LINKING EXISTING DATABASES TO MONITOR AND IMPROVE DIABETES CARE

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ABSTRACT

Background

Lack of population based data is a critical problem in diabetes surveillance in New Zealand. This thesis looks at the feasibility, strengths and weaknesses of linking existing databases to create a regional diabetes register in the Waikato.

Methods

Completeness and validity of key databases and agreement between common data items have been studied using the following audits and studies linking multiple data sources:

- A pilot study in a rural town (Taumarunui), linking multiple data sources including the secondary care based Waikato Regional Diabetes Service (WRDS) database and the Get Checked data from primary care.
- A general practice based study in Hamilton, linking primary care data (diagnosis codes, prescriptions, laboratory tests, Get Checked) with the WRDS database.
- Another general practice based study in Rotorua, a town with high Maori population, linking primary care data with deprivation scores.
- Audits using WRDS data and Waikato DHB hospital systems to assess data agreement.
- Retention of patients in the Get Checked programme was examined using Waikato Primary Health's data.
- Three retrospective studies linking the WRDS data with Waikato DHB hospital systems and national mortality data, which looked at hospital admissions, progression of renal disease and mortality.

The studies used several methods of data validation including comparison of datasets, manual search of patient records, direct contact with patients and comparison of data from external sources. Linked datasets were used to identify disparities in prevalence of diabetes, access to diabetes care, diabetes complications and mortality.

Results

- The coverage of the WRDS database was high (86%-91%), but newly diagnosed patients and older patients not needing retinal screening are under-represented. Case identification using primary care systems was high, but the coverage of the "Get Checked" programme (62%-80%) varied depending on practice IT systems, data handling procedures and patient characteristics.
- The Rotorua study shows that diabetes prevalence rises with increasing deprivation among Europeans, but not among Maori.
- Maori and Asian patients were less likely to access retinal screening in Hamilton. Patients aged<40 years, those of Maori or Asian origin, and those with Type 1 diabetes were less likely to be retained in the Get Checked programme with regular checks. Almost all patients had barriers to diabetes care in Taumarunui. Psychological barriers to diabetes care rank highly for all subgroups of ethnicity, age, gender, duration of diabetes and insulin treatment.
- Outcomes analyses showed that compared with Europeans with diabetes, Maori diabetes patients had a significantly higher risk of end-stage renal disease (ESRD), renal admission and renal death (46-fold, seven-fold and four-fold increases, respectively). Maori patients progressed at a significantly faster rate from first hospital admission for chronic renal disease to ESRD. Maori were more likely than Europeans to have diabetes reported on mortality coding. They were also were more likely to die from cardiovascular disease, cancer and renal disease [Hazard-ratios 2.31(1.6-3.3), 1.83(1.1-3), and 11.74(4.8-29) respectively].

Discussion

The advantages and the difficulties of linking primary care and secondary care databases to identifying diagnosed diabetes patients, the potential barriers to implementation of a diabetes register and the critical factors for a successful system are discussed. This research has demonstrated the potential of linking databases to monitor diabetes care and outcomes, but implementation would need substantial policy changes and financial backing.

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ABBREVIATIONS

ACHI	Australian Classification of Health Interventions
ACS	Australian Coding Standards
ACR	Albumin-Creatinine Ratio
ANZDATA	Australia and New Zealand Dialysis and Transplant
BMI	Body Mass Index
BP	Blood Pressure
CDC	Center for Disease Control and Prevention
CG	Cockcroft-Gault
C.I	Confidence Interval
CKD	Chronic Kidney Disease
CVD	Cardiovascular Disease
DAR	Diabetes Annual Review
DHAH	Diabetes Heart and Health
DHB	District Health Board
ESRD	End Stage Renal Disease
GDM	Gestational Diabetes Mellitus
GFR	Glomerular Filtration Rate
GP	General Practitioner
HbA_{1c}	Glycosylated Haemoglobin A_{1c}
ICD	International Classification of Diseases
IDCI	Integrated Diabetes Care Initiative
IFG	Impaired Fasting Glucose
IGT	Impaired Glucose Tolerance
IT	Information Technology
LDT	Local Diabetes Team
MDRD	Modification of Diet in Renal Disease
MoH	Ministry of Health
NHI	National Health Index
NMDS	National Minimum Dataset
NZ	New Zealand

NZDep	New Zealand Deprivation
NZHIS	National Health Information Service
NZHS	New Zealand Health Survey
PGL	Pinnacle Group Ltd
PHO	Primary Health Organisation
PMS	Patient Management System
RDIS	Regional Diabetes Information Service
RGPG	Rotorua General Practice Group
SADP	South Auckland Diabetes Project
SAS	Statistical Analysis System
SMR	Standardised Mortality Ratio
WHO	World Health Organization
WPH	Waikato Primary Health
WRDS	Waikato Regional Diabetes Service

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CHAPTER 1 INTRODUCTION

1.1 Diabetes Mellitus

The term diabetes mellitus describes a metabolic disorder of multiple aetiology characterised by chronic hyperglycaemia with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both.[1] Diabetes and its complications impose significant economic consequences on people with diabetes, their families, health systems and countries. Diabetes increases the risk of heart disease and stroke.[2] It is also one of the leading causes of kidney failure.

The World Health Organization (WHO) estimates that that there were 180 million people with diabetes in 2008.[2] The total number of people with diabetes worldwide was projected to rise from 171 million in 2000 to 366 million in 2030.[3] This trend will pose an increasing burden on governmental healthcare budgets.[4] The total estimated cost of diabetes in the US in 2007 was $174 billion[5], excluding social cost of intangibles such as pain and suffering, care provided by non-paid caregivers, excess medical costs associated with undiagnosed diabetes, and diabetes-attributed costs for health care expenditures categories, health care system administrative costs, over-the-counter medications, clinician training programmes, and research and infrastructure development.

1.2 Classification of Diabetes and Natural History

1.2.1 Classification of Diabetes

Etiologically, there are four main types of diabetes: Type 1, Type 2, other types and gestational diabetes mellitus (GDM).[1] Diabetes may progress through several clinical stages regardless of etiology (Figure 1-1) and the WHO classification encompasses both clinical stages, etiological types of diabetes mellitus and other stages of hyperglycemia.[6]

Figure 1-1. Aetiological types and clinical stages of glycaemic disorders
Source: Diabetes Mellitus: Diagnosis and Classification by Ekoé J-M and Zimmet P. [6]

Stages	Normo-glycemia	Hyperglycemia			
Types	Normal Glucose tolerance		Diabetes Mellitus		
		IGT and/or IFG	Not insulin requiring	Insulin: for control	Insulin: for survival
Type 1					
Autoimmune					
Idiopathic					
Type 2 *					
Predominantly insulin resistance					
Predominantly secretary defects					
Other specific types *					
Gestational hyperglycemia *					

* Patients may require insulin for survival.
IGT: Impaired glucose tolerance, IFG: Impaired fasting glucose

Type 1 diabetes is caused primarily due to pancreatic islet beta-cell destruction, leading to total lack of insulin production in the body. Type 1 patients are prone to ketoacidosis and depend on insulin treatment.

Type 2 is the most common form of diabetes which results from defect(s) in insulin secretion, almost always with a major contribution from insulin resistance. Patients may require insulin depending on the severity of the condition. Type 2 diabetes accounts for about 85% diagnosed cases in New Zealand.

GDM is carbohydrate intolerance resulting in hyperglycaemia of variable severity with onset or first recognition during pregnancy, which can include previously undiagnosed Type 1 diabetes and Type 2 diabetes.

Other types include genetic defects of beta-cell function, genetic defects in insulin action, diseases of the exocrine pancreas, endocrinopathies, drug or chemical induced infections, uncommon forms of immune-mediated diabetes and other genetic syndromes sometimes associated with diabetes.

Diabetes could be asymptomatic or it may present with characteristic symptoms such as excess thirst, polyuria, blurred vision, recurrent infections and weight loss. Due to unrecognised or absent symptoms, hyperglycaemia may go undiagnosed and untreated for a long time.[7] After several changes over the years[7-10], the WHO recommended diagnostic criteria are currently used in New Zealand.[1]

1.2.2 Determinants

Development of Type 2 diabetes mellitus is a result of a complex interplay between environmental factors/lifestyle, genetic susceptibility, demographic factors and their interactions.[8] Some are non-modifiable factors like aging, gender, family history of diabetes, genetic predisposition, intrauterine exposure to diabetes[9] and ethnic heritage. But factors like unhealthy diet, overweight and inactive lifestyle are modifiable. Several genetic studies have identified susceptibility genes for Type 2 diabetes and diabetes pre-disposing genes.[10 11] History of GDM or having had a previous baby weighing over

nine pounds are associated with later risk of developing diabetes. Urbanisation and migration has been shown to influence lifestyle and in turn the prevalence of diabetes.[12] Virus infections, diabetogenic drugs, in-utero malnutrition, endocrine diseases and certain nutrients can cause beta-cell damage leading to diabetes.

Socio-economic deprivation influences obesity levels, which in turn are associated with Type 2 diabetes.[13] Growing evidence points to the economic gap between people as an important predictor of health, independent of absolute standard of living.[14]

Genetic and, as yet undefined, environmental factors act together to precipitate Type 1 diabetes.[15] Progression to Type 1 diabetes typically requires the combination of genetic disease susceptibility (e.g. HLA DQ8, HLA DQ2), a diabetogenic trigger (e.g. enterovirus infection) and a high exposure to a driving antigen (e.g. bovine insulin in cow's milk based infant formula).[16] Aetiological determinants and risk factors for Type 2 diabetes are summarised below (Table 1-1).

Table 1-1. Aetiological determinants and risk factors for Type 2 diabetes.
Source: Epidemiology, Evidence for Prevention: Type 2 Diabetes by Zimmet .P et.al.[17]

A. Genetic factors
B. Demographic determinants Age, Gender, Ethnicity
C. Behavioural & lifestyle related risk factors Obesity (including distribution and duration of obesity) Physical inactivity Diet Stress Westernisation, urbanisation, modernisation
D. Metabolic determinants and intermediate risk categories Impaired glucose tolerance, impaired fasting glycaemia Insulin resistance Pregnancy related determinants (parity, gestational diabetes, diabetes in offspring of women with diabetes during pregnancy, intrauterine environment).

