure 24, among level 2 responders, all the participants received the confirmation of appointment via a letter in the mail. Only one participant said they received a PTC letter with the contact details, where they were asked to contact to arrange a date and time for an appointment. The other five out of six of participants confirmed that they could not remember any phone call from the scheduling team to discuss an appointment. Instead, these participants received a letter confirming an appointment with the date and time included. Half of these participants were able to remember a reminder call that they received a day prior to the appointment. All the participants expressed that the letter was easy to read. Five out of six participants said

the letter explained what to bring to the appointment, for example glucometer and medicine including insulin and participants received the laboratory test form.

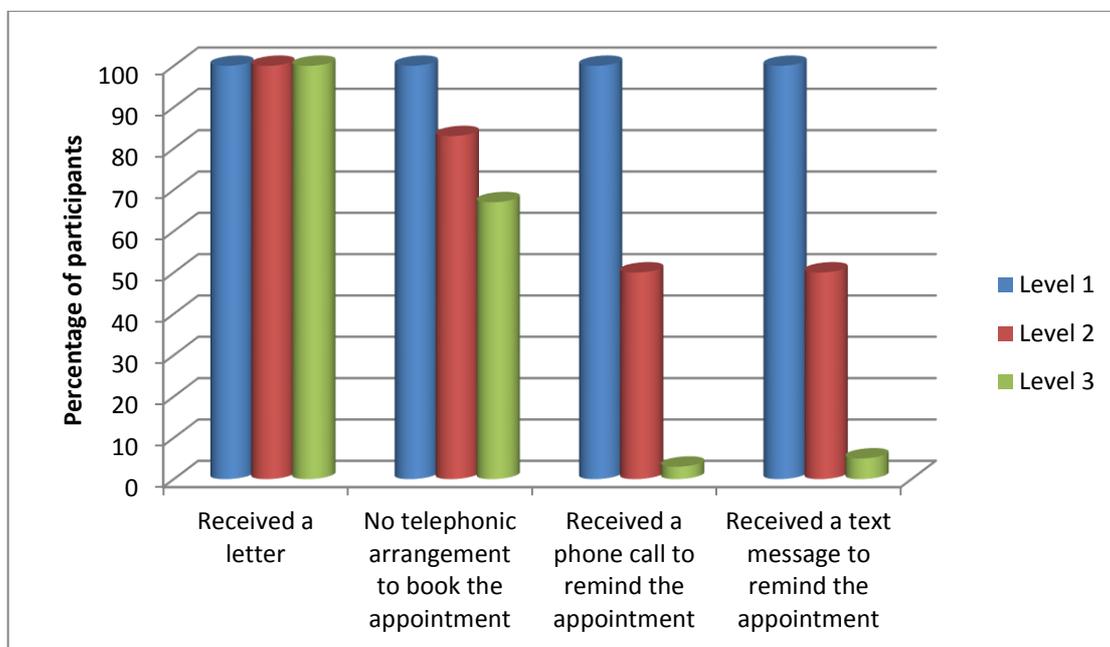
One participant confirmed being told by the DNS that he would receive a laboratory form with the appointment letter, but the participant did not receive this. This participant then visited the clinic for the laboratory form, but the receptionist did not provide the form and instead advised the patient to contact their GP for a form. This response was not received as a helpful response. Five out of six participants confirmed receiving the letter prior to the appointment, with a duration varying from 3 days to 4 weeks. But one participant reported that letter came one day after the booked appointment and that was the reason the participant couldn't attend. In regards to non-attendance by level 2 participants, figure 19 highlighted the perceived reasons, which are further summarised in figure 23 which has highlighted intentional and un-intentional non-attendance.



**Figure 23 Expression of non-attendance by level 2 participants**

Among level 3 responders, two said they received a PTC letter. The remaining four confirmed that they couldn't remember any phone call from the scheduling team to discuss scheduling of the appointment. Instead these participants received a confirmation letter containing appointment details on it. All the participants expressed that the letter was easy to read.

Thus, participants from three levels have confirmed that they didn't receive a phone call from the scheduling team and only two participants confirmed receiving a PTC letter, to negotiate the appointment arrangements. They rather received an appointment letter confirming appointment details, which did not allow patients to express whether these appointments were suitable to them or not. Though the invitation letters request that the patient informs the service if they do not want to attend the appointment, patients who already had nil interest in DM self-care did not feel the need to act upon this. There was another finding, that participants received the letter after the appointment, which was the reason for their non-attendance.



**Figure 24 Correspondence from the scheduler team of Whitiora Diabetes Service**

### ***5.7.2 Referral process***

Participants of level 1 were referred by their GP or midwife. The reason for referral for one participant was newly diagnosed DM requiring support with DM education. This participant expressed that he knew the reason for the consultation. The other participant was transitioned from midwifery care to the adult DM service. This patient was unable to remember any explanation given by the health professional regarding the reason for referral. Thus this patient did not realize the need to attend.

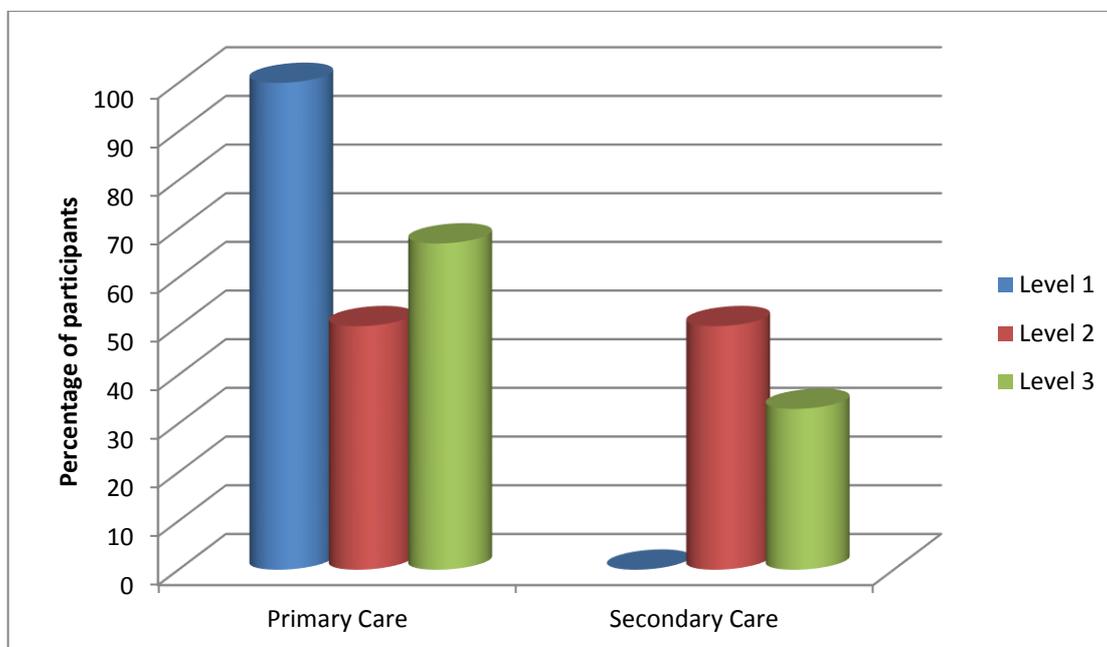
Among level 2, half of the participants were referred by GPs and half were referred by medical or nursing staff from Middlemore hospital during their most recent hospital admission, as mentioned in Figure 25. For those participants who were referred by Middlemore hospital, four of them understood the reason for the referral, as it was explained by the person who referred. The main reason verbalised was for monitoring of DM and once under control then participants would be discharged to GP care.

Among those who were referred by a GP, all of the participants understood the

reasons for the referral. The reasons for referral were explained, as receiving guidance on diet, food items best avoided and weight management. Level 2 participants didn't perceive the reasons for GP referrals positively.

Among level 3, four out of six participants were referred by GPs and two of them were referred by medical or nursing staff from Middlemore hospital. Those participants, who were referred by Middlemore hospital, understood the reason for referral. Among those who were referred by their GP, only one out of four participants understood the reasons for the referral.

Thus, those participants who were explanation for the reason for referral were able to attend their appointments. However these participants expressed their view of the scope of DNS practice, as being limited to information about foods best avoided and weight management. The DNS's role has a wider scope of practice, which needs to be advertised well to the referrers, who can then explain to patients at the time of referrals.



**Figure 25 Source of referral to Whitiara Diabetes Care**

### ***5.7.3 Expectations of participants from CMH***

Among Level 1, a participant expressed their expectation to learn more about DM and gain self-management skills. The motivation to learn and engage decreased over the waiting time. The other participant was not aware of the reason for referral; hence participant had no expectations thus did not realize the need to attend the booked appointment.

Among level 2 participants, expectations ranged from participant wished to learn more about DM and gain self-management skills; to the participants having great trust in the service provision. All of these participants responded that the service served them beyond their expectations. A similar response rate was received by participants from level 3, who expressed their expectations which included; seeking clarity about DM when feeling lost in a flood of information, gaining self-management skills and

having great trust in the service provision. These responders also gave a 100% response that the service had served them beyond their expectations.

Thus, having expectations was an enabler to attend the appointments in level 2 and level 3. There was an expression of satisfaction when those expectations were well met by the DNS.

#### ***5.7.4 Ability to remember the appointment details***

Both participants from level 1 could not remember the date, time or venue of the appointment. These participants expressed that they often write such appointments on a calendar to remind themselves. These responders received a text message and phone call as a reminder of the appointment, despite preferring not to attend.

Among level 2, half of the participants did not remember the date or time of the appointment. The remaining half managed to remember the appointments. However all participants needed to set a physical reminder for the appointments. All participants confirmed receiving the text messages as a reminder to attend the appointments and half of the participants were given phone calls as a reminder to attend the appointment.

Among level 3, two participants did not remember the appointment details. The other four participants managed to remember the appointments. All of these participants also have to set a physical reminder for the appointments. All participants confirmed receiving the text messages as a reminder to attend the appointment and half of the participants were given phone calls as a reminder to attend the appointment.

Thus, setting a physical reminder such as marking on a calendar was an enabler to attendance. The attempts of text message and phone call were not effective ways to enhance attendance for level 1 but was perceived as an enabler by levels 2 and 3.

### **5.8 Summary of qualitative results**

The qualitative research findings have explored patients' perspectives in regards to attendance and non-attendance with DNLCs and have highlighted the influence of demographic data upon attendance and non-attendance. The influence of identified psycho-social-economic factors was studied as patient factors which were perceived by participants as either facilitator or a barrier for engagement as reflected by attendance and non-attendance. The DM service provision related factors were studied as external factors, which included the impression of patients' thoughts upon referral from primary and secondary care and their feedback on service provision. Their experience with Whitiora DM service highlighted some gaps in administration and management systems including the referral process. Non-attendance from levels 1 and 2 was mostly associated with; un-realistic expectation from naïve participants, inadequate explanation from the referrers, unhelpful expression from frontline staff and administrator system failures when participants were not given timely notification with the details of appointments. Attendance from level 2 and level 3 highlighted participants' perception of facilitators and satisfactory experience with DNSs, which acted as an enabler for most of the participants and generated positive feedback towards DNLCs. This section has also highlighted patients' perceptions on areas of improvement, which can make a difference in patient care.

### **5.9 Conclusion of this chapter**

This chapter has presented patients' experiences and factors associated with their attendance and non-attendance with DNLCs. Patients' perspectives have highlighted their perceptions of healthcare delivery and their relevant expectations from primary and secondary care. Qualitative and quantitative research results will be merged to provide an integration of findings in the next chapter.

## **Chapter 6: Mixed Methods Results: the integration of quantitative and qualitative results**

### **6.1 Introduction**

The purpose of utilizing the mixed methods approach was to utilize the strengths of each method to best answer the research question. The following findings were found significant to answer the research question from quantitative and qualitative research methods.

### **6.2 Current extent of attendance and non-attendance and associated factors**

The quantitative research findings have confirmed the exact extent of the research problem as 65% attendance with 35% non-attendance in between two regions. The comparison of two regions confirmed the higher attendance in Botany with a proportion of 74% and 58% in Mangere DNLC. The causative factors were explored with quantitative and qualitative methods as described below:

#### ***6.2.1 Age and duration of DM***

Age was found to be a significant factor in quantitative and qualitative method results. Patients who attended all the booked appointments were 5 years older than those who default their booked appointments. A similar expression was confirmed by qualitative research findings, when those with longer duration of DM attended the booked appointments compared of those with shorter duration of DM. Participants identified the priority of going to work to earn a living for the family has the higher priority than attending the appointment for their health. Those who attended their booked appointments were either retired or were found to be in a stable employment or business state, where time off from work was acceptable.

### **6.2.2 Ethnicity**

Ethnicity was found to be a significant factor, which showed a statistical significance among different ethnic groups with a p-value of  $<0.001$ . This significance was further tested with a chi-square test for the significant difference amongst ethnic groups with the highest rates of non-attendance among PIs and Māori. The chi square test confirmed participants with PI are statistically significant for non-attendance as compared to other ethnic group's studies. This expression was further confirmed by qualitative research methods when participants from PI origins confirmed that migration influenced their tendency to develop DM. The reasons for non-attendance were related to influence of culture when bringing up with high carbohydrates and fat rich food influences their inability to control the portion size. These participants raised the dependence upon carbohydrates and expressed their helplessness to control the portion size as advised by DNS despite their due desires of doing so. This factor seems to affect their attendance a rate when patients know they feel like they haven't done what was expected from them in regards to their dietary changes.

### **6.2.3 Gender**

Gender was found to be a non-significant factor in the quantitative research analysis. However, factors such as childbearing age and childcare appeared to be associated with non-attendance in qualitative phase. Women of childbearing age with dependent children and un-availability of childcare, was found to be associated with non-attendance.

#### **6.2.4 New Zealand Deprivation Index**

The quantitative research confirmed that geography matters in regards to patient's attendance and non-attendance, which was further clarified by the inversely proportional relationship of attendance with NZDI. The participants from the most deprived population have significant lower attendance rates in comparison to those from least deprived economic regions having lower non-attendance rates. This finding was further confirmed by qualitative research when participants confirmed a lack readily availability of unhealthy food at home and in neighbourhood markets enhances the uptake of available unhealthy resources. Participants confirmed that socio-economic factors influence their ease to buy unhealthy options instead of driving to buy healthy options, which again involves the cost factor. Thus, this factor makes them feel guilt of not been able to follow DNSs advice on expected lifestyle changes and is associated with non-attendance. Participants appreciated that they were booked for appointments with DNLC closer to their home. However, they experienced the traffic in Auckland and cost of travel as a barrier, which influence their tendency to attend especially when they return from work.

#### **6.2.5 Association of non-attendance with higher hospital admissions**

There was a statistically significant causative association between non-attendance and hospital admissions due to acute health conditions as shown by quantitative methods. This finding was further confirmed by qualitative research methods when from non-attendance group were admitted to hospital due to infected boils, which was a late presentation and was linked to not to consult with GP as it may lead to hospitalization and an inhibition to work and earning for life. Thus non-attendance to DNLCs is

associated with higher cost of management of those health issues is the hospital which could have been well managed if participants could have attended their appointments.

### ***6.2.6 Diabetes related complications***

The mixed methods approach has confirmed no statistical significant association of attendance and non-attendance with diabetes related complications including microvascular and macrovascular complications. The reasons behind this non-significant association may be due to the current referral process, whereby those patients seen by secondary care mainly have poor glycaemic control and hence all have similar levels of complications. This reason highlights that patients with DM may have already undergone the pathologic changes, which increases their risk of having such complications. However, there was a reflection from patients that attending multiple appointments with different sub-specialities were perceived overwhelming and participants prioritised their attendance on the basis of their own understanding of their condition while perceiving DNS has a limited role which is mainly focussed on diabetes care only.

### ***6.2.7 The PPC programme***

The quantitative research has confirmed that enrolment with the PPC programme has no significant relationship with patients' attendance and non-attendance. Similarly, participants did not express any experience of benefits from PPC in their interviews in qualitative research methods. Participants expressed lesser time devotion, lesser knowledge provision towards the care of DM from their GPs and PNs.

### ***6.3. Summary of this chapter***

This chapter has successfully merged the quantitative and qualitative research findings. Both research methods have discovered more relevant information which will be discussed in the following chapter.

## **Chapter 7: Discussion**

### **7.1 Introduction**

This chapter will allow discussion around the research findings from quantitative and qualitative research results. In the beginning, this research project proposed to identify the extent of attendance and non-attendance and to explore patients' perspectives around associated factors. The research question was raised, due to an existing gap in literature and knowledge, which is sufficiently filled by these research findings with the mixed methods approach.

### **7.2 Current level of engagement**

The quantitative research methods have confirmed overall attendance, amongst two regions of DNLCs as 65% and a non-attendance rate of 35%. Prior to this research, there was no such audit published in CMH to assess the extent of engagement. Thus, this research has filled the gap of knowledge in literature. An audit done in Hut Valley District Health Board (HVDHB) confirmed the overall DNA rate for their clinics, which was 8% during the year of 2012-2013. The DNA rate varied in different ethnic groups, clinics and age groups (Dayal, Puketapu, & Gush, 2015). This research has confirmed a much higher non-attendance rate in comparison to the audit results for non-attendance from HVDHB, demonstrating how challenging CMH patients are to engage. However, similar patterns in variation of non-attendance with ethnicity, clinic appointment type and age were noted in both CMH and HVDHB.

The qualitative research findings have confirmed, that those participants who have attended their booked appointments with DNSs, expressed 100% satisfaction with the DNSs and DNLCs. Bhattacharya et al performed a care satisfaction audit in 2007 in

England, where a semi structured interview questionnaire was posted to 91 randomly selected individuals who received care from a DNS through outpatient DNLCs. The audit confirmed 100% satisfaction from responders. Patients expressed their positive views on; detailed education from DNSs, individualized care, being supported and empowered, and acknowledgement of family support (Bhattacharya et al., 2007). This research has also confirmed similar satisfactory viewpoints of patients, who attended the booked appointment with DNLCs.

An extensive national and international literature review (as mentioned in chapter 2), confirmed patients' perspectives around psycho-social needs and themes including; patient-centered care enhances patient engagement, the need for ongoing support, education and sharing knowledge, the need to empower people with DM and disparate vision between patients and their DNSs (Bhattacharya et al., 2007; Edwall et al., 2010; Edwall et al., 2008; Isaksson et al., 2015; Lorenzo, 2013; Silva et al., 2011). Interestingly, the qualitative research findings have confirmed similar findings as identified from international literature. These findings were grouped under emergent themes of patients' expressions of experience with DNS consultation including; motivation and empowerment, raising health literacy, seeking confirmation and guidance is important, and perception of individualized care. However, this research has also highlighted the factors associated with non-attendance, which were categorized under emerging themes of; psychological, social and economic factors. Although above-mentioned factors appeared to influence the decision making of those participants, who did not attend the appointments. However, those participants who have attended some of their appointments also seem to experience such an influence, especially around following the advice of health professionals to endure healthy

lifestyle changes. Till date, nil research has explored association of these factors with non-attendance.

### **7.3 Psycho-Socio-Economic Position of people with Health inequalities**

The quantitative and qualitative research findings have well highlighted the interwoven associations of demographic features including; geographical area of residence, NZDI, ethnicity, migration, culture, age and gender as causative factors for non-attendance. The influence of psychological, social and economic factors on participants' decision making to attend appointments was also investigated. Other factors including; enrollment with PPC, role of initial advice, DM related complications, hospital presentations, transport and its cost, traffic, life commitments such as work, childcare, weather, forgetfulness, previous experience with DNS and service related factors were also explored for their influence on participants' attendance and non-attendance rates to DNLCs.