1.2.3 Complications

Diabetes is a progressive and chronic disease that potentially affects every organ in the body. The long-term effects of diabetes mellitus include progressive development of the specific complications due to microvascular damage (small blood vessels), macrovascular damage (large blood vessels) and some complications which do not fit entirely into either category (glove and stocking peripheral neuropathy, cranial neuropathies, entrapment neuropathies, proximal motor neuropathies, autonomic neuropathy, various sorts of cataract and diabetic cheiroarthropathy).[18] Microvascular complications include retinopathy with potential blindness, nephropathy that may lead to renal failure, and/or neuropathy with risk of foot ulcers, amputation, Charcot joints, and features of autonomic dysfunction, including sexual dysfunction. Due to macro vascular damage, people with diabetes are at increased risk of cardiovascular, peripheral vascular and cerebrovascular disease.

1.2.4 Implications for Diabetes Patients

The resulting complications and the lifestyle modifications needed in managing the disease could significantly reduce the quality of life for diabetes patients. People with diabetes have to cope with lifestyle changes and medical treatments in order to reduce their risk of developing complications. Many of those with diabetes face a multitude of barriers to quality diabetes care and self-care[19 20], including financial barriers[19] and psycho-social problems.[22] People with complications of diabetes may need special shoes and low vision aids which further increases the cost burden for individuals.

1.2.5 Cost of Diabetes to Health Service

Diabetic patients are more than twice as costly to manage as non-diabetic patients, due mainly to the high costs associated with management of diabetic complications.[7]

Diabetes UK estimates that 10% of National Health Service spending goes on diabetes, which equates to £9 billion a year.[20] The total estimated cost of diabetes in the US in 2007 is $174 billion, including $116 billion in excess medical expenditures and $58 billion in reduced national productivity.[5] One in five health care dollars in the US is spent caring for someone with diagnosed diabetes, while one in ten health care dollars is attributed to diabetes. The burden of diagnosed Type 2 diabetes in Australia is an estimated $3 billion a year, with average costs per person at $5,360 plus $5,540 in benefits, totalling $10,900.[21]

1.3 Diabetes in New Zealand

1.3.1 Population Structure of New Zealand

The estimated resident population of New Zealand was 4.23 million at 30 June 2007.[22] New Zealand, along with other OECD countries, has an ageing population structure as a result of low fertility and low mortality. The 65 years and over age group itself is increasing in numbers and this partly reflects the continuing improvement in longevity. Males and females aged 90 years and over recorded the largest growth during the last decade, up 74.8% and 57.0% respectively.

The Maori population, the indigenous people and the largest non-European ethnic group in New Zealand, is much younger than the total population. The estimated resident Maori population, those who have some Maori ancestry and who identify themselves with Maori, at 30 June 2007 was 632,900 (15%). Maori known as tangata whenua (people of the land) are descendants of the Polynesians who first arrived in New Zealand between 950 and 1130 AD. European settlers first arrived in the 17th century and colonisation began much later in the 19th century. New Zealand's society reflects many years of migration from all parts of the globe. The majority are of British

descent, along with other European cultures such as French, Dutch, Dalmatian, Scandinavian, Greek, Italian and German. More recently people from islands throughout the Western Pacific, including Samoa, Fiji, Tonga and Cook Islands have migrated here, along with immigrants from Asia. Between 2001 and 2021, the broad Asian, Pacific and Maori ethnic populations are all projected to grow faster than the New Zealand population overall. In the case of the Asian population, the growth is mainly driven by net migration gains. In the case of the Pacific and Maori populations, the growth is mainly driven by higher fertility rates combined with a youthful age structure.

1.3.2 Impact of Diabetes

The rising diabetes prevalence is a major problem in New Zealand, especially among the non-European ethnic groups[23], catalysed by the increasing obesity rates, sedentary lifestyle and ageing population structure. The prevalence of both Type 2 and Type 1 diabetes has been rapidly rising in New Zealand, with an associated increase in need for diabetes-related services.[24] New Zealand had an estimated 150,000 people diagnosed with diabetes in 2006.[25] The annual health costs for diabetes services (in 1998/99 dollars) for Type 2 diabetes alone was projected to reach NZ$1.066 billion by year 2021.[26] The complex mix of ethnic, socio-economic, geographic and service delivery factors has contributed to inequalities in the risk of disease, access to, and the quality of diabetes care. A full literature review of the epidemiology of diabetes in New Zealand has been undertaken, including the prevalence of diabetes and its risk factors, metabolic control, diabetes related complications and mortality[23] (Chapter 2).

PricewaterhouseCoopers'[27] outcomes model produced three scenarios of future government spending on services (treatment and prevention) for Type 2 diabetes under

different assumptions about the level of preventative interventions. Scenarios 1 and 2 are intended to estimate the upper and lower range for existing diabetes services.

- Scenario 1: 2000 Service Level. Forecasts based on services and treatments as described in the Diabetes 2000 report from the former Health Funding Authority;
- Scenario 2: Enhanced Services. Forecasts the effect of additional funding (of $20-40 million per year) for diabetes prevention, detection and treatment services; and
- Scenario 3: Optimal Services. Assumes a significant, immediate increase (of approximately $60 million per year) in funding for diabetes prevention, detection and treatment services. The key focus of this scenario is the use of prevention initiatives.

The following table (Table 1-2) presents the forecast cost of Type 2 diabetes health services under the three scenarios based on prevalence data produced by the Ministry of Health (MoH) in 2006.

Table 1-2. Forecast cost of Type 2 diabetes using 2006 (2006 dollars)

Source: PricewaterhouseCoopers modelling[27] based on Ministry of Heath diabetes prevalence data for 2006.[28]

Cost of Type 2 Diabetes	2006/07 ($m)	2011/12 ($m)	2016/17 ($m)	2021/22 ($m)
2000 Service Level	540	840	1240	1780
Enhanced Services	570	850	1200	1410
Optimal Services	590	830	1080	1410

Expenditure on health services for Type 2 diabetes services ($540 million in 2006/07 assuming the modest service level spending) is expected to rise significantly in the next 15 years.[27] An increased investment of $60 million a year (in 2006 dollars) in prevention, self-management and early detection services for Type 2 diabetes has the potential to reduce the government's health expenditure by as much as $370 million in

2021. Up-to-date and reliable data on utilisation rates and costs of health services and treatments for people with Type 2 diabetes is necessary to monitor the implications.

1.4 Structure of Diabetes Care in New Zealand

Management of diabetes involves lifestyle modifications (diet and exercise), diabetes treatment, education and support, monitoring of body functions (glycaemic control, blood pressure, lipids), complication screening (foot check, renal function test, retinal screening) and prompt and appropriate treatment. Diabetes care involves a broad spectrum of health care providers including: general practitioners, diabetologists, diabetes nurses/educators, dieticians, podiatrists, ophthalmologists, pharmacists and other secondary care specialists. But flow of patient level information between primary care and secondary care is very limited, making the two sectors of care run in parallel.

In New Zealand general practices function as the first line of contact for health care, providing diagnosis, management, continuity of care, health promotion, prevention and screening for individuals and their families. Many general practices run as private businesses but organisations such as community trusts, accident and emergency services, or Maori health providers employ general practitioners (GPs); the consultation fee charged varies depending on the subsidies available and local market forces.[29]

People with Type 2 diabetes in New Zealand are largely managed by GPs and practice nurses who are employed by the general practices. Access to specialist care (diabetologists, opthalmologists, renal physicians, surgeons, cardiologists) and diabetes support services (foot-care, diet advice, support lifestyle change, coaching and co-ordination) are through referrals from primary care. The majority of people with Type 2 diabetes do not require referral to specialist physicians until complications have developed or routine treatment is not effective.

Formal shared care arrangements between GPs and secondary care diabetes services are indicated for people with diabetes that have:

- Diabetic nephropathy
- Unstable diabetes
- High cardiovascular risk
- Type 1 diabetes
- Previous significant diabetes complication(s)
- Other significant co-morbidities impacting on diabetes management

Apart from one "Get Checked" annual diabetes review offered through the primary care services, patients pay for their GP visits as usual. Patients with community service cards (low income groups) enjoy the benefits of subsidy in consultation fees. In the Waikato, patients without existing eye disease are referred to the secondary service for retinal screening.

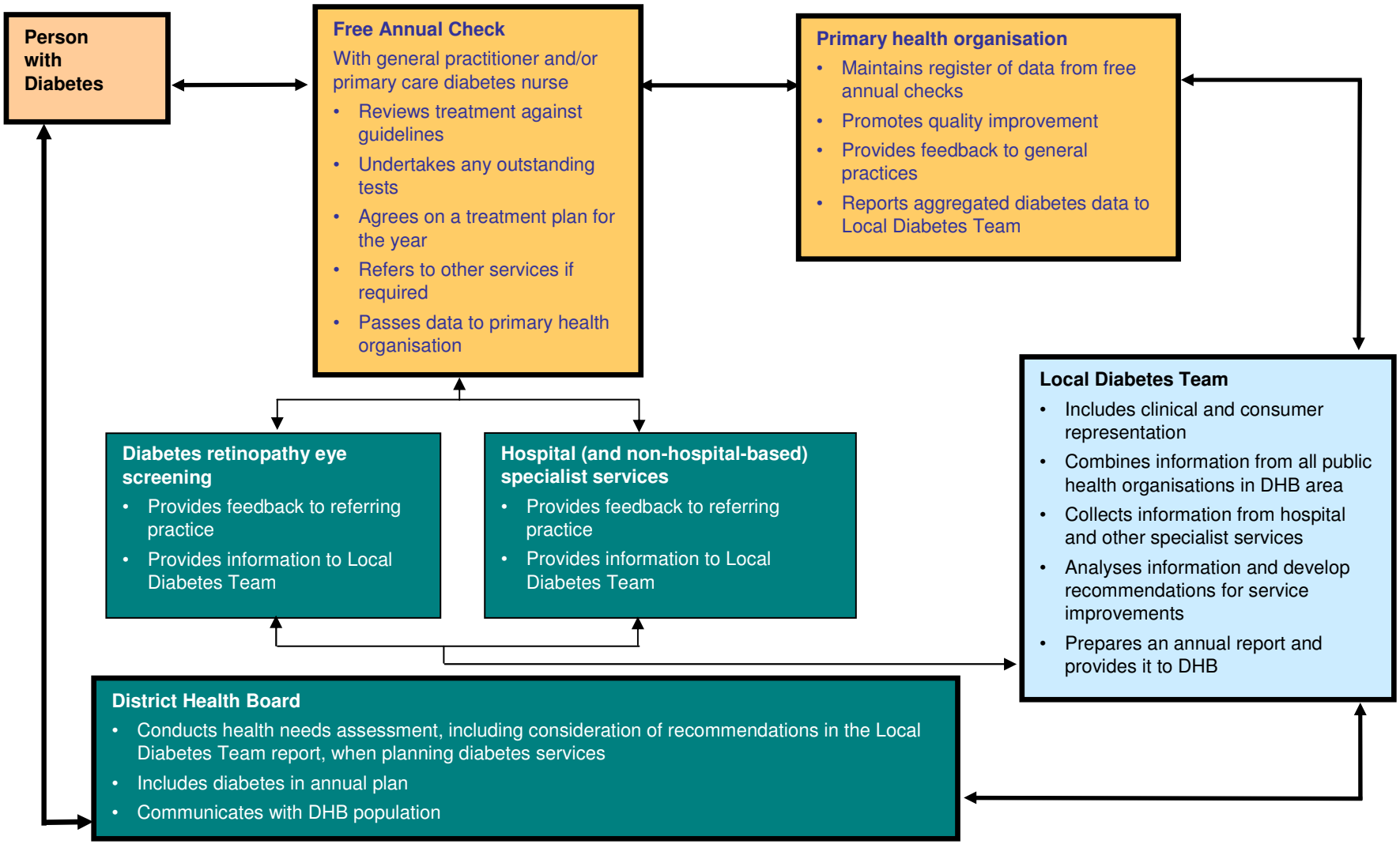
Local structures called Primary Health Organisations (PHOs) deliver and co-ordinate primary health care services for patients enrolled with practices they manage. PHOs get a set amount of funding from the government to subsidise a range of health services.[30] The funding is based on the numbers and characteristics (e.g. age, sex, ethnicity) of people enrolled with them.