#### **7.3.1 Geography Matters**

The quantitative research findings confirmed that Mangere DNLCs have higher non-attendance rates than Botany DNLCs. This finding was again found to be intertwined with socio-economic derivatives, especially for patients from the least deprived geographical regions as per NZDI. Patients from the least deprived areas attended 100% of appointments in Mangere and 86% of appointments in Botany. In comparison, those clients who were from the most deprived geographical region of residence attended 47% of appointments in Botany and 55% in Mangere as mentioned in Table 7. This finding was further supported by qualitative research findings, which has also highlighted that socio-economic factors and their association with financial

deprivation have a direct relation with non-attendance rates. This research has emphasized patients' subjective call of prioritizing to attend work to earn their daily living instead of attending the booked appointments, despite being aware of the fact that these consultations do not have any surcharge attached to them. Conclusively, this research has confirmed that social, economic factors and NZDI play an important role as social determinants for the uptake of health-care provision. The relationship of this finding to existing literature will be discussed in the following section.

### **7.3.2 Influence of NZDI as a marker of socio – economic deprivation**

Furthermore, this study has also revealed, that the attendance with a DNLC is inversely proportionate with the level of NZDI. Higher attendance was seen among people from the lower NZDI decile, which represents the most affluent population. This finding has confirmed the stronger association of higher NZDI, which represents the most deprived population, and its association with non-attendance. National studies have confirmed a similar relationship of NZDI. Warin observed that regions representing higher NZDI have higher prevalence of DM (Warin et al., 2016). In addition, relevant poor health outcomes are more prevalent among economically challenged communities (Raphael et al., 2003). The inter-linkage of non-attendance with geography, further confirms the existing evidence on prevalence of DM with relevant burden remaining higher among patients from deprived ethnic and geographical groups.

There was no such research done to date in NZ, to study the relationship of socio-economic deprivation factors on patients' engagement with healthcare providers in NZ. However, existing research does support the influence of such deprivation

variables with the higher prevalence of T2DM and poor health outcomes (Warin et al., 2016). This research has confirmed that non-attendance with DNLCs follows a parallel trend, to the prevalence of DM for geography and ethnicity nationally (Warin et al., 2016), and influences of socio-economic factors internationally (M. Cox, Boyle, Davey, Feng, & Morris, 2007; Fano et al., 2012; Raphael et al., 2003). Consequently, national and international literature has called for new measures to support the deprived and highly prevalent geographical regions and ethnic inequalities.

Warin et al (2016) investigated the variation in prevalence of DM in the Auckland region in 2011, and found the variation in prevalence of DM to be 3% in the North Shore and 17% in Mangere SA. They also found variation in prevalence across age, gender and ethnicity. Similar to Warin's findings, this research has revealed that variation in engagement of patients with DM varied significantly within different geographical regions of SA. Warin found a higher attendance rate of 74% with a DNLC on the eastern edge of SA and 58% with DNLC in Mangere, which is geographically located in the central southern district. This research has confirmed that geography does not only matter for the prevalence of DM in NZ, but geography also matters in regards to patients' engagement with healthcare providers and uptake of the offered healthcare provision.

Internationally, a study examined whether the incidence of T2DM in small geographical areas of Scotland has any association with deprivation in the surrounding neighbouring areas (Cox et al, 2007). This study confirmed that people living in deprived areas who are surrounded by less deprived areas, have lower risk of DM as compared to those areas who are surrounded by relatively equal or more

deprived areas. This research has generated similar findings, confirming that those who are disadvantaged socially, economically and geographically, have shown association with non-attendance, inability to achieve increase in physical activities and engagement with health professionals.

In light of the increase in mortality rates during the mid-1980s among people with DM with low income communities, Raphael et al studied the role played by social determinants of health, mainly in management of T2DM in Canada. Raphael commented that there is uncertainty about how these social determinants including; low income, material deprivation, psychological factors such as stress and neighbourhood, influences the incidence of DM. Raphael made recommendations to the healthcare system and researchers, highlighting that the crisis of DM needs new ways of thinking about the disease, its pathology and its management (Raphael et al., 2003). There are multiple other international studies, which have supported that social determinants play an important role in prevalence, self-management and outcomes of patients with DM (M. Cox et al., 2007; Fano et al., 2012; Fitchen, 1987). This research has confirmed the influence of social determinants including; psychological, social and economic factors upon the incidence of DM, its management and relevant engagement with health professionals.

Participants expressed their realistic prioritization to their commitment for earnings for survival and to support their families, instead of up-taking appointments for a disease (DM) which was perceived as only a problem if uncontrolled by the participants who did not attend. This finding calls for new innovative ways to meet the needs of our people who are struggling to meet their basic daily needs. Sadly DM

doesn't cause enough early symptoms and signs to make people realise that DM self-management is a priority until it gets too late.

### **7.3.3 Social and environmental impacts**

Participants from levels 1 and 2 identified that their cultural dietary habits and availability of un-favourable food in their surrounding areas as barriers to DM self-control. This response was further explored by testing its interlinkage with participants' living experiences with DM and DNS consultation, to understand any causative relationship with attendance and non-attendance. The participants clearly stated that DNSs' advice is culturally sensitive, especially when DNSs suggest consumption of the same cultural food items but with the appropriate portion size. However, participants expressed difficulty in controlling the portion size due to lack of self-control, peer pressure and availability of food in their surroundings including at home and nearby markets. Thus, this research further confirms two factors. Firstly, that surroundings and neighbourhood matter to endure lifestyle changes for DM self-management. Secondly, verbal advice from a health professional isn't sufficient enough to enhance expected change in personal eating behaviour, especially when the participants are surrounded by un-favourable carbohydrate rich food sources in the home and in nearby markets with multiple takeaway outlets. Thus, when participants were unable to endure healthy lifestyles due to psycho-socio-economic factors, it hindered their tendency to attend the follow up appointments with the DNS. In addition, a participant from PI ethnic group expressed a fear of being judged by the pacific health professionals if they do not achieve the targets. However, due to limited participants in the research, this remained a single finding only instead of a theme.

A study was conducted to investigate the associations of neighbourhood, social and physical surroundings with the prevalence of T2DM among African Americans, utilising data from Jackson's heart study (Gebreab et al., 2017). Jackson's heart study was a longitudinal cohort, which was designed to investigate the predictors of cardiovascular disease, during the year of 2000-2004. Gebreab utilized descriptive analysis with a total number of 4693 participants. Gebreab confirmed that neighbourhood social cohesion and unhealthy food outlets in the neighbourhood were significant factors related to incidence of DM (Gebreab et al., 2017). This study has confirmed similar associations of the negative influence of socio-economic deprivation and geographical variables. Thus this research provides solid evidence that our stakeholders are negatively influenced by socio-economic deprivation, hence making lifestyle adjustments for those from the most deprived regions (including Mangere with a vast supply of unhealthy food outlets) is not as easy as compared to those who are not challenged by socio-economic deprivation. Thus a learning from this research finding, is that there is a need for new efforts to promote healthy eating habits among families, no matter if they have DM or not. Most importantly, Government need to make strategies to control the number of takeaway outlets and vegetable shops in each region.

Furthermore, national research from grey literature has confirmed that lesser physical activity is also associated with lower income and unsafe surroundings, which seems to be associated with the life course findings in relation to prevalence of DM and poor outcomes of DM (Mayes, 2010). International studies have also supported this association in multiple studies (Blanksby, Anderson, & Douglas, 1996; Mensink, Loose, & Oomen, 1997).

Thus, the learning from this research is that health professionals need to acknowledge and support participants' while considering their everyday struggles and priorities.

There is a need to set realistic targets and expectations in behaviour changes from participants. Participants need to be supported at an individual pace, so that they can feel more comfortable in expressing themselves, instead of feeling judged by health professionals. Raphael et al (2003) also emphasized in his research, that life-course factors require crucial consideration while thinking of new ways of engaging with dis-engaged people due to complex disadvantageous life circumstances.

#### **7.4 Ethnicity**

This study has also investigated the ethnic trends towards attendance and non-attendance with DNLCs. Whitiara DM services' stakeholders are multiethnic, which were found to have a proportion of 50% of people being from Pacific origin, followed by Europeans 22%, Māori 10%, Indian 10%, Asians 6% and others 2% in the quantitative research. The ethnic composition for the qualitative part of this research was 43% PI (including 21% Tongans, 7% Samoans, 7% Niuean and 7% Fiji Indian), 36% NZ Europeans, and 14% NZ Māori, and 7% Asians (Chinese). The quantitative research confirmed that the highest attendance was shown by Asians, which was followed by Indians, Europeans, and other ethnic groups contributing 40% of CMH stakeholders. PI and Māori patients have shown the highest non-attendance rates of 48% and 51% respectively and together contribute towards 60% of the composition of CMH total stakeholders. A similar expression of attendance and non-attendance was seen when both the clinics were compared with each other. The ethnic groups with the highest expression of non-attendance, also have the highest prevalence of DM in NZ

(Balalla, 2013; Sundborn, 2009). This finding confirms the fact, that ethnicity follows similar trends for non-engagement, as it does for the prevalence of DM (Warin et al, 2016). Existing literature also supports this finding as mentioned in chapter 2, when Simmons & Flemings (2000) conducted a cross-sectional study to describe the prevalence of non-attendance and to identify the characteristics among patients with diagnosed DM in SA with a household survey with 1709 subjects. The results revealed that overall 6.3% of patients did not see a GP or DM specialist service in the previous 10 months. A significant ethnic difference in non-attendance was noted. Non-attendance was highest in Māori patients, followed by Pacific, European then others (Simmons & Fleming, 2000). It also highlights the existing ethnic inequalities within a small area of a metropolitan city, Auckland. The NZ Health Survey states that the prevalence of DM among Europeans is 2.9%, Māori 8%, Asians 8.4% and PI people 10.1% (Joshy & Simmons, 2006).