District Health Boards (DHBs) have established Local Diabetes Teams (LDTs) to meet the need, as identified in Diabetes 2000[31], for a team of local stakeholders to oversee the planning, implementation and integration of diabetes services in their district. The service specification for LDTs[32] identifies the minimum set of organisations that should be represented on them, including representatives from the DHB, diabetes providers (from primary to tertiary care), diabetes consumer organisations, and Maori and Pacific communities.

The major output of LDTs, as stated in the service specification, is the preparation of an annual report summarising the ”Get Checked” data from primary care organisations throughout the district, and recommending improvements to diabetes services. The National Diabetes Framework and information flow among key stakeholders is shown below is shown below (Figure 1-2).

Figure 1-2. National diabetes framework: information flow among key stakeholders

Source: New Zealand Health Strategy's DHB Tool kit for Diabetes[33]



1.4.1 Get Checked Annual Diabetes Review Programme

A strategy used in the UK and Australia to ensure that each person with diabetes received regular structured assessment has been the annual diabetes review.[34-36] The "Get Checked"[31] free annual diabetes review programme in New Zealand, a MoH initiative which started in June 2000, was established to address both the need for structured care and to help overcome personal expenses as a barrier to diabetes care. This national programme is delivered through GP services. All people with a known diagnosis of Type 1 or Type 2 diabetes mellitus are eligible to receive this service once every 12 months. The service is free of charge to all people eligible to receive it and who consent to the transfer of information to the PHO. Patients are expected to return for review every year.

The objectives of the "Get Checked" programme are:

- To systematically screen for the risk factors and complications of diabetes to promote early detection and intervention
- To agree on an updated treatment plan for each person with diabetes
- To update the information in the diabetes register used as a basis for clinical audit and planning improvements to diabetes services in the area
- To prescribe treatment and refer for specialist or other care if appropriate.

A GP or a practice nurse reviews patient's treatment plans against guidelines, carries out any outstanding checks and records the results, prepares a treatment plan for the following year, and refers the patient to other services if necessary. The diabetes review includes:

1. Physical examination: height, weight, systolic blood pressure, diastolic blood pressure, foot examination and eye check, ensuring that retinal examination has been done
2. Check of smoking status
3. Fasting blood test: total cholesterol, HDL-cholesterol, triglyceride
4. Blood test: glycosylated haemoglobin (HbA_{1c})
5. Urine test for nephropathy (if clinically indicated)
6. Review of medication and management, including prescriptions for medication, glucose test strips, and glucose monitors as required

The general practice maintains records of the check on its patient management system (PMS). The DHBs in New Zealand have targets for increasing the proportion of diabetes patients who receive the free annual diabetes check.[37] The DHBs have funding arrangements with a number of different organisations to administer the programme. The dataset collected from each free annual check at primary care practice level must be provided by the practice to the programme administrator, usually a PHO. The PHO then undertakes analysis of that information and provides an aggregated dataset to the Local Diabetes Team. This information is used to improve the quality of diabetes care by giving feedback to general practices. The LDTs combine all the information received from programme administrators and collects information from hospital and non-hospital specialist diabetes services. It analyses the information, develops recommendations for service improvements, prepares an annual report, and sends it to the DHB and the Ministry. The DHBs consider the LDT report recommendations when planning diabetes services. The programme provides for a payment of $40 to GPs for each “Get Checked” review. This payment is not always considered sufficient and most DHBs allowed PHOs and programme administrators to increase the payment out of their funding.[38] As a result, the amounts paid to GPs differed among PHOs and programme administrators.

Nationally, the percentage of people with diabetes enrolled in the "Get Checked" programme increased from 33% in 2001 to 59% in 2005, but still the figures are sub-optimal, especially for Maori.[37] The data purportedly provide insight into diabetes care across New Zealand[39] [40], but there are problems around retention of patients in the programme[41] and the assessment of programme coverage itself.[38] In the absence of a diabetes register and adequate prevalence data, the coverage of the programme is assessed using estimates of the total number of diabetes patients derived from forecast models.[42]

1.4.2 Waikato Regional Diabetes Service

Waikato DHB serves approximately 9% (339,189 according to 2006 census) of the total New Zealand population (Figure 1-3). Waikato has a high proportion of people who identify themselves as Maori (20%), compared with national figures (14%). The Waikato Regional Diabetes Service (WRDS) delivers the Waikato DHB's secondary diabetes services including the retinal screening programme.

Early detection of retinopathy is needed to prevent loss of vision. Early retinopathy can only be detected by direct expert examination. A mobile retinal photo screening service is made available to all diabetes patients through the WRDS.

All diabetes patients without visual loss or known eye disease are referred to the WRDS for retinal screening. Patients with Type 2 diabetes are reviewed from diagnosis and minimally two yearly thereafter. Type 1 patients are reviewed from 10 years of age or three to five years after diagnosis. At photo screening, the patients' pupils are widely dilated and colour photographs taken of each fundus. Glaucoma screening is not part of the service. The slides are read by an ophthalmologist and the results and recommended action reported to the general practitioner and the patient. Patients in

whom eye review is recommended are automatically referred to the Waikato Ophthalmology Service.

Figure 1-3. Waikato DHB map showing areas covered by the WRDS retinal screening programme

Note: Major population pockets near the Waikato DHB boundary, which are not part of the Waikato DHB are circled.

As per the referral guidelines[43], the following patients are not referred for retinal screening:

- Patients attending a specialist or specialist eye clinic for ongoing review/treatment.
- Patients who should not have their pupils dilated.
- Patients with unstable angina.
- Patients during pregnancy.
- Patients with new onset visual loss or reduction of vision.

Other programmes offered by the diabetes unit include:

1. Insulin infusion pump programme for Type 1 diabetes patients.
2. Adolescent and young adult clinic for Type 1 and 2 with diabetes 12 to 20 years of age.
3. Weight management programme for patients with a body mass index (BMI) > 35 (both diabetes patients and non-diabetes patients with other co-morbidity).
4. High risk foot clinic including outreach clinics conducted at Tokoroa, Taumarunui, Te Kuiti.
5. Diabetes and Pregnancy Clinic for Type 1, Type 2 and gestational diabetes patients.
6. Diabetes education and follow-up throughout the Waikato.
7. Paediatric service for all diabetic children up to age 12 (and progressively to age 15).
8. Outreach clinics in Thames, Tokoroa, Taumarunui.

1.5 Data Systems Relevant for Diabetes Surveillance in New Zealand

There are six major groups of data systems in New Zealand. These are described below.

1.5.1 Primary Care Data Systems

Most practices are in Primary Health Organisations and receive funding based on their enrolled population in the age/sex register. Almost all practices in New Zealand are computerised to some extent and use specifically designed PMS software to assist with recording of patient and clinical consultation.[44] Most (80%) are equipped with internet connection as well. Eighty percent of practices using PMS software packages use one of Healthtech Medtech 32, Houston GP or Intrahealth Profile (for PC or Mac). Some practices use their IT systems only for reception activities such as an age/sex register, daily log, and accounts, but increasingly practices have fully integrated clinical notes, integrated lab results and clinic letters, and email and internet access.[29] Although New Zealand health care IT has reached high standards without specific government intervention, these systems would need to be refined in order to ensure compatibility and standardisation between general practices, laboratories, pharmacies, secondary health care services and national data collection facilities.[45] In New Zealand, the Read Code system is predominantly used by GPs[46], however, diagnoses are not consistently coded.[47]

1.5.2 The "Get Checked" Database

The DHBs ensure that there are registers of data from the free annual checks recorded in primary care (the diabetes registers, maintained by programme administrators). The general practices send a minimum dataset collected as part of the "Get Checked" free

annual review to the programme administrator. Patient details [the national health index (NHI) number, gender, date of birth, ethnic origin], date of annual review, type of diabetes, year of diagnosis of diabetes and the examination results are required to be recorded in the diabetes register.[48] A full description of the minimum dataset is included in the Appendix 1.

In 2003, the evidence-based guideline on which this programme is based was updated[49] and supplemented with a specific guideline for cardiovascular disease.[50] Subsequently, the PMSs and PHO IT systems were upgraded by December 2007 to reflect the changes to Get Checked.[51] This provided PHOs with an option for collecting clinical information from their practice PMS to support quality improvement and a wider range of clinical services. Practices and PHOs have the choice of upgrading for IT systems, using the upgraded "Get Checked" database for diabetes reviews more often than annually and for quality improvement initiatives for cardiovascular disease (CVD) risk assessment in people without diabetes.

1.5.3 Secondary Diabetes Service Database

The LDTs include information received from specialist diabetes services reports in their annual report to the DHBs. But there is no specific national guideline for the secondary diabetes services for collection and recording of data. These data are kept separately from primary care data and the "Get Checked" dataset.

The WRDS database was set up in 1997 using Microsoft Access. The database stores the NHI number, demographic details, patient identified single ethnicity, year of diagnosis of diabetes, type of diabetes, retinal screening bookings and outcomes and other details depending on patient's programme participation. The data dictionary is included in the Appendix 2.

1.5.4 Hospital Inpatient Management Systems

The clinical notes from all inpatient and day patients discharged from New Zealand hospitals are coded and recorded in the hospital's PMS. Coded summaries of these discharges are forwarded to the MoH, where the information is loaded and stored in the National Minimum Dataset (NMDS).

1.5.5 National Minimum Dataset (NMDS) of Hospital Events

The NMDS is a national collection of public and private hospital discharge information, including clinical information, for inpatients and day patients. Unit record data are collected and stored.[52] All records are required to have a valid NHI number. Public hospitals have been submitting data electronically in an agreed format since 1993. The private hospital discharge information for publicly funded events, such as birth events and geriatric care, has been collected since 1997. The current NMDS was introduced in 1999.

1.5.6 National Health Information Service Mortality Collection

The National Health Information Service (NZHIS) Mortality Collection classifies the underlying cause of death for all deaths registered in New Zealand, including all registered fetal deaths (stillbirths), using the International Classification of Diseases (ICD)-10-AM 2nd Edition and the WHO Rules and Guidelines for Mortality Coding.[52] Deaths registered in New Zealand from 1988 onwards are held in the mortality database.

1.6 Variables in Data Systems

1.6.1 NHI Number

The NHI number is an alpha-numeric seven digit number which uniquely identifies every health user in New Zealand. Personal information about a person booked to receive or receiving healthcare resulting from direct contact with a healthcare provider where the healthcare results in the use of resources associated with observation, assessment, diagnosis, consultation, rehabilitation or treatment are stored in the national register.[53] The NHI number replaced the National Master Patient Index in 1993. Newborn babies have been registered on the national system since 1992. When duplicate records for a healthcare user are identified when they are linked, one of their NHI numbers will be deemed to be the primary (or master), and the others become secondary NHI numbers. Variables held on the national register against the master NHI number include:

- Name (family name, family name soundex, three fields for given name and preferred name)
- Sex
- Date of birth (with a separate field flagging partial date of birth)
- Date of death
- Ethnic group codes (up to three entries using Level 2 of Statistics New Zealand's ethnicity coding).
- Address (including city/town, country/region)
- Domicile code (Statistics NZ Health Domicile Code)
- NZ resident status
- The date of last update to a healthcare user's information

Following the publication of the Wave Report[54] in 2001, NZHIS undertook a 12 month NHI upgrade programme, which included identification and resolving of duplicate NHIs. The rate of creation of duplicate NHI numbers throughout all DHBs has reduced

significantly since the beginning of 2003.[55] From 1 July 1996 up to three ethnic group codes can be collected for each healthcare user and each event. Where more than three ethnic group codes are reported, the Statistics NZ prioritisation algorithm is used to report only three values. Because ethnicity is self-identified, it can change over time. NZHIS collects ethnicity information for each health event to account for changing ethnicity, rather than relying on the data in the National Health Index (which does not include historical data).

1.6.2 Ethnicity

The concept of ethnicity is complex and multidimensional. Ethnicity being self-perceived, a person can belong to more than one ethnic group and can change his/her ethnic affiliation, both over time and in different contexts.[56] The definition of ethnicity based on the Smith's work[57], used by Statistics New Zealand[58] is:

A social group whose members have one or more of the following four characteristics:

- they share a sense of common origins
- they claim a common and distinctive history and destiny
- they possess one or more dimensions of collective cultural individuality
- they feel a sense of unique collective solidarity.

The standard ethnicity question for the health and disability sector mirrors the Statistics New Zealand 2001 Census ethnicity question (Figure 1-4).

Figure 1-4. New Zealand 2001 census ethnicity question and standard ethnicity question used in the health and disability sector

Source: Statistics New Zealand, 2001 Census

Health data systems that output data to MoH National Systems are required to be capable of storing and outputting up to three ethnicities. Where more than three ethnicities are available to be output, the prioritisation method (Table 1-3) described in the protocols must be used.

Three standard methods used to output ethnicity data collected are:

- **Sole/combination output**: sole ethnic categories for respondents who report only one ethnic group, and combination categories for respondents who give more than one ethnic group. Example: Samoan/Tongan, NZ European/Maori and Maori/Pacific.
- **Total response**: each respondent is counted in each of the ethnic groups that they reported. Because individuals who indicate more than one ethnic group are counted more than once, the sum of the ethnic group populations will exceed the total population of New Zealand. The advantage is that it represents all those people who identify with any given ethnic group.

- **Prioritised output**: each respondent is allocated to a single ethnic group using the priority system (Maori, Pacific peoples, Asian, other groups except NZ European and NZ European). The aim of prioritisation is to ensure that where some need exists to assign people to a single ethnic group, ethnic groups of policy importance, or of small size, are not swamped by the NZ European ethnic group. The major limitations are that this process over-represents some groups at the expense of others and it goes against the principle of self-identification.

Table 1-3. Statistics New Zealand's Level 2 ethnicity codes and order of prioritisation for ethnic groups

Source: Ethnicity Data Protocols for the Health and Disability Sector[56]

Priority order	***Ethnic group code (L2)***	***Ethnic group code description***
1	21	Maori
2	35	Tokelauan
3	36	Fijian
4	34	Niuean
5	33	Tongan
6	32	Cook Island Maori
7	31	Samoan
8	37	Other Pacific Island
9	30	Pacific Island NFD
10	41	South East Asian
11	43	Indian
12	42	Chinese
13	44	Other Asian
14	40	Asian NFD
15	52	Latin American / Hispanic
16	53	African
17	51	Middle Eastern
18	54	Other
19	12	Other European
20	10	European NFD
21	11	NZ European
-	99	Not Stated

NFD - Not Further Defined

Ethnicity in Primary Care Sector

Each PHO in New Zealand is required to submit its patient register to the MoH's Sector Services Unit on a quarterly basis as part of the national PHO payment system. PHO registers include ethnicity data for each registered patient taken from general practice PMSs. Ethnicity information in PMSs may have been retrieved from the national NHI register, or may have been self-identified or obtained through some other process[59],

and the accuracy of recorded ethnicity is under question.[60] Ethnicity information obtained directly from the patient may or may not have been acquired via the use of the census ethnicity question which is the protocol for collecting ethnicity data in the New Zealand Health Sector.[56] Although the practice systems can hold up to three ethnicity responses, for reporting purposes if more than one response is given, a prioritised ethnicity is used.[59] There are issues around the completeness of ethnicity recording[61], with variations between practices.[47]

Ethnicity in secondary care

The inpatient management systems in secondary care are capable of recording up to three ethnicities and report them to the NMDS. But the level of recording of ethnicity in secondary care is high.[62] Personal communications with frontline staff involved with patient registration in the Waikato DHB indicates that methods of ethnicity data collection vary widely, as in the case of primary care. Patients are often prompted to identify a single ethnicity. The WRDS database, which is not linked to the hospital inpatient system, stores a single ethnicity. Validation of ethnicity of the WRDS database shows that ethnicity data were concordant for 71% (67%,75%) of Maori and 99% (99%,100%) of non-Maori.[63]

One of the benefits of linking primary and secondary care data is that patient demographic data may be easily migrated between the primary and secondary care components of an integrated healthcare dataset to update data items with missing or erroneous values.[62] In the case of data mismatches, decision algorithms would need to be developed to prioritise one set of data over the other.

1.6.3 Diagnosis Code

The ICD[64] is the international standard diagnostic classification used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and health records. In addition to enabling the storage and retrieval of diagnostic information for clinical, epidemiological and quality purposes, these records also provide the basis for the compilation of national mortality and morbidity statistics by WHO Member States.

In mid 1999, New Zealand hospitals changed from using versions of the ICD-9 coding system to using versions of the ICD-10 coding scheme to summarise the injury(s)/disease(s) of patients. Morbidity data are collected in New Zealand using The International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), The Australian Classification of Health Interventions (ACHI) and the Australian Coding Standards (ACS).[65] The current 6th edition came into effect from 1 July 2008. The rules and conventions of ICD-10-AM/ACHI/ACS govern clinical coding practice and underpin consistency and accuracy of clinical coded information submitted to the NMDS.

Trend information on diabetes complications using hospital data, extending across 1999-00 and 2000-01, have to take the coding changes and the classification into consideration.[66] From July 2000, an additional diagnosis of diabetes or its complication in hospital data indicates that the diabetes co-exists with the complication without inference of causality. Coding changes do not have a major impact on this thesis, since morbidity and mortality analyses are limited to 2003 onwards.

Audits have revealed as much as 29% discordance between discharge diagnoses recorded in hospital medical records and their ICD codes.[67] Accurate coding of discharge diagnosis continues to be a challenge for coders.[68]

1.6.4 Domicile Code

The Domicile code used for health collections from 1 July 2003 is the four-digit 2001 Health Domicile Code specially created by Statistics NZ from their 2001 six-digit Census Area Unit Code.[53] Some older Domicile codes are still held for healthcare users whose addresses are not sufficiently detailed for a mapping to a new version of the Domicile code.

Statistics NZ Health Domicile Code represents a person's usual residential address. If a person usually lives in a rest home or a hospital, that is considered their usual residential address. Domicile codes are key variables for determining the characteristics of the population that are using the health sector.

Since 1996, Domicile code has been automatically assigned on the NHI database using the address provided. This can result in rural addresses being assigned to an urban Domicile code where there is insufficient data to generate the correct code. This is because the automated software relies on generating a post code in order to determine where in a related table it should look to find the code. New general codes have been added for DHBs from 1 July 2001. According to the data dictionary, general DHB codes are meant be a last resort, and should be used only if the correct Domicile code cannot be determined.

1.6.5 NZDep2001 Scores

The New Zealand deprivation (NZDep2001) scores have been generated from the 2001 census data as an attempt to measure special health needs, calculated as a function of nine socio-economic variables.[69] The general theory is that an area with a high NZDep2001 score is, on the whole, more likely to need health services than one with a low NZDep2001 score. These variables have been shown through the literature

to be associated with mortality or morbidity or some type of disadvantage.[70] NZDep2001 is an updated version of the NZDep91 and NZDep96 indices of socio-economic deprivation.