Existing literature has confirmed, that ethnicity and socio-economic factors are intertwined, influencing patients' own fiscal capability while living in complex socio-economically deprived circumstances to access the healthcare system and thus healthcare provision becomes difficult for them (Carter et al., 2008). However, in relation to the stakeholders of Whitiara DM Service, there is no surcharge attached to the appointments. Considering the results of this research upon non-attendance, disengagement and non-significant influence of PPC with attendance and non-attendance; it would be interesting to find out how often these patients consult with their GPs, where they are expected to pay surcharges for their consultations for their chronic condition if not enrolled with PPC.

The causative factors of DM may be complex, with a multitude of reasons behind these variations, ranging from the study of genes to the extent of cultural and social influence with traditional practices including lifestyle (Raphael et al., 2003). These causal factors may start from being in utero and continue throughout the lifespan, and were further explored by the qualitative part of this research. The existing literature has confirmed, that the highest prevalence of DM is among PI people which are followed by South Asians and Māori in NZ (Smith et al., 2008; Warin et al., 2016). Existing literature also supports similar social courses including socio-economic status, dispersed cultural legacies and well recognised distinctive lifestyle factors. The above-mentioned factors were studied in the US, which confirmed mortality rate was two-three fold higher due to cardiovascular disease among patients with DM from unlike groups of income in-equalities and patterns of different ethnic origins (Cooper, 2001).

The Researcher would like to clarify that this study doesn't confirm that genetic makeup is the core reason behind incidence of DM, poor outcomes and non-engagement. This study has rather highlighted the relationship of psychological, social and economic factors, which are faced by the stakeholders of CMH, representing highest non-attendance rates. This research has confirmed that these societal contributing factors have direct influence on patients' engagement. The researcher again calls for the need of new ways of thinking to decrease the gap of these equalities.

### **7.5 Influence of migration**

The researcher studied the influence of the above-mentioned factors alongside the influence of change in environment, post migration. The history of NZ confirms, that people from the PIs and South Asians have experienced migration and those with Māori origin have also experienced rehoming from rural to urban regions. Thus, collectively these ethnic groups have experienced the influence of westernization. This factor was difficult to explore in the quantitative methods due to no data being available regarding migration status in the standard records in PIMS. The qualitative research findings have highlighted patients' perspectives towards development of DM post migration under the influence of exposure to westernization.

The highest proportion of migration was seen in level 2 as 50% and level 3 as 33%. These participants highlighted three main associated factors; lifestyle changes, including readily available fast food, sedentary lifestyle, and vigilant screening for DM in NZ as compared to their home country. Thus, this research has confirmed that those born overseas are more likely to attend their booked appointments as compared to those born in NZ. NZ Statistics and NZ based information sources do not clearly confirm the extent of DM among migrants. However, international studies confirm the un-favourable relationship of migrants especially with low socio-economic status. Migrants face challenges to settle in a new country, which is further fuelled by social inequalities and cultural effects, influencing both the migrants with their health outcomes and consequently the nation (Montesi, Caletti, & Marchesini, 2016).

Although the specific rationale was not explored in-depth in this research. However, this finding appeared to be associated with participants' expression, that they

perceived the NZ healthcare system to be more vigilant in diagnosing DM far earlier, as compared to their home country. The existing literature confirms this finding, where diagnosis of DM in China is mainly endorsed by glucose-based tests (J. C. Chan, Chow, & Luk, 2017) instead of glycated haemoglobin as the standard practice of diagnosis in NZ (Florkowski, 2013). Literature supports similar findings in PIs where diagnosis is often made on the basis of fasting blood glucose  $>7$  mmol/L (Lin et al., 2017). Although glycated haemoglobin testing is available in PIs, resources remain scarce (Hou, 2017). This difference in testing criteria highlights the gap of diagnosing DM in China and PI as compared to NZ. NZ has a more appropriate way of diagnosing DM, on the basis of chronic glycaemic control using a glycaemic index of 120 days, instead of a single check at a random point of life (Florkowski, 2013). Florkowski (2013) expressed the need to establish diagnostic criteria by glycated haemoglobin testing, as an ideal way of diagnosis of DM in China. Considering the NZ Society for the Study of Diabetes' position statement on diagnosing DM, Glycated haemoglobin is considered the gold standard test for establishing the diagnosis, along with screening of high risk populations which is well recognised in NZ (Baatvedt et al., 2012).

Ethnicity refers to genetic factors and the influence of migration refers to changes in environmental factors, both of which are the underlying influences for the development of DM and suggestive of its relative management (Dagogo-Jack, 2017). Considering a vivid rise in prevalence of DM worldwide, in a shorter span of time, there is a doubtful suggestion of ethnic factors causing a gene mutation, which cannot happen suddenly resulting in an increase prevalence of DM. Instead, this dramatic

increase in prevalence of DM is rather more suggestive of changes in environmental factors induced by migration (Dagogo-Jack, 2017).

This research has highlighted that migrant participants confirmed that they did not have DM prior to coming to NZ. They highlighted changes in their environmental factors as compared to their home country. An international study confirmed the above-mentioned phenomenon, when a threefold higher prevalence of T2DM was noted amongst a second generation of migrated Japanese in the United States, as compared to native Japanese (Fujimoto et al., 1987).

According to Stats NZ (2012), a noticeable change in estimated population growth was seen throughout NZ, in which Auckland ranked the highest for growth in population at 1.6% (Stats NZ, 2012). Stats NZ (2012) further showed the components of change in population growth as; natural reason including birth and death, and migration during a period of one year from June 2010 to June 2011. Auckland remained the main area of attraction to migrants, with a contribution of 6600 in June 2010 which further increased to 8400 in June 2011. This also confirmed the highest contribution of migration in Auckland for population growth as compared to population growth nationwide.

In contrast, a very recent study from the Ministry of Health, Wellington has revised the Virtual Diabetes Register over the years of 2010 to 2016, which confirmed that the rates of DM were rising rapidly, with rates highest among PI and Indian ethnic groups (Drury, Nicolson, Burgess, Lofthouse, & Telfer, 2018). However, these rising rates have significantly slowed among all ethnic groups including Indian, Māori,

Europeans and others except PI. This trend has made Drury et al question whether NZ has now reached a state of plateaux in prevalence (Drury et al., 2018).

The extent of population mainly due to immigration growth was 1.6% per annum of the total population during the selected years of this research, 2010-2016. These research findings have highlighted that migrants expressed developing DM post-migration. Thus, in regards to the answer to the most recent research on prevalence of DM, there will likely be an increasing need for programs to create awareness about healthy eating and prevention of DM among migrants. The researcher of this portfolio has not come across funded measures to promote awareness about prevention of DM to migrants, prior to diagnosis from primary and secondary care provision. However, some similar awareness programmes are available among community groups, which are non-government organisations and work on the basis of volunteer roles.

Thus, this research confirms, that there is a need to consider the fact that DM develops post migration. Healthcare must consider how migrants can make suitable lifestyle changes with a purpose to protect them from this non-infectious spread of disease. Otherwise, the time is not far away when the state of plateaux will revert to a rising tide in prevalence of DM, congruent with higher rates of migration and settlement in NZ. Though the above-mentioned discussion is not about attendance rates, this discussion is around the core reasons of the problem with engagement of patients with DM.

Nevertheless, the interesting part remains the same, that those participants who have migrated from overseas, though they developed DM after migration, they seem to

engage well with healthcare providers, as reflected by their tendency to attend.

Whereas those, who were born in NZ seem not to attend appointments. The above-mentioned factors of non-engagement directs towards enormous costs of medical and surgical management of DM and its complications. The additional cost of absenteeism further adds to the cost for care considering the progressive nature of the disease with un-favourable consequences for the individual with DM, their families and the nation economically.

### **7.6 Initial advice on Carbohydrates as a signal to change – do people like it?**

Reduction in dietary carbohydrates is considered as the first approach to manage DM worldwide (Feinman et al., 2015). Carbohydrate restriction undoubtedly leads to successful significant difference in glycaemic control, in a short span of time and can favour hugely for DM management and prevention from DM related complications (Lim et al., 2011; Taylor, 2013). However, this research has confirmed that participants did not understand this approach well when initial advice on restriction of carbohydrate was given in simple sentences, which lacked information; including words like ‘stop, don’t and cut down’. Participants also did not perceive the referral to consult with a DNS well, when it was pitched at a level of dietary restrictions and weight reduction in the initial phase.

Thus, the above-mentioned factors influenced patients’ subjective call to not attend the appointments, since they did not want to hear the similar approach of management which demands behavioural changes, from a DNS. Those participants, who attended the appointments and appreciated detailed education on dietary adjustments, still struggle to make change. DNSs gave culturally sensitive advice utilising the patient’s

usual food sources but with appropriate education regarding portion size of carbohydrates. Despite, those participants who are engaging well and trying to self-manage DM, expressed difficulty in controlling the portion size especially for carbohydrates.

It is a well-established fact, that there are mainly eight pathological impairments which can possibly result in development of T2DM including; impairment in insulin secretion, insulin resistance, reduced glucagon suppression, increased lipolysis, excessive hepatic gluconeogenesis, defected renal tubular glucose re-absorption and defects in the central nervous system which includes defected dopaminergic tone and lack of satiety (Dagogo-Jack, 2017). The researcher of this portfolio believes that it is equally important to explore and understand the associated physiology behind this response of the participants, where they expressed this as a challenge to adjust to the portion size of carbohydrates.

Dietrich highlighted the involvement of the central nervous system releasing anorexigenic, an appetite inhibiting neurotransmitter and orexigenic, an appetite stimulating neurotransmitter (Dietrich, 2017). Thus, these signals including; leptin, insulin and ghrelin have effects on dopaminergic pathways resulting in impairment, which in turn influences the motivation process of overeating and acts as reward related eating. Thus, internally, neurotransmitters start a vicious phase in which people with DM or that overweight struggle to escape with their will power only. This process somehow directs towards the answer as to why participants do not engage, simply because advice on carbohydrate portion control does not endure, due to their body's inability to cease release of long-standing neurotransmitters and their related

consequences which are mainly around over-eating and lack of satiety. Science has confirmed, that feeding behaviours including distinct steps of hormonal induction stimulate neurogenic pathways, which involves one's behaviour, metabolic physiology and nervous system pathways (Blundell, 1991). Therefore, the healthcare system must understand new ways to meet our patients' needs, to help them to control their portion size while supporting their wish to do so; since this was a reason associated with non-attendance, when participants felt helpless to control their portion size despite a positive desire of doing so. Participants also verbalised that they had been eating carbohydrate rich food since childhood, hence making this change post diagnosis of DM was expressed as a challenge.