The variables are calculated by meshblock and then aggregated up to domicile area (using population weights), where a domicile is a geographical area defined by Statistics New Zealand for census and related purposes. The aggregation to domiciles was undertaken in order to be able to match with hospital discharge information. The list of variables used for calculating NZDep2001 scores are given in the table below (Table 1-4).

Table 1-4. Census variables used for calculating NZDep2001 scores

Source: Salmond and Crampton[69]

Name of variable	Description of variable (in order of decreasing weight)
Income	People aged 18-59 receiving a means tested benefit
Employment	Unemployed people aged 18-59
Income	Equivalised* household income below an income threshold
Communication	People with no access to a telephone
Transport	People with no access to a car
Support	People aged <60 living in a single parent family
Qualifications	People aged 18–59 without any qualifications
Owned home	People not living in own home
Living space	Equivalised household below a bedroom occupancy threshold

* Equivalisation: methods used to control for family composition.

1.7 Limitations of Existing Systems as Audit Tools

Robust reliable regional level diabetes prevalence data are needed for better planning and provision of diabetes services at DHB level, to monitor the diabetes epidemic (prevalence, coverage of diabetes care programmes like the “Get Checked” and retinal screening, interventions aimed at early identification and intensive management of patients at risk of complications like amputation and renal disease). New Zealand does

not presently have a national diabetes surveillance system/register that is regularly updated, accurate and actually used to monitor and improve services.

The current diabetes care system falls short in its ability to access:

1. the true number of people diagnosed with diabetes, in a timely fashion
2. the coverage of the "Get Checked" programme
3. the coverage of the retinal screening programme
4. impact of diabetes and its complications on health service utilisation
5. mortality trends among diabetes patients.

1.7.1 The True Number of People Diagnosed with Diabetes

In 2002, Public Health Intelligence, a section of the MoH, built a multi-state life table model[71] to provide estimates for the descriptive epidemiology of diagnosed Type 2 diabetes in New Zealand, based on the 1996/97 New Zealand Health Survey.[72] This model has proved useful for planning and funding diabetes services and for developing diabetes prevention strategies. In 2007, this model was updated[25], using data from the 2002/03 New Zealand Health Survey.[73]

The key limitation is that the validity and reliability of the model depends on the quality of input data. NZ Health Survey relies on self-reported diabetes which may not be accurate.[74] Response rate could also pose a problem (68% for the latest 2006/07 survey). The model provides estimates of prevalence rate and expected number of diabetes patients at national level. But the smaller the region predicted for, the wider the confidence intervals (C.Is). As a result, regional level prevalence estimates derived from the model are less reliable. Many PHOs find that there are more patients coded with diabetes than the estimated number of patients (for example, 8379 (105%) instead of 7978 estimated in the case of Waikato PHO in 2006-07).[42] There is no doubt that the

number of diabetes patients derived from national prevalence rates is not a robust denominator to assess programme regional coverage.

1.7.2 The Coverage of the 'Get Checked' Diabetes Annual Review Programme in the Waikato

The Diabetes Implementation Plan[31] envisaged the establishment of diabetes registers (including Type 1 and 2) in PHOs, that are updated annually following the "Get Checked" annual reviews. PHOs contracted by DHBs manage the "Get Checked" data, generate summary reports and contribute data to the national "Get Checked" database. Waikato DHB has contracted Waikato Primary Health (WPH) to manage the "Get Checked" database for the DHB. LDTs use the "Get Checked" review summary data from PHOs in their annual report submitted to DHBs.

But the database falls short for a diabetes register with the annual "Get Checked" review uptake of 60% of the estimated number of diabetes patients.[37] Currently there are minimal data indicating the expected number of diabetes patients in general practices and it is difficult to access the coverage of the "Get Checked" programme.[38]

1.7.3 The Coverage of the Retinal Screening Programme in the Waikato

The absolute number of people with diabetes in the Waikato DHB region is not known; researchers have to rely on diabetes prevalence estimates from elsewhere.[75] The "Get Checked" review collects information on retinal screening referrals, but this information has not been validated.

1.7.4 Impact of Diabetes and its Complications on Health Service Utilisation

Currently, there is no agreed sharing of diabetes related data between primary care and secondary care services in the Waikato. Due to the lack of a common diabetes register, official estimates of health service utilisation among diabetes patients rely on diabetes diagnosis coding on routinely collected data. The Health Needs Assessments conducted by all DHBs are carried out using the NMDS for hospital events and the national mortality collection from the NZHIS. Although the results are up-to-date and can be compared with national figures, there are several critical limitations to this cross sectional approach, particularly when applied to diabetes admissions.

Diabetes admissions usually present as “non-diabetes” events such as infections, heart attacks and strokes and are not usually directly attributable to diabetes. Hospital admissions for diabetes (codes E10-E14) are routinely analysed to assess the morbidity levels among diabetes patients and their service utilisation. Only the primary diagnosis codes are used for this exercise. An analysis involving only primary diagnosis codes misses out all of the admissions for diabetes related complications.

Another issue is the under-coding of diabetes on NZHIS admissions and discharge data, even with secondary admission codes included in the analysis. On all audits to date of discharge coding, diabetes which is known to the attending medical teams is not entered or coded in the discharge process in about 50% of cases.[63 69 70]

Cohort analysis including secondary diagnosis codes, based on a cohort of patients identified from a diabetes register, is needed to overcome these problems.[76]

1.7.5 Mortality Among Diabetes Patients

The NZHIS mortality records are routinely analysed, looking at deaths due to diabetes. In contrast to infectious diseases or cancer, diabetes patients develop several complications as the disease progresses. Many diabetes patients die from coronary artery disease and renal complications. There are issues around coding of diabetes on death certificates when diabetes patients die of complications. Difficulties in the coding of diabetes have been recognised for many years[77], yet continue to be rediscovered[78 79] with 45%-55% under-coding especially among non-insulin using (Type 2) patients. This is partly due to changes in coding regulations. In 2005, 165 deaths were recorded among the 9303 diabetes patients registered with the WRDS. The NZHIS records for the same year have 68 diabetes coded deaths registered for Waikato.[76] Thus mortality records from NZHIS are hugely underestimating deaths among diabetes patients. In spite of their huge gaps, these figures are used in the planning and funding of diabetes services.[76]

1.8 The Case for a Regional Diabetes Information Service (RDIS)

Structured care has been shown to improve patient care and outcomes.[80-82] Controlling the Type 2 diabetes epidemic will require changes to the structure of healthcare delivery. Well-resourced interventions will be required, with effective co-ordination between all levels of government, health care agencies, multidisciplinary health care teams, professional organisations, and patient advocacy groups.[7] The MoH's Quality Improvement Plan[24] puts strong emphasis on the need for adequate systems and processes to be established in many areas to ensure continuous improvement of clinical services for diabetes care. This includes pilot programmes, collaboration and the sharing of information.

The government targets for diabetes[83], to be measured across ethnic groups, include :

1. To increase the proportion of people with diagnosed diabetes who have a free annual diabetes check.
2. To increase the proportion of people on the diabetes register who have satisfactory or better diabetes management.
3. To increase the proportion of people on the diabetes register who have had retinal screening in the preceding two years.

In order to successfully implement these targets, it is vital that DHBs develop diabetes information systems with internal validity and external validity. Registries are a critical and necessary first step towards improving quality of care but must then lead to other quality improvement strategies.[84] This thesis examines whether it is possible to identify most diabetes patients through queries on general practice computer systems including diagnosis code for diabetes, prescription of anti-hyperglycaemic medications and participation in the "Get Checked" programme. Results from the "Get Checked" reviews and retinal screening data could be linked using the NHI number. The NHI number is a unique identification number assigned to patients when they use health and disability services in New Zealand. It is possible to match information from different data sources using the NHI number. Health professionals have been using a form of the NHI number for more than 20 years. All New Zealand-born children receive their own NHI number at birth. About 95% of New Zealand citizens now have their own NHI number. It is estimated that about 8% of individuals have more than one unique identifying NHI number.[85]

The Waikato DHB's 2008 Health Needs Assessment[76] has recommended that a dynamic link be established between the primary care databases and the WRDS database. A diabetes register with a dynamic link to the "Get Checked" database and the WRDS database, with periodic updates from the NZHIS mortality database and

DHB's hospital admissions database, can potentially serve as the Regional Diabetes Information System (RDIS). Once functional, it could eliminate the current drawbacks identified in Section 1.5 and function as an audit and feedback tool featuring decision support for clinicians, automatic reminders for patients, disease surveillance and monitoring of care.

1.8.1 Data Components of RDIS

The use of computers by New Zealand general practices is one of the highest in the world.[44] General practices in New Zealand use the UK Read Code disease coding system to capture diagnostic information[46], although diagnosis codes are not consistently recorded in compliance with national minimum dataset standards.[47] Almost all New Zealand GPs use a PMS software application and nearly two-thirds of practices use the Read Code system for coding for clinical diagnoses.[44] The Practice Management Systems used in general practices also store self-identified ethnicity for all patients and captures complete prescribing data.

The WPH is the largest PHO in the Waikato area with a registered population of 294,510 in 2006. It covers 90% of the 328,510 Waikato DHB population enrolled with a PHO[86 87], with an estimated 10,604 people diagnosed with diabetes.[88] Pinnacle Group Ltd provides "Get Checked" data management for WPH and Te Kohao Health, accounting for 97% of reviews in 2007.[76] The other five "Get Checked" providers in Waikato (Te Rohe Potae, Raukura Hauora, Te Korowai Hauora o Hauraki, Kokiri Trust and ToiOra), who provided 3% of reviews in 2007, manage their data independently.

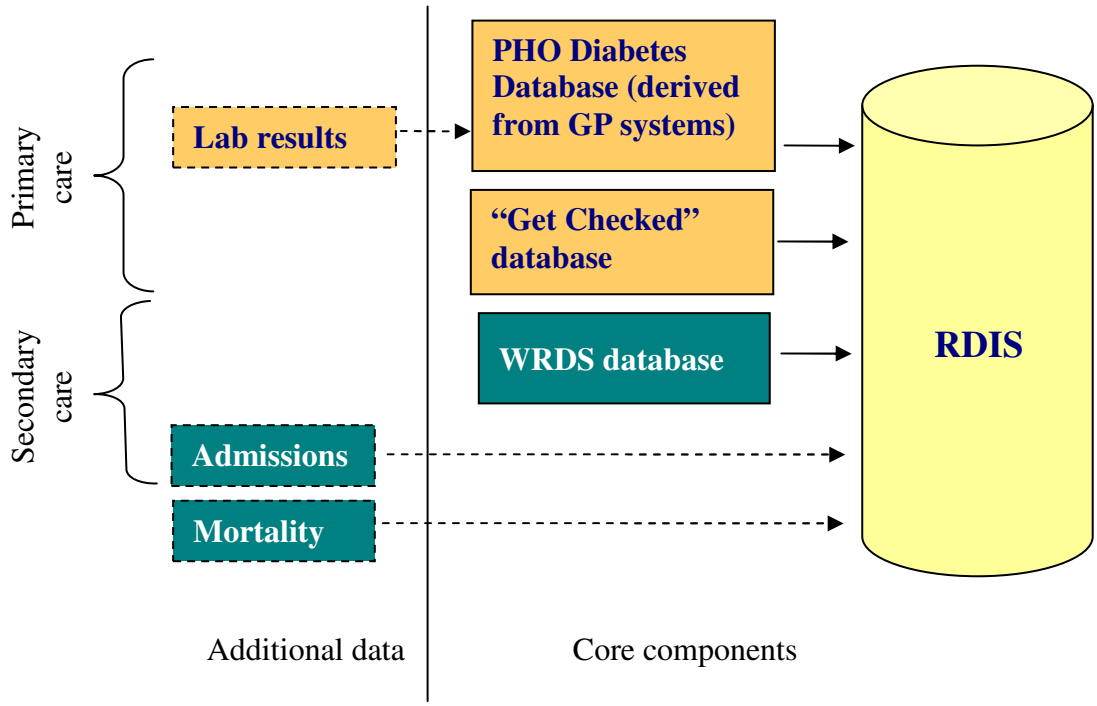
The first step in the development toward RDIS is establishing a dynamic link between the two existing databases, Pinnacle's "Get Checked" database and the WRDS retinal screening database. The RDIS steering group, which is a partnership between the Waikato DHB (Information Service, Planning & Funding and the Diabetes Service),

Pinnacle Group Ltd and Waikato Clinical School, is working towards this goal. A detailed analysis of the financial commitments and resource requirements for the establishment and maintenance of such a link is outside the scope of this thesis. Effective management of RDIS requires a multi-disciplinary taskforce with the relevant expertise and organisational links, committed to improving treatment outcomes for people with Type 2 diabetes.

The next step is to link in the primary care databases, identifying patients with a diagnosis code for diabetes patients or prescriptions for anti diabetes medications. This process can identify diabetes patients using the "Get Checked" programme or secondary services. Although practices report the aggregate number of diabetes patients based on diagnosis codes to PHOs, most practices do not provide this information with patient level details. PHOs may have to tap into automatic querying of diagnosis codes, prescriptions and lab results using the age/sex register of the practice registered population as a base, in order to successfully create a comprehensive primary care diabetes database. Once functional, these three databases will form the cornerstones of RDIS (Figure 1-5). Data from the three core sources (PHO diabetes database, "Get Checked" & Retinal Screening) will have to be linked, carefully implementing algorithms for data mismatches and updates. Coverage and validity of existing databases and data agreement has been tested using three pilot studies in this thesis.

The third step involves adding on additional data (lab results, prescriptions, hospital admissions and mortality). These databases need not have a dynamic link to RDIS, but extracted when needed for evaluation and research.

Figure 1-5. Proposed Data Components for the RDIS



1.8.2 Evolution of the RDIS in the Waikato

The first draft proposal on the development of an integrated approach to diabetes data exchange was developed in 2003 by Prof David Simmons, then of the University of Auckland's Waikato Clinical School, Waikato DHB and Pinnacle Group Ltd (PGL). The plan was to link primary care, Health Waikato diabetes service and Waikato DHB's secondary and tertiary service databases to provide a robust system for monitoring changes in diabetes care and outcomes across the district. The proposed collaboration between PHOs and the Waikato DHB would be capable of displaying core clinical data on diabetes patients in the DHB at the point of use. In a way this was meant to be a shared electronic health record.

A steering group was subsequently formed in January 2005, involving stakeholders from Waikato DHB (Information Service, Planning & Funding), Diabetes Service, Waikato Clinical School and PGL. The proposed data warehouse was planned to reside physically on a purpose built server at PGL and interact with existing computing resources that contain the “Get Checked” data, population demographic data and primary care utilisation data. The “Get Checked” data from primary care and outpatient data from the WDHB Diabetes Service were targeted for the first phase of integration.

The RDIS primary care component was ready by October 2005. This included five sets of data (Get Checked, age/sex register, lab testing utilisation (excluding lab results), general practice utilisation and Read Codes of diagnoses). Three options were available for reporting interface: Excel based interface, custom built interface and universal off-the-shelf programmes. The Waikato DHB information service undertook an analysis of the functional capabilities of the Diabetes Service database. Processes were identified and database structure, data elements and rules were defined by the end of 2005.

The RDIS Proposal and governance structure (Principles for Guardianship and Management) were drafted in 2006. This document has been included in the Appendix 3. The steering group explored the possibility of involving Health IT Cluster to develop and custom build the interface for RDIS. But after several rounds of meetings and much discussion, the steering committee decided to stop negotiating with the Health IT Cluster to build the replacement information system for Diabetes Service database in May 2007. Key issues were system flexibility to accommodate changes and the development timeline. Drafts of Security Policy, Authorised User Agreement were ready by then.

In view of the difficulties with the practical progress of the RDIS project, the steering group decided to refashion the project by the end of 2007. The plan was to build on the

work that has been completed and refocus the RDIS to provide a comprehensive register of diabetes patients in the Waikato DHB catchment area. External consultant Simpl Group Ltd was engaged in June 2008 to facilitate the process.

1.8.3 Implications to Thesis

Although the RDIS was expected to be functional by 2006, the project has faced several setbacks and the regional diabetes register is yet to be built. As a result, linked data could not be used to monitor diabetes care and outcomes. Instead, this thesis forms the groundwork for establishing the regional diabetes register. The studies presented in this thesis use existing databases linked using NHI numbers. The potential uses of creating a diabetes register are demonstrated and developmental issues discussed. The IT system requirements, data sharing principles and governance are outside the scope of this thesis.

1.9 Specific Research Objectives

The objectives of this thesis are:

1. To evaluate the feasibility of a regional diabetes register by quantifying the coverage, validity and agreement between databases using database audits and pilot studies which link existing databases.
2. To demonstrate the potential uses of a register in studying the disparities in prevalence of diabetes, access to diabetes care and the burden of diabetes complications, using robust hypothesis tests.

1.10 Hypotheses to be Tested

Using data generated by combining multiple databases to test the null hypotheses that there are no significant ethnic disparities in:

1. Prevalence of diabetes.
2. Access to diabetes care (coverage of the “Get Checked” programme coverage of retinal screening programme, retention in the “Get Checked” programme and barriers to diabetes care).
3. Diabetes complications (hospital admissions for diabetes complications, progression of renal disease and mortality).

1.11 Structure of this Thesis and Author's Role

Chapter 2 is a comprehensive literature review of the epidemiology of diabetes in New Zealand, including the prevalence of diabetes and its risk factors, metabolic control, diabetes related complications and mortality. The design and methodology of all the studies undertaken, including data conversions and statistical analyses, are detailed in Chapter 3. Results are reported in Chapter 4 and Chapter 5 with their own discussion. The concluding Chapter 6 summarises all the findings and the next steps.

1.11.1 Author's Involvement

The author of this thesis was involved with the following aspects of this study:

- Member of RDIS steering group.
- Writing of research proposal and ethics application for projects involving retrospective review of data.
- Involvement and input into the study design and methodology for all the projects.
- Training and managing community health workers for the Taumarunui project.
- Design of questionnaires for Taumarunui project.
- Data management for Taumarunui Project.
- Feedback to participants: reporting laboratory values and physical measurements to Taumarunui participants.
- Data analyses: validation, coding, creation of analysis datasets, running analyses in SAS for all projects.
- Drafting the peer reviewed publications[23 41 89-94], reports[95-97] and abstracts[12 98-111] for all projects.
- Writing all chapters of this thesis.

CHAPTER 2 LITERATURE REVIEW

2.1 Introduction

This chapter provides the context for the thesis. Two literature reviews have been carried out. The first section describes the evolution of the burden of diabetes, its risk factors and complications in New Zealand, and the current national strategies underway to tackle a condition likely to impact on the national ability to afford other health services. The second section is a review of national and regional information systems for diabetes surveillance. Provisions for diabetes surveillance in different parts of the world have been looked at.

2.2 Epidemiology of Diabetes in New Zealand

2.2.1 Background

In 1998, Dr Hilary King[112] of the WHO predicted that the number of people with known diabetes will rise from 140 million in 1998 to 300 million in 2025, due to rising rates of Type 2 diabetes worldwide. New Zealand has its own share of increasing diabetes burden due to increasing proportions of high risk populations, lifestyle changes, urbanisation and improvements in diabetes detection rates.

Almost a decade has passed since Simmons[113 114] painted the portrait of diabetes epidemiology in New Zealand and warned about the increasing risk of diabetes and its complications, especially for Maori and Pacific peoples. When Moore and Lunt[115] re-examined the situation in 2000, they found the burden of diabetes and its complications escalating, especially end stage renal failure. They also noted the ageing population structure, increasing Pacific population and the obesity epidemic. Since this time, the

population has continued to age (median age has increased 2.5 years over 10 years), has grown by 6%, with a 40% increase in the Asian population (2001-2005).[116] New Zealand Census groups 41 different ethnic groups under the term "Asian", which is strategic on one hand and disguises difference on the other. The major Asian ethnic groups in New Zealand are Chinese (42%), Asian Indians (25%), Koreans (8%), Filipinos (5%) and Japanese (3%).[117] Asians are the fastest growing ethnic group in New Zealand. According to the 2006 population estimates, European New Zealanders make up 77% of the population, Maori 15%, Pacific people 7% with Asians accounting for 9%.[118] By 2021 Asians are expected to make up 15% of New Zealand's total population. These figures point to an increasing Type 2 diabetes burden for New Zealand.