Literature supports that food addiction exists scientifically, especially to macro-nutrients such as carbohydrates, fat and possibly processed high salt foods, which is resulting in higher prevalence of obesity and uncontrolled DM (Hebebrand et al., 2014). Hebebrand further described, how such chronic intake of carbohydrates or relevant addiction occurs, due to the altered neuro-chemicals generated by the hypothalamus, including dopamine and endogenous opioids (Lutter & Nestler, 2009). Altered physiology of the body, leads to lack of satiety with a lesser portion size and enhances chronic overeating, which results in obesity and progresses to development of T2DM and subsequent poor control and self-management of DM (Lutter & Nestler, 2009). Thus the above-mentioned physiology confirms that verbal advice on carbohydrate doesn't favour the body, which makes people choose not to engage because the given advice is not easy to endure. Thus, levels 1 and 2 participants expressed that current ways of creating awareness about DM are not effective enough to raise self-motivation and self-control on carbohydrate portion size, which was

perceived as a hindrance to follow the advice of health professionals. Consequently, it was perceived as nearly impossible to achieve.

In summary, this research finding calls for new ways of creating awareness about DM and management of DM, since participants reported verbal advice is insufficient to stimulate behaviour changes especially among those who did not attend. Thus, new ways of management can be an addition of pharmacological management to support patients with their will to control their portion size, which may be more feasible for patients with DM to follow, instead of leaving the next step to surgical interventions such as bariatric surgery.

An assessment of food dependence with a food addiction scale could be well utilised in DNLCS. The Yale food addiction scale (YFAS) is a reliable preliminary assessment tool, to identify addiction behaviours for food (Gearhardt, Corbin, & Brownell, 2009). This assessment may influence DNSs to set realistic expectations from their patients and possibly think for the need to involve other pharmacological management and/or psychological therapy for such changes in behaviour to support patients with their desire to control their portion size. This way, it can be ensured that patients do not feel failure, while following DNSs' verbal advice and subsequently not attend the follow up appointments. Therefore, educating patients with psychological interventions while considering cognitive and behavioural strengths and weaknesses and/or utilizing the pharmacological interventions for chronic or compulsive overeating is essential (Corsica & Pelchat, 2010). Such interventions may lead to patient locus of control, which may possibly then effect their motivation to get engaged with healthcare, thus influencing attendance rates.

Non-attendance due to negative messages about restriction in carbohydrates can also be associated with other factors, which may be beyond the above-mentioned physiology. This research highlighted that participants expressed a lack of information on dietary advice by healthcare providers who announced the diagnosis of DM. This research also highlighted that health professionals gave simple brief messages on restriction of carbohydrates, weight reduction and self-management of DM, which were not perceived as helpful by the participants. Those brief messages did not emphasise how to make such changes. Furthermore, referrals to DNLCs were not perceived positively by participants, since they perceived that DNSs will also emphasise simple verbal change messages, which are not easy to make as desired, to self-manage DM. Thus, the learning from this research is that it is important to be mindful, to consider the tone of voice and selection of words in the conversation, which may have negative connotations and may influence disengagement. This research finding is well supported by an existing national research, which has also highlighted the importance of positive words to promote engagement (Best Practice Advocacy Centre, 2018).

### **7.7 Personal Attributes**

This study has also confirmed the statistical significance between demographic features of the population living in the Mangere region versus Botany region. The quantitative research findings have confirmed, that people who tend to attend their appointments, are 5 years older than those who do not tend to attend, with a mean age of 50 years. The qualitative research has confirmed the rationale behind this expression. Participants verbalised their convenience to attend when they are retired

and have no dependent childcare responsibilities, as compared to those who are working and have dependent children. The barriers to attend were identified as; taking leave from work to attend the appointment, financial loss for taking unpaid leave, traffic especially when returning from work, care of a dependent child, responsibility for earning a living for dependents and travel cost to attend the appointment. An enabler to attend appointments was identified as appointments being offered in clinics closer to residential address. Thus, life commitments and priorities have their special place above engagement with health professionals, for DM management.

An international longitudinal survey amongst Pennsylvanian patients, who were diagnosed with colorectal cancer in 2005, included 305 participants for follow up surveillance after curative treatment for colorectal cancer. The study confirmed higher patient engagement with curative treatments. The study confirmed those participants who had greater physician and patient communication, reported better engagement (Tan et al., 2012) Similarly, engagement may improve if initial explanation of disease control is explained well and perceived well by patients.

### ***7.7.1 Age – Engagement improved with maturity***

A noticeable difference was seen for the variable of age group in each level of attendance. The age factor reflected that engagement improved with maturity in age, as patients grew older in terms of years. It was further confirmed, that level 1 participants were the youngest, level 2 were middle aged and level 3 varied from middle aged to senior citizen. Qualitative research further confirmed that those participants who were most attenders were either retired or were found to be in skilled

jobs or business, thus they had established careers which facilitated their ability to attend the appointments.

As mentioned earlier in the literature review, Isaksson et al (2015) asked 159 people with T2DM to describe their perceptions of the need for self-management support in a rural community of Sweden. The study results have shown, that women and non-retired persons needed more support, compared with men and retired persons.

Participants needed support from health professionals and also from family members, due to living in a rural community and having limited access to healthcare facilities. Considering this information and the current research, although most CMH patients are not from rural regions, still patients valued the support from family members and friends. This research also confirmed that the need for ongoing support persists throughout all ages.

### ***7.7.2 Duration of DM influences engagement***

There was an obvious difference for duration of DM between the three levels. In level 1, the duration varied from a few months to 13 years. Among level 2 participants, it varied from 3 years to 23 years, whereas level 3 had a duration range of 27 years to 35 years with exception of one participant who had duration of 1 year only. Thus, the participants with longer duration of DM attended all the booked appointments as compared to those with shorter duration of DM. Patients, who were newly diagnosed with T2DM and those who had been diagnosed for 10-15 years, similarly expressed the need for ongoing self-management support. This confirms that the need for ongoing support from health professionals persists, even among patients with long

duration of DM. As mentioned above by Isaksson, ongoing support is desired even among those who have DM for a long duration (Isaksson et al., 2015).

### **7.7.3 Gender**

Gender remained a non-significant factor in the quantitative research findings. However, when compared within two DNLCs, it was noted that females from Mangere are almost twice as likely to default their appointments with the DNLCs as compared to females from the Botany region. The proportion of female attenders remained lower than males, which itself reflects the above-mentioned findings from qualitative research data regarding life commitments for women. Existing literature has confirmed, that women from low socioeconomic groups and of child bearing age, appear afflicted with DM and cardiovascular disease in an international study (Raphael et al., 2003). Furthermore, in a grounded study in Canada in 2002, engagement was explored by interviewing three women from low income families with limited food sources. These women reported prioritising; food to others in the family and responsibility for the care of dependent children, rather than self-management of their DM (Anstice, 2003). Isaksson (2015) also confirmed that women needs more support to self-manage DM as compared to men.

### **7.8 Role of in-formal support from family and friends**

This research has confirmed, that those participants who received and accepted support from family members and friends, tend to engage better with their self-management and attendance with DNLCs. This finding is well supported by a UK study, in which fifty two adolescent participants were recruited from four regional hospitals in south England and were followed over a period of 6 months. An

assessment tool including twenty one important factors mainly focussed around self-management of DM, their wellbeing and social support was utilised. This study confirmed that both family members and friends are important components, as support factors for self-management of DM (Skinner, John, & Hampson, 2000). Although the participant population were only adolescents living with T1DM whereas the current research involves those 18 years and older with both types of DM, still the findings are supportive of this research finding. Isaksson (2015) has also highlighted that those people, who were living in extended families, expressed a higher perception of emotional support from relatives as compared to those living alone.

### **7.9 Health Literacy and self-activation**

Health literacy refers to one's capacity to understand the basic health information and make subsequent sound decisions based on one's literacy to favour health (Koh et al., 2012). This research has confirmed level 3 group, who attended all their appointments, had higher health literacy about DM and had adapted to the details of self-management adjustments, as compared to those from level 1 and level 2 participants, who did not attend booked appointments. This finding is well supported by existing literature as mentioned by Lorenzo (2013) who concluded that engaged, informed and activated people with DM working in partnership with health professionals, might enhance patients' clinical outcomes in his observational study.

Another observational study was conducted with patients undergoing day surgery during the period of October 2015 to July 2016. This study included 704 patients in Sweden who were assessed for their health literacy and its association with healthcare contacts, quality of recovery and health related quality of life. This research

concluded inadequate health literacy was associated with poor post-operative recovery and lower quality of life (Nyman, Nilsson, Dahlberg, & Jaensson, 2018). Thus, learning from this research, for the sake of managing the crisis of DM, it is crucial for the health sector to ensure an increase in health literacy of its stakeholders, so that people can be activated to know more about their condition, thus generating self-interest and self-motivation to engage in self-care management and activities.

### **7.10 Role of initial emotions and experience of DM complications influences engagement**

All the participants from the three levels reported their experience of negative emotions and non-acceptance of the diagnosis of DM initially. Participants also expressed, that they had different priorities of life upon the diagnosis and that was the reason behind their lack of motivation to self-manage. Thus, there was a variation in self-motivation among participants while experiencing those negative emotions. Interestingly, level 3 participants who attended all appointments expressed their reflections of being unaware at the time diagnosis, of the real problems that DM can really cause with its complications. Their thoughts of non-acceptance of diagnosis were converted to acceptance of diagnosis, expressed as the undertaking of self-motivation due to a fear of death and wishing to stay alive for their families. Thus, those participants who experienced self-motivation and self-realization of DM and its progressive nature seem to attend their appointments as compared to those who have not self-actualise the consequences of DM just yet.

Therefore, the content of the initial consultation at diagnosis remains crucial to enhance patients' engagement with health professionals, to gain self-management skills. The participants expressed their lived experience of complications, but this

knowledge itself does not seem to impress their decision making, to attend or not attend the booked appointments. Level 2 and level 3 participants, who are partial attenders and always attenders, expressed their views that learning from real life examples may make people living with DM self-realise and self-actualise about the reality of the progressive nature of DM. This in turn may raise people's self-motivation, which will indirectly help them self-control and engage better by active listening with care providers.

An international qualitative research interviewed 148 adult patients with T1DM and T2DM, in regards to patients' learning about DM related microvascular complications. This research confirmed that participants want to learn about these complications and the preventive measures to avoid such events as early as possible. The research reported that 86% of participants improved DM care after having such an event (Ritholz, MacNeil, & Weinger, 2017). This matches the findings of this study, where participants expressed the wish to be more aware and cautious to avoid such complications. Thus, this research has opened the doors to trial new ways of creating awareness about DM and its complications so that people can learn from this. There may be ethical issues around such presentations to enhance learning. However, Ritholz, MacNeil & Weinger have emphasised, with which the researcher of this portfolio agrees, that it's important to discuss the danger of DM related complications with true and constructive messages, so that people with DM may be fully educated and informed about the real face of DM.

### **7.11 Service Provision – Patient and Clinic related factors**

The research has identified wasted resources when patients did not attend the offered appointments. Wastage includes: clinic slot, DNSs time, economic loss to the service, lengthening of the waiting list and underutilisation of available resources. These research results have also highlighted the barriers and facilitators for patients in relation to our service provision. These facilitators and barriers filled the existing gap in knowledge, which is the core purpose of this research study. It was considered crucial for the researcher to report the revealed patients' perspectives of Whitiora DM care, so that the service providers can acknowledge these factors to promote patients' engagement. The research findings confirmed the need for establishment of group presentations of live examples, where those patients' who have experienced the severe effects of complications can reflect their self-realization that self-management could have saved them from such bad experiences.

This research has also discovered un-intentional non-attendance with DNLCs, due to patient and clinic related factors. Patient factors included forgetting to attend, lack of childcare, difficulty with transportation in relation to cost and traffic. Clinic related factors included incorrect contact details in PIMS, change in address, delay in offer of appointment, lack of negotiation for the time and date of the appointment in a timely manner, lack and late notification of appointments as discussed below.

### **7.12 Administrative gaps in service provision**

This study has confirmed that there are gaps in administrative measures especially in notification and scheduling of appointments. Participants expressed either no notification or notification post clinic appointment, as reasons for non-attendance.

There was a quasi-experimental, controlled longitudinal study in Kenya in which 1894 patients of age 18 years and above were selected from 12 rural district hospitals. The effect of a health system facility based intervention was measured, to improve clinic attendance and patient adherence. Six hospitals were chosen for intervention and six for the control group. All the clinic staff utilized appointment-tracking data to calculate adherence and discussed outcomes regularly on a monthly basis.

Conclusively, the appointment keeping data system and monthly performance monitoring was strengthened and patient attendance was improved (Boruett et al., 2013). The researcher believes monthly performance monitoring for attendance rates, may invite close monitoring of population that does not attend and will give the opportunity for administrative staff to find innovative ways to manage non-attendance.

### **7.13 Correspondence Failure**

The research findings depict the need for change in administration systems and frontline care providers. It is vital at the time of referral, the referral and appointment process is explained to patients with rationale. This research has also un-intentional non-attendance with DNLCs. Patient factors included forgetting to attend, lack of childcare, difficulty in transportation in relation to cost and traffic. Clinic related factors included in-correct contact details in PIMS, change in address, delay in offer of appointment, lack of negotiation for the time and date of the appointment in a timely manner, lack and late notification of appointments. Also, research revealed participants' expression of minimal opportunities for negotiation of appointments, which highlights varied methods of handling appointment invites by the scheduling administrative team. The survey undertaken by staff from HVDHB clinics, confirmed

similar patient and clinic administrative factors, which were intervened by a project called “99% attendance”. The process included consultation with hundreds (exact number not specified) of patients, who were in the waiting area prior to appointments and others who did not attend their appointments. On the basis of key themes, performance indicators and standard practice procedures were reviewed. In addition, Māori and Pacific Health teams developed culturally appropriate methods to enhance engagement. This project showed improvement in attendance by 3% among Māori and PIs and 1% among other ethnic groups (Dayal et al., 2015).

### **7.16 Conclusion**

Patient engagement remains the central crucial part of any healthcare service provision. The need for reducing gaps in en-equalities in societal determinants exists. The need to equip people with DM with self-management skills, confidence and health literacy persists, which needs to begin at the point of diagnosis. Strengthening the patient’s role as a driver of their health right from the beginning to self-manage their disease with the support from health professionals, can make a huge difference with patients’ self-activation and favourable health outcomes.

## **Chapter 8 Portfolio Conclusions and Recommendations**

### **8.1 Introduction**

The previous chapter presented discussion on research findings with its relevance to available national and international research and literature. This chapter will present the strengths and limitations of the study design, draw portfolio conclusions and provide relevant recommendations to promote patient engagement, while reporting identified dimensions for future opportunities of research to gain more knowledge on the research topic.

### **8.2 Strengths of the study design**

This study is the first study to gauge the extent of patients' engagement with DNLCs in CMH. This study has also explored patients' perspectives in regards to their point of view for care delivery, which remains the most important component of healthcare provision. This research has contributed knowledge and information to the current small volume of available literature on patient engagement both nationally and internationally. Mixed methods remained the strength of this study which allowed a systematic approach to find the answer to the research question, while gaining feedback regarding the reasons behind patient engagement and dis-engagement. This study has highlighted patients' perspectives which are the most important to consider for efficient care delivery. This research has allowed some lessons for health professionals, to enhance their learning for patient engagement.

### **8.3 Limitations of the study design**

Limitations of this research included the inability to recruit those patients who did not attend booked appointments. This was the main challenge for the researcher and the

research topic. Although telephonic interviews were kept as an option for the data collection design, incorrect contact details and frequent change in patients contact details were found to be obstacles. Thus, the qualitative sample size was based upon; the in-ability to contact patients from their recorded contact details in PIMS, no response to posted invitation for interview and people did not have much interest to participate in the research. Thus exhaustion of the relevant existing list of patients mainly for levels 1 and 2 participants was reached. Data saturation was mainly achieved among level 3 participants, who attended all of their appointments.

Time limit was another constraint, since this research was completed as fulfilment for Masters in Nursing. The expected timeline to complete this academic research project was 18 months, which also imposed some limitations on expanding the dimensions of the study. Word limit of reporting the research findings was also a constraint. Thus, some important findings which are irrelevant to attendance of patients with DNLCs but still relevant for CMH healthcare providers to learn from will be shared in the future under separate projects with CMH.

#### **8.4 Portfolio Conclusion**

This research has answered the research question and fulfilled the critical gap in knowledge and literature, by identifying patients' prospective on the ways to better engage with patients who have DM, to enhance patient empowerment. This research has answered the main objectives of; reporting attendance rates and exploring patients' perspectives towards their attendance perceived benefit by attending the clinics. This research has also gained feedback from participants for improvements to the service provision.

The gained understanding about patient needs and their experiences has guided new strategies to enhance engagement. The raised issues from patients' perceptions may direct decisions towards tailoring service provision with the above-mentioned perspectives to promote patient engagement for their disease management.

### **8.5 Recommendations to promote patient engagement**

Patients' engagement remains the crucial sensitive part for the uptake of healthcare delivery in any scope of practice. Thus, learning from this research are for the healthcare providers and policy makers to ensure to consider patients' perspectives while planning for the care delivery.

1. Health professionals must remember that initial advice and guidance influences patients' engagement with health professionals and their self-management of DM.
2. Explanation of referral is required. Modes of service provision need to be discussed with patients at the time of referral by the referrer.
3. There needs to be a standardised protocol for appointment invitations. All staff should be advised to follow the same approach.
4. People living in SA relocate frequently, thus provision of free post cards to update the address to care providers may encourage timely communication of contact details and new address.
5. Government needs to add more initiatives to support people to grow their own vegetables at their homes especially when the weather and rain in NZ is conducive for such efforts. This can be an economical national step in reducing socio-economic

disparities and can simultaneously support people to self-manage their DM with lifestyle changes including diet and exercise.

6. Health professionals need to acknowledge psycho-social and economic challenges while setting goals. Care plans must be individualised.

7. Embracement of the role of nurse practitioners working within DM services is required. There needs to be broader coverage in the scope of DNLCs, for DM related co-morbidities including cardiac and renal.

8. There is a need to assess eating behaviour formerly using authenticated tools, with ongoing support to those who are struggling to control portion size.

9. There is a need to advance the pharmacological management and psychological therapies by DNSs.

10. Government must gear society, so that those socio-economically challenged, can make easy lifestyle choices.

11. There needs to be advertisement to the referrers and patients about the role of Whitiora DM service.

### **8.6 Opportunities for future research**

This research has created evidence of relevant data and more knowledge in relation to patients' perspectives. It has fulfilled the existing gap in current local literature.

However, there were different dimensions identified during the course of the research, which were not explored, due to the above-mentioned limits. The following recommendations are made for the future opportunities of research.

1. There is a need to identify whether country of origin and patients' spoken language influences their tendency to engage with healthcare providers.