Diabetes Mellitus: a Model for Health Maintenance[119], a service planning tool for diabetes, was published in 1988. The New Zealand Health Strategy[120] recognised the importance of reducing the inequalities to achieve priority health objectives, which included reducing the incidence and impact of diabetes. The New Zealand Ministry of Health has responded to the growing diabetes epidemic with a diabetes strategic plan[121] in 1997 , a Diabetes Implementation Plan[31] in 2000, a "Diabetes Toolkit"[33] for DHBs in 2001 and a Diabetes and Cardiovascular Disease Quality Improvement Plan (QIP)[24] in 2008. The toolkit included the establishment of Local Diabetes Teams at DHB level and the free annual "Get Checked" programme for diabetes patients. A set of guidelines for the management of Type 2 diabetes was released in 2003.[49] A Ministry of Health/Health Research Council grant aiming at diabetes prevention was put out to tender in 2001 and again in 2003, which was subsequently awarded to the Te Wai o Rona: Diabetes Prevention Strategy team in the Waikato/Lakes districts.[122] The Quality Improvement Plan set out specific, practical recommendations and areas for priority actions across different clinical settings. Priority areas for diabetes are kidney disease (from early detection onwards), foot disease (from early detection to high-risk

foot), diabetic retinopathy (from retinal screening onwards), improving hospital inpatient services and Type 1 diabetes (initially in children and young people). The national diabetes epidemiology workshop organised by the MoH explored ways to create a reliable national prevalence data and monitor access to diabetes care, but could not reach consensus.[85] The MoH is currently considering the possibility of using the System Dynamics Model which has been adopted by the Center for Disease Control in the US.[123]

Results to a large number of important studies have been published since the last review, which have confirmed the picture of a disease increasing in numbers, especially at a younger age and consistent with a lowering of the age at onset of Type 2 diabetes. The aim of this review is to describe the current burden of diabetes and the current district based strategies underway, to tackle a condition likely to impact on the ability of New Zealand to afford other health services.

2.2.2 Methods

A comprehensive review was undertaken using MEDLINE database, reviewing diabetes prevalence or complications studies and surveys reporting New Zealand specific figures. Experimental intervention trials have been excluded. The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) Reports from 1990-2004, the MoH publications and reports and New Zealand Society for Study of Diabetes conference abstract books from 2000 have been reviewed. The latest unpublished results from the "Get-Checked" programme, being the only national diabetes surveillance tool, were obtained from the MoH. The diabetes teams in all DHBs were consulted via e-mail regarding current (unpublished) initiatives on diabetes control and prevention (10/21, 48% response). While a comprehensive attempt has been made to

include current unpublished diabetes initiatives, there could be a limitation on the number of such initiatives included in this article due to the limited response.

2.2.3 Prevalence of Diabetes

At present there are no up-to-date national diabetes prevalence data for New Zealand. A series of epidemiological surveys and studies have provided the knowledge base for diabetes prevalence in New Zealand. Studies conducted by Prior and colleagues[124-127], starting from the early 1960s, provided the first glimpses of ethnic variations in diabetes prevalence. The workforce surveys in Christchurch and Auckland provided further evidence of high prevalence of diabetes among the non-European ethnic groups. A household survey of 100,000 residents was undertaken in South Auckland[128] between 1991 and 1995 with a nested study of those with undiagnosed diabetes undertaken thereafter.[129] The New Zealand Health Survey included self-reported diabetes from 1996/97. The latest Health Survey[130] showed little difference by DHB area in the prevalence of diabetes, except in Counties Manukau DHB. Prevalence of diabetes was associated with higher neighbourhood deprivation. Men have higher prevalence in general than women. Table 2-1 and Table 2-2 show the prevalence of diagnosed and undiagnosed diabetes in different population based surveys by ethnic group. Gender specific prevalence estimates were not always available. Prevalence data have been integrated in the tables.

Table 2-1. Prevalence (%) of known & undiagnosed diabetes and IGT/IFG in New Zealand by ethnicity

	Year	Age	European	Maori	Pacific	Asian
Prevalence % of Known Diabetes- all ages						
Christchurch Workforce Survey[131]	1982-83[†]	>15	2.78%	11.27%	-	-
SADP Household Survey [132]	1992-95*	All ages	1.86%	5.21%	4.01%	4.32%
New Zealand Health Survey[72]	1996/97*[‡]	>15	3.10%	8.30%	8.10%	4%
New Zealand Health Survey[73]	2002/03*[§]	>15	2.9%	8%	10.1%	8.4%
New Zealand Health Survey[130]	2006/07*[§]	>15	4.3%	5.8%	10.0%	6.5%
Pacific Study[133]	1996*	>20	-	-	12.0%	-
Diabetes Heart & Health Survey [134]	2002*	35-74	5.7%	15.8%	23.5%	-
Ngatai Porou Hauora Register [135]	2003*	>25	-	7.1%	-	-
Northland Survey[136]	2003		6% (no ethnic specific data reported)			
Prevalence % of Known Diabetes – 40+ age group						
Auckland Workforce [137]	1990[a]	40-64	1.06%	5.26%	5.28%	2.82%
Christchurch Elderly[138]	1991	>65	10%	-	-	-
Auckland Surgical Ward[139]	1990-91	40-59	6.0%	18.3%	16.1%	7.8%
		60-69	7.9%	31.7%	30.2%	16.7%
SADP Household Survey [77]	1992-95	40-49	1.5%	6.8%	4.7%	4.1%
		50-59	3.8%	13.1%	12.1%	8.0%
		60-69	5.6%	15.0%	12.6%	11.4%
Pacific Study[133]	1996	40-49			7.6%	
		50-59			23.1%	
Prevalence of diabetes in other subgroups						
Christchurch, Type 1 (prevalence/100,000) [140]	2005	<25	274	81	77	52
Gestational Diabetes[141]	1994-95		3.3%	7.9%	8.1%	5.5%

SADP: South Auckland Diabetes Project

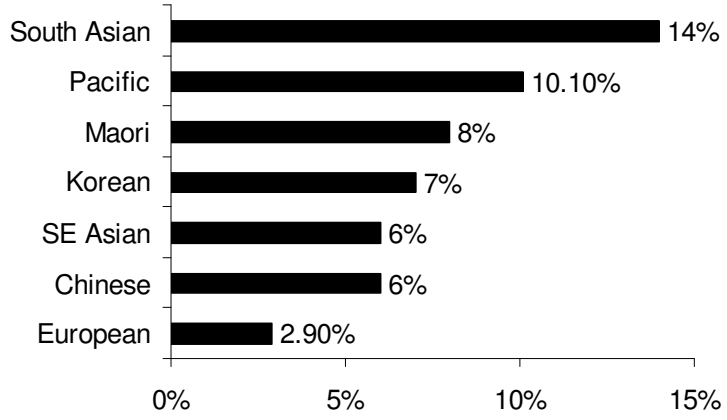
Table 2-2. Prevalence (%) of undiagnosed diabetes and IGT/IFG in New Zealand by ethnicity

	Year	Age	European	Maori	Pacific	Asian
Prevalence % of Undiagnosed Diabetes (percentage of total diabetes)						
Dunedin General Practice[142]	1990	50-69	(20)			
Christchurch Elderly[138]	1991	>65	4.0 (30)			
Waikato Discover Diabetes	1993	40-59	0.8	4.6		
		60-79	2.1	6.1		
Auckland Workforce Survey [137]	1990	40-64	0.8 (42)	4.64 (48)	3.59 (40)	4.72 (57)
SADP [129]	1996	40-59	3.3 (30)	10.6 (48)	13.7 (51)	
		60-79	2.7 (24)	7.9 (33)	9.1 (29)	
Auckland Diabetes Heart & Health Survey[134]	2002*	35-74	1.8 (32)	3.8 (24)	4.0 (17)	
Te Wai o Rona, Waikato [143 144]	2004	45-64		7.0		
Prevalence(%) of IGT/IFG						
Auckland Workforce Survey [137]	1990	40-64	1.93	7.40	5.21	7.82
SADP [129]	1996	40-59	7.4	22.7	19.4	
		60-79	22.1	22.3	16.9	
IGT in Diabetes Heart & Health Survey[134]	2002*	35-74	6.7	7.3	7.9	
Te Wai o Rona, 2004 [143 144]	2004	45-64		15.5		

* Age standardised. † Crude prevalence, Europeans include Asians, Maori include Polynesians. ‡ Asians include others. § Europeans include others.

Consistent reporting of higher prevalence of diabetes among Maori and Pacific groups compared with Europeans is evident from the results above. The New Zealand Health Surveys which rely on self-reported diabetes are likely to be underestimates since diagnosis of diabetes is not verified. Self-report surveys also miss undiagnosed diabetes among those who have diabetes and are yet to be diagnosed. The workforce surveys are likely to be biased due to the "healthy worker" effect. The South Auckland Diabetes Project (SADP) survey[132] which included verification with general practice records for diagnosis of diabetes, and the Diabetes Heart and Health (DHAH) survey[134] which included a glucose tolerance test for all non-diabetic participants provide sound population based estimates for the prevalence of diabetes. These two surveys also included good numbers of both Maori and Pacific people.[134] The DHAH survey did not include Asians but the SADP survey[132] found a high prevalence of diabetes among South Asians. Low diabetes prevalence found in the SADP survey among the Chinese and the Cambodians is similar to the low prevalence of diabetes among Chinese on the Middlemore Hospital surgical wards[139] at this time and in other Chinese populations.[145] The New Zealand Health Survey (NZHS) 2002/03 results showed an increased diabetes prevalence of 8.4% among Asians living in New Zealand when compared with 1996/97, although South Asians were also included in the Asian category. Scragg and Maitra's analysis of Asian people in the NZHS 2002/03 showed that prevalence of diabetes among Asians is becoming closer to that among Maori and Pacific people, the highest diabetes prevalence among South Asians (Figure 2-1).[146]

Figure 2-1. Age standardised prevalence of known diabetes from the NZHS 2002-2003
Source: Asian Health in Aotearoa: An analysis of the 2002/03 New Zealand Health Survey[146]