2. There is a need to identify whether the scheduling team have standard guidelines to follow when contacting patients and negotiating appointment details.
3. There is a need to check if primary care providers are aware of referral criteria to our service.
4. There is a need to further investigate the model of care. Mangere administration is managed more like a chronic care centre, where a receptionist knows the patients more closely as compared to Botany, where the setup has an acute care focus.
5. There is need to identify how clerical staff approach patients on the telephone, in regards to the scheduling of appointments.
6. Although this research has confirmed the attendance rates with secondary care DNLCs, where patients were referred from primary and secondary care sources, it would be interesting to find the extent of engagement of patients with DM (including T1DM and T2DM) with primary care providers especially when they get care free of cost under PPC. There is a need to explore patients' perceptions about the care they received and patients' ability to follow the advice given by primary care providers.
7. It would be further interesting to find patients' engagement with primary care providers who also have a surcharge attached to the consultation, in addition to government funding, if not enrolled with PPC. It would be further interesting to survey if our stakeholders in NZ are even aware of their entitlements while being enrolled with PPC.
8. This portfolio has made connections with pathological defects around the CNS involvement in impaired satiety and overeating. A pilot project could be trialled to determine whether the current practice of behaviour modification therapy in CMH populations is sufficient to achieve behaviour change, or whether pharmacological support is more efficient to encourage behaviour change for food satiety. While

keeping in mind that we need a valid economical option to manage this change, which doesn't seem to happen successfully with current practice, as participants clearly reiterated that words themselves, are not sufficient enough to motivate them.

9. This study has not evaluated the influence of neighbourhood by exact difference of takeaway food outlets in Mangere as compared to Botany. However this is an interesting research topic to explore, what is the difference between the two? Do governing powers need to put limit on outlets or investigate the nutritive values of the food that these outlets serve in our disadvantaged communities?

10. This research findings have confirmed that those patients who do not attend DNLCs often present to hospital quite frequently with acute complications of DM. Thus, recruitment of participants from inpatient settings with their respective consent can be a valid option to consider by future researchers on projects on non-attendance.

### **8.7 Conclusion**

As evident throughout this portfolio and concluded above that the implication of these findings may enhance Whitiara DM service to save time, money and human resources. This may help promote health by enhancing DM self-management and patient empowerment.

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## Appendix 1 – Interview Tool

### Steps of Interview

1. Introduce myself and seek introduction from the participant
2. Answer if participant have any questions
3. Explain the purpose of the interview
4. Gain participant’s consent once confirmed the participation
5. Ensure participant is relaxed and comfortable
6. Follow the interview questionnaire
7. Thanks the participant. Give the Gift voucher to thank their precious time and attendance.

Venue of Interview: Clinic 1 (Botany)  
Or Clinic 2 (Mangere)

### Code of attendance record:

- Code 1: DNA’d first appointment, DNA any f/u and/or no f/u in record  
 Code 2: Attended first appointment and DNA’d any f/up  
 Code 3: DNA’d first appointment and attended all follow up  
 Code 4: Attended all first appointment and Follow up; attended FSA with no follow up record.

Interpreter Required:

### Demographic Data

Name  
 NHI  
 Date of birth/Age  
 Gender  
 Ethnicity  
 Country of origin  
 Migration Status  
 Address

### Education status

Nil	Primary School	Secondary School	Senior Secondary School
Diploma	Graduation	Post Graduation diploma	Masters
PHD	Something else.....		

### Employment Status

### Social Welfare status

### Social/Living status

Alone      With partner only      with partner and children below 18 years

With/without partner and adult children and their partners

**Interview questions in relation to living with Diabetes**

1. Please tell me about your experience of general living with Diabetes?  
What are the main ways Diabetes is affecting you?
2. When were you first diagnosed with Diabetes?
3. Who told you the diagnosis?
4. Do you remember what advice was given to you at that time about how to manage your diabetes?
5. What were your initial thoughts or feelings after hearing the diagnosis of Diabetes?
6. How has your life changed since you've had diabetes?"  
Or  
What were the three biggest changes in your life after the diagnosis?  
Or  
How has it affected your relationships? Work? Life goals
7. Do you think your life has changed since you have diabetes in terms of  
Taking medication - If yes, how?  
Diet - If yes, how?  
Exercise- If yes, how?  
Smoking- If yes, how?
8. Can you grade your readiness to make above mentioned changes in your life when you were diagnosed with diabetes from 1 to 5?  
(Grade 1 being least interested/ ready and 5 being most interested/ ready)
9. What are your feelings about your diabetes self-management?  
Grade it from 0-5: 0 being needs improvement and 5 means very well managed.
10. Who do you think helps or supports you with your diabetes management?  
  
If health professional, whom and how / the ways?  
If people from personal life, whom and how/the ways?
11. What are your views in regards to understanding diabetes as a disease?
12. Is there something else that you want to discuss in regards to your diabetes?

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**Interview questions in relation to Diabetes Nurse – led clinics**

I have noted you had an appointment with Diabetes Nurse – led clinic in last year.

Can you please tell me

1. How did you come to know about the invitation for that appointment?
  - 1.1.1. If it was a letter, how easy was it to read?
  - 1.1.2. Did the letter explain what you need to bring with you for the appointment like glucometer, medicines etc.
  - 1.1.3. Did you receive a blood test form? Yes/No
  - 1.1.4. If yes, did you manage to go for a blood test? Yes/No
  - 1.1.5. If No, can you tell the reason please?
  - 1.1.6. How many days prior to the appointment did you receive the invitation?
2. Were you expecting an invitation for appointment with Diabetes Nurse - led clinic?
3. Please tell me who referred you to Diabetes Nurse – led clinic?
4. Did the person who made referral explain you about the consultation with Diabetes Nurse – led clinics?
5. Were you able to remember the date and time of the appointment?
6. How did you remind yourself about the appointment?
7. Did you receive any text message or phone call from Diabetes Service to remind you about the appointment?
8. Please share your experiences for attending the appointment in relation to
  - Transport and its cost
  - Duration of travel and traffic
  - Childcare or other commitments
  - Taking leave from work
  - Diabetes Nurse Consultation
9. Please share your expectations from the Diabetes Nurse – led clinic?
10. Did that consultation met your expectations or needs? How?
11. How satisfied were your with consultation with Diabetes Nurse
  - 1 not at all and 5 being most satisfied.
12. I am interested in hearing from you that what made you attend/not attend your appointment?
13. If attended, can you please share your experience with the diabetes nurse - led clinic and the facilitators?
14. If not attended, what were your perceptions or fears or barriers about the diabetes nurse- led clinic?
15. Do you think attending this clinic benefits you or helps you with the better ways to manage your diabetes? How?
16. Please share your views about what can be done to improve your experience with Diabetes Nurse led clinic?
17. Is there something else that you want to discuss about Diabetes Nurse-led clinic?

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**Interview questions in relation to service provision by Diabetes Nurse**

**Specialist** In this part of interview, I seek your feedback on the service provision by Diabetes Nurse Specialist

1. Tell me about your experience having Diabetes Nurse Specialist involved in your diabetes management?
2. Since when have you received the care from Diabetes Nurse Specialist?
3. Can you tell me about the effect or benefits of Diabetes Nurse Specialist on how you manage your diabetes?
4. Please share your views on the education that Diabetes Nurse provided to you?
5. Did Diabetes Nurse Specialist use some education material to help you understand the content of discussion? If yes, what and how it helped?
6. Did Diabetes Nurse Specialist give you general advice and / or advice on your individual diabetes management while considering your lifestyle?
7. Do you think the advice given by Diabetes Nurse Specialist was practical in your circumstances? How/ Why?
8. “How well do you feel you’re managing your diabetes based on the nurse specialist’s advice, from 0-5 (needs improvement to very well manage)?”  
In terms of
  - i) Diet
  - ii) Exercise
  - iii) Medication and/or Insulin
9. Can you tell me how well the information provided to you fitted in with your lifestyle, culture and/ or beliefs?
10. Please share your experience with other health professionals like Practice Nurse and/or GP in comparison to care or education provided by Diabetes Nurse Specialist.
11. Do you think you get enough time to seek advice about your diabetes management from your
  - GP
  - Practice Nurse
  - Diabetes Nurse Specialist
12. Did your Diabetes Nurse specialist prescribe medicines for you? Please share your views about having a DNS who can prescribe diabetes medicine for you?
13. Please share your ideas that how can your experience be improved with Diabetes Nurse Specialist care provision?

## Appendix 2 – Letter from Counties Manukau Health

Whitiora Diabetes Service  
Middlemore Hospital  
Private Bag 93311  
Otahuhu  
Auckland



To whom it may concern,

Re: University of Auckland Human participants ethics Committee letter of support of proposed research project as academic requirements to complete Masters of Nursing

We are writing to support Harpreet Kaur in her proposed research study to explore patients' perspectives associated with the current attendance and non-attendance to diabetes nurse led clinics in Counties Manukau Health. The study will recruit patients who were offered appointments with two randomly selected diabetes nurse led clinics. It will involve interviews by Harpreet Kaur. Harpreet works as a diabetes clinical nurse specialist for Whitiora Diabetes Service based at Middlemore Hospital. She has completed nursing research paper (Nursing 782 H) Research Methods in Nursing and Health from the University of Auckland. Harpreet is aware of the ethical considerations in relation to relevant policies and ethics relevant to her proposed research study including privacy and confidentiality requirements.

The proposed research study is relevant to our service as it is anticipated that this study will provide information about patients' perspectives, their needs and may identify ways to promote engagement which will reduce the 'did not attend' rate.

Please do not hesitate to contact our service about any questions you may have.

Yours faithfully

A handwritten signature in black ink, appearing to read "Brandon Orr-Walker".

Brandon Orr-Walker  
Clinical Head  
Whitiora Diabetes Service

A handwritten signature in blue ink, appearing to read "Roberta Milne".

Roberta Milne  
Clinical Nurse Manager  
Whitiora Diabetes Service

A handwritten signature in blue ink, appearing to read "Catherine Tracy".

Catherine Tracy  
Service Manager  
Medicine

Counties Manukau District Health Board  
Middlemore Hospital  
Private Bag 93311, Otahuhu, Auckland 1640  
T: +64 9 276 0000 | [countiesmanukau.health.nz](http://countiesmanukau.health.nz)

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## Appendix 3 – CMH Research Office Confirmation



31 October 2016

Dear Harpreet,

Thank you for registering your proposed study with the Counties Manukau Health Research Office:

Research Registration Number: -

Research Project Title: **What matters to our patients with diabetes in regards to their attendance and non-attendance with Diabetes nurse-led clinics in Counties Manukau Health?**

Please accept this letter as confirmation of provisional approval for your proposed study to proceed at our CM Health. Final approval will be provided once we have received confirmation of ethical approval via your institutional ethics committee, final CM Health Departmental or Professional Leader approval has been obtained and approval for the research to proceed from our Director of Hospital Services has been provided.

Yours sincerely

Dr Shamshad Karatela  
**Research Manager**  
Counties Manukau Health  
*Under delegated authority from CMH Research Committee and Director of Hospital Services*

## Appendix 4 – University of Auckland Human Participants Ethics Committee Approval

Office of the Vice-Chancellor  
Finance, Ethics and Compliance



The University of Auckland  
Private Bag 92019  
Auckland, New Zealand  
Level 10, 49 Symonds Street  
Telephone: 64 9 373 7599  
Extension: 87850 / 83761  
Facsimile: 64 9 373 7432

### UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

20-Jan-2017

#### MEMORANDUM TO:

Dr John Parsons  
Nursing

**Re: Application for Ethics Approval (Our Ref. 018575): Approved with comment**

The Committee considered your application for ethics approval for your project entitled **What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties manukau Health**.

Ethics approval was given for a period of three years with the following comment(s):

Please make the following minor corrections to the public documents.

1. Letter of Invitation: Please review the grammar and English language usage, e.g. "growing in New Zealand same as worldwide" and "She wish to explore" and "You would be requested".
2. PIS:
  - a. Section 3 "type2diabetes" -> "type 2 diabetes".
  - b. Section 4, please include information about how participants may withdraw should they wish, e.g. who to contact in order to withdraw data provided.Section 5: Please separate the first sentence into two. The first phrase is about intervention. The second is unrelated and is about counselling.
3. PIS and CF: Please ensure that the statement about contacting the Chair UAHPEC for ethical concerns appears before the final approval statement, not after. Only the approval statement, not the statement about contacting the Chair needs to appear on the CF.

The expiry date for this approval is 20-Jan-2020.

If the project changes significantly you are required to resubmit a new application to UAHPEC for further consideration.

In order that an up-to-date record can be maintained, you are requested to notify UAHPEC once your project is completed.

The Chair and the members of UAHPEC would be happy to discuss general matters relating to ethics approvals if you wish to do so. Contact should be made through the UAHPEC Ethics Administrators at

## Appendix 5 – Participant Information Sheet



*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*

Please keep this sheet for your information.  
For questions, please contact: Harpreet Kaur –  
Harpreet.Kaur@middlemore.co.nz

### Participant Information

My name is Harpreet Kaur and I am an Accredited Diabetes Nurse Specialist who works for Diabetes Service. In addition I am a student studying for a Master of Nursing at The University of Auckland. The study is called “*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*” and my supervisor for this project is Dr John Parsons. You are invited to take part in a study on type 2 diabetes because you have been offered an appointment to attend a nurse-led clinic in the Counties Manukau Diabetes Service. We are interested in talking to people in one of three groups:

Those patients who have attended all the offered appointments  
Those patients who did not attend the first offered appointment  
Or those patients who did not attend follow up appointments.

This study forms part of my Master of Nursing. Whether or not you take part is your choice. If you don’t want to take part, you don’t have to give a reason, and it won’t affect the care delivered to you. If you do want to take part now, but change your mind later, you can pull out of the study and withdraw your data up to four weeks after the interview. If you choose to participate, you will be given a \$20 gift voucher to thank you for your time.

This Participant Information Sheet will help you decide if you’d like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. We expect the interview will take about 60 minutes. You may also want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is four pages long. Please make sure you have all the pages.

#### 1. Why are we doing the study?

The purpose of this study is explore the patients’ experiences with diabetes nurse-led clinics. The prevalence of diabetes is growing in New Zealand same as worldwide. I wish to explore what are the perspectives associated in regards to patient’s experiences which influence their attendance and nonattendance to Diabetes nurse led clinics. This research

Participant information sheet

*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*

1



*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*

*Please keep this sheet for your information.  
For questions, please contact: Harpreet Kaur –  
Harpreet.Kaur@middlemore.co.nz*

may guide towards development of ways to helping our people to get the maximum benefit of services that we offer.

This study is in partial fulfilment of obtaining Masters of Nursing degree as required by the University of Auckland. If you have any questions feel free to contact either me, Harpreet Kaur on the phone number above or my supervisor Dr John Parsons on 9233935. Ethics approval for the study is obtained from the University of Auckland Human Participants Ethics Committee (UAHPEC)

2. What would your participation involve?

Your participation will involve a one off interview with the researcher, which will take approximately 60 minutes. This interview will be organised in a convenient place for you. I will ask you some questions about your experiences with diabetes type 2 and the services that you have received. The interview will need to be audio recorded. Even if you have agreed to be recorded, you may choose to have the recorder turned off at any time. The recorded interview will be transcribed by me, and the transcripts will be analysed for themes across interviews. You will be provided with the chance to look at the transcript and be given up to two weeks to make any changes you wish. The study is expected to be completed by December 2017

3. What are the possible benefits and risks to you of participating?

It is expected that the study will improve the care provided to patients with diabetes type 2. This will occur through improved education of staff and also improved advice and support for relatives. Your participation in this study will have a direct effect on this.

There are no foreseeable risks to you associated with the study, but as this study involves the exploration of past experiences and includes questions about migration to New Zealand, this may provoke hidden feelings and thoughts which may not have been spoken about before. If you are not happy to tell me about your experiences at any time, feel free to stop the interview. I can provide you with the details for a professional counselling service if you feel that this is necessary.

4. What are the rights of participants in the study?

Your participation in the study is voluntary and you can choose not to participate or to withdraw from the study at any time after the interview with me. Any information that you provide will be used for the purpose of the study and will be included in my masters' thesis

Participant information sheet

*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*

2



*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*

*Please keep this sheet for your information.  
For questions, please contact: Harpreet Kaur –  
Harpreet.Kaur@middlemore.co.nz*

and may be used in presentations at conferences or in published journal articles. However your confidentiality will be preserved at all times.

5. What will happen after the study ends, or if you pull out?

There is no anticipated intervention with this study, but if needed you can be provided with the details of a professional counselling service. All documents regarding the study including the transcript of recorded interviews will be locked up in a filing cabinet at the University of Auckland for a period of six years. After this time, it will be destroyed in a secure manner.

No material that could personally identify you will be used in any reports on this study. Study data will be kept on a password protected computer at the University of Auckland. Electronic information that could identify you will be destroyed after six years.

At the end of the study, the findings will be communicated to you in written or electronic form whichever suits you most. Finally, the findings may be published in a nursing journal.

6. Where can you go for more information about the study, or to raise concerns or complaints?

If you have any questions, concerns or complaints about the study at any stage, please contact:

DR JOHN PARSONS (SUPERVISOR)

09)9233935

[j.parsons@auckland.ac.nz](mailto:j.parsons@auckland.ac.nz)

ASSOC PROF JUDY KILPATRICK (HEAD OF DEPARTMENT)

09)9232897

[j.kilpatrick@auckland.ac.nz](mailto:j.kilpatrick@auckland.ac.nz)

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Participant information sheet

*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*



*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*

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Harpreet.Kaur@middlemore.co.nz*

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

Chair contact details: "For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 extn. 87830/83761. Email: [humanethics@auckland.ac.nz](mailto:humanethics@auckland.ac.nz)."

Approved by the University of Auckland Human Participants Ethics Committee on 20<sup>th</sup> January 2017 for (3) years, Reference Number 018575

Participant information sheet

*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*

**Appendix 6 – Consent Form**



*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*

*Please keep this sheet for your information.  
For questions, please contact: Harpreet Kaur – 021 738 600*

**Participant’s Consent Form**

(This consent form will be held for a period of six years)

**Research Topic:**

What matters to our patients with diabetes in regards to their attendance and non-attendance with nurse-led diabetes clinics in Counties Manukau Health?

**Researcher:**

Harpreet Kaur, (PG Dip in advanced Nursing, Clinical Nurse Specialist – Diabetes)  
John Parsons PhD NZRP

**Declaration by participant:**

- I have read and fully understand the information sheet dated December 2016 to volunteer taking part in this study.
- I agree to take part in this research.
- I understand that taking part in this study is entirely voluntary.  
I may withdraw myself from the study at any time after without giving a reason.
- My participation and withdrawal will not affect my future care from the service in any way.
- I have had time to make decision whether to take part in this research.
- I understand that the interview will be audio recorded and transcribed.
- I understand that I can request for a copy of my transcript and that I can contact the research team up to two weeks after my interview to add or change my transcript
- I understand that the digital recordings will be destroyed within 12 months after the research has ended.
- I understand that all other data or information will be stored securely for a period of six years, after which time it will be securely destroyed.
- I wish/ do not wish to receive a summary of the research findings.

Participant’s name:

.....

Participant’s signature: ..... Date.....

Participants email address (If wish to receive copy of summary of findings):

.....

Approved by the University of Auckland Human Participants Ethics Committee

Consent Form

*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*

*December 2016*



*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*

*Please keep this sheet for your information.  
For questions, please contact: Harpreet  
Kaur – 021 738 600*

on 20<sup>th</sup> January 2017 for (3) years, Reference Number 018575

Chair contact details: "For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 extn. 87830/83761. Email: [humanethics@auckland.ac.nz](mailto:humanethics@auckland.ac.nz)."

#### Consent Form

*What matters to our patients with diabetes in regards to their attendance and nonattendance with diabetes nurse-led clinics in Counties Manukau Health?*

*December 2016*