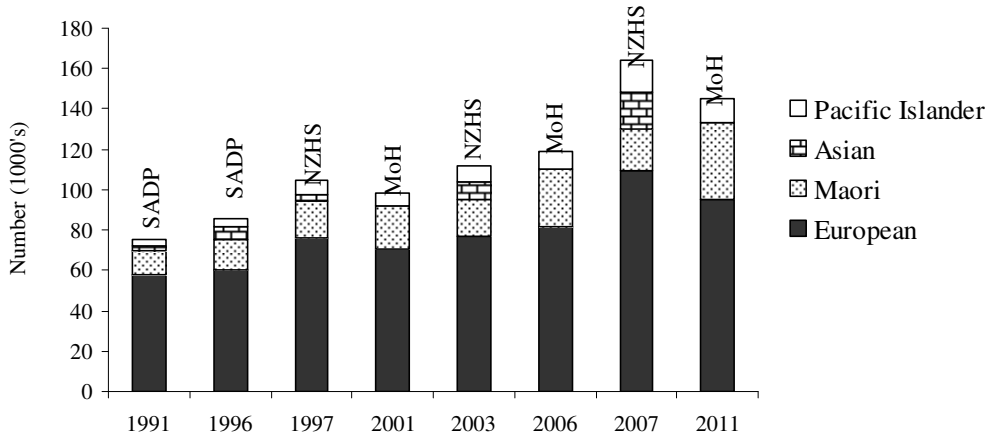
Following the workforce survey in the early nineties, it was believed that as much as 50% of diabetes remained undiagnosed. The SADP survey showed that detection rates improved for Europeans by 1996, when one-third of diabetes remained undiagnosed. Compared with Europeans aged ≥ 40 years, the prevalence of undiagnosed diabetes was more than threefold among Maori and more than fourfold among Pacific peoples.[147] Latest figures from the DHAH survey[134] indicate that one-third of Europeans, one-fourth of Maori and one-fifth of Pacific people with diabetes remain undiagnosed. Results from Te Wai O Rona Diabetes Prevention Strategy[148] in the Waikato are consistent with the South Auckland data but the age-specific prevalence of undiagnosed diabetes was greater than predicted in the younger age groups.[149] Low prevalence of diabetic retinopathy among newly diagnosed Maori diabetes patients indicate that community based case detection for diabetes may be improving.[148] Detection rates among Asians are unclear. HbA_{1c} screening of 50,819 subjects aged 20+ years found that Maori, Pacific people and Indians had particularly high rates of elevated HbA_{1c}, indicating possible high levels of undiagnosed diabetes among Indians. The age-standardised proportion of individuals with HbA_{1c} >6% in these ethnic groups were increased sixfold. Risk factor screening is still recommended in New Zealand[150], although many of those with undiagnosed diabetes (25.0%) and dysglycaemia (31.4%)

have no diabetes risk factors.[151] Past studies have indicated the earlier onset of Type 2 diabetes in Maori (8-10 years earlier) and Pacific people (5-9 years earlier) than Europeans.[152 153] The NZHS 1996/97 figures are in agreement with the results from the SADP survey regarding age at diagnosis among Europeans (50-55.5 years), Maori (41-43 years) and Pacific (45-47 years), but the NZHS 2002/03 results for Maori and Pacific are contradictory (50 and 51 years respectively).

About 10-15% of diagnosed diabetes is Type 1 diabetes among European New Zealanders and approximately 5% among other ethnic groups. The incidence of Type 1 diabetes diagnosed before 20 years in Canterbury has increased 3.4 fold in 30 years, from 6.79 to 22.79 patients/100,000 per year starting from 1970.[154] This increase is considered consistent with a worldwide increase in Type 1 diabetes. In the most recent national study, Campbell-Stokes et al[155] estimated the average annual incidence in 1999/2000 to be 17.9 per 100,000 (95% CI: 15.9-20.0) among children under 15 years. Unlike earlier studies this study found that Maori, Pacific people and Asians all had significantly lower incidence rates (both absolute and relative to their respective population proportions) than Europeans, although the basis of the ethnicity definition is not stated. Although the prevalence of Type 1 diabetes was found to be lower in non-Europeans in a recent Christchurch study, they also noted the increasing number of Maori, Pacific and Asian people with diabetes.[140]

Figure 2-2. The changing epidemiology of diabetes in New Zealand: 1991-2011

Sources - 1991& 1996: SADP survey estimates [77]; 1997: NZHS 1996/97[72], 2003: NZHS 2002/03 counting Europeans with Others [73]; 2007: NZHS 2006/07 counting Europeans with Others[130]; 2001, 2006 & 2011: MoH estimate [71].



Notes:
Ethnic grouping in NZHS 2002/03 NZHS 2006/07 were Maori, Pacific, Asian and Other.
The number of "Others" in these two surveys, which are predominantly European, are presented under the European category in this graph.
NZHS 1996/97 ethnic groupings were European, Maori, and Other. The "Other" category, which included Asians, is presented under the Asian category in this graph.

Figure 2-2 shows the projected numbers with known diabetes by ethnic group across all surveys to date. Although the cross comparisons are limited by the changing definitions of ethnicity and diabetes. Figure 2 also shows the different MoH diabetes forecasts for New Zealand, which may be underestimates (e.g. the 2003 predictions were already less than the prevalence of diabetes among Europeans, Pacific peoples and Maori males in the NZHS 2002/03 survey). Due to the small population proportion, and low diabetes prevalence according to the then existing literature, the MoH's diabetes model[71] did not include Asians as a separate category. But the Asian population in New Zealand has grown at a rapid pace and has outnumbered Pacific people. The Ministry's diabetes surveillance paper released in 2007 modelled Asians as a separate ethnic category, reflecting the growing diabetes burden among Asians.[28]

The age at onset of Type 2 diabetes has also been dropping with increasing numbers of children and adolescents with Type 2 diabetes and women with Type 2 diabetes in

pregnancy. The Auckland Diabetes Centre has reported increasing prevalence of Type 2 diabetes in adolescents.[156] The prevalence of Type 2 diabetes among the clinic attendees was 1.8% in 1996, and 11.0% in 2002. Northland Diabetes Service has reported that Type 2 diabetes presents before the age of 30 years in 2.66% of Maori diagnosed with diabetes.[157] Among South Auckland women with GDM, a high proportion (4.3% European, 21% Maori, 21% Pacific) of Polynesians had permanent diabetes post-natally.[158]

Gestational Diabetes

A review of 1994/95 hospital records in South Auckland showed high rates of GDM in Maori and Pacific women who attended the oral glucose tolerance test compared with Europeans.[141] This study found that Pacific women were more likely to be screened (68.5%) when compared with Maori (47.3%) when both have high rates of GDM and Type 2 diabetes. During follow up of Northland NZ women (66% Maori) with GDM, nearly one-third developed diabetes or IGT at little more than two years after delivery.[159] Over one-third probably had undiagnosed glucose intolerance before pregnancy.

Risk Factors for Diabetes

Age, obesity, sedentary lifestyle and smoking are the main risk factors in the progression from the pre-diabetes state to Type 2 diabetes.[160-162] The prevalence of obesity has increased from 9.4% in 1977 to 19.9% in 2003 among males and from 10.8% to 22.1% among females.[163] Maori and Pacific people have a particularly high prevalence of obesity[129], physical inactivity[73], insulin resistance[73] and metabolic syndrome[147] compared with Europeans (Table 2-3). BMI accounted for most of the ethnic differences in metabolic syndrome.[164] The association between body composition and central fat distribution with risk of diabetes appears to be independent

of ethnicity.[165] While Asians appear to have comparatively lower obesity[166], Rush et al[167] have found high body fat composition for Asian Indians compared with Europeans for a given BMI. It is evident from national health surveys that a high proportion of Asians lead a sedentary lifestyle. The low levels of physical activity are found even among children.[168]

Table 2-3. Prevalence of Risk Factors for Diabetes and its Complications

		European	Maori	Pacific	Asian
Metabolic Syndrome (%) by ATP III criteria**	SADP 1996 [147], 40-59yr Males	24.6	52.8	48.5	
	Females	13.4	51.8	45.5	
	Auckland 2002/2003[164†], 35-74	16	32	39	
Insulin resistance (%)	East Coast 2003 [135], 25-29yr		43		
	30-39yr		44		
Sedentary (%)	NZHS 1996/97*§	14.7	19.8	14.1	20.5
	NZHS 2002/03 [166*†]	11.2	12.6	17.8	22.3
	NZHS 2006/07[130*†]	13.8	14.0	19.4	23.0
	SPARC Survey[168] 1997-01§, 5-17	8.0	10.0	19.0	12.0
	≥ 18	9.0	12.0	10.0	17.0
Obesity (%)	NZHS 2002/03[166 *†](BMI‡)	18.9	28.3	43.0	5.7
	NZHS 2006/07[130*†] (BMI ≥ 30)	24.3	41.7	63.7	11.0
	NZHS 2006/07*†, 2-14 years	5.5	11.8	23.3	5.9
	Church study [133]. (BMI>32) * ,			45	
	Male				
	Female			60	
	SADP 1996 [129] (BMI≥31), 40-79yr	26	63	69	
Smoking (%)	NZHS 2002/03 [166*†]	21	47	33	11

*Age Standardised. † European includes Other.
**The ATP III criteria for metabolic syndrome were considered to have been met when 3 or more of the following factors were present: waist circumference >102cm for men or >88cm for women, treated hypertension or sBP ≥130mmHg and/or dBP ≥85mmHg as mean of two readings, triglycerides ≥1.7mmol/l, HDL <1.04mmol/l for men or <1.29mmol/l for women, FBG ≥6.1mmol/l, or diabetes.
‡ Obesity is BMI ≥ 30 for European/Other/Asian, BMI ≥ 32 for Maori/Pacific. § Asian include Other.

2.2.4 Complications

Table 2-4 shows the risk factors for microvascular and macrovascular disease in the New Zealand studies to date. The poor glycaemic and lipid control among patients attending the Waikato Diabetes Clinic from 1992-95[169] appears to have continued into this century. The Otago register has reported a mean HbA_{1c} of 7.2% for Type 2

patients, 50.1% had HbA_{1c} result >7% in 1998.[170] The results of the "Get Checked" programme showed that 63% Europeans, 27% Maori and 92% Pacific people with diabetes had a free annual check in 2004. But the denominators are derived from the MoH forecast estimates and actual percentage of Pacific people getting free checks may be much lower. Results from the South Auckland audit[171] indicate that 44.9% of Indians have HbA_{1c} >8% whereas 30.2% Other Asians, 22.7% Europeans and 49.5% Maori fall in this category. Although Maori and Pacific people audited had undergone similar levels of examinations and investigations as Europeans, they were more likely to have a range of adverse risk factors for diabetes complications than Europeans. Maori and Pacific people with Type 2 diabetes who attended the diabetes annual review in 2004 received similar high rates of appropriate CVD and renal preventive drug therapy to Europeans, but their prevalence of smoking, obesity, raised HbA_{1c} and albuminuria were substantially higher.[39] This could be just the tip of the iceberg, given the low diabetes annual review attendance rates for Maori.[172] There are limited data on clinical characteristics of diabetes patients (Table 2-4). “Get Checked” results from 242 Southlink general practices indicate that Maori and Pacific Islanders had poorer glycaemic control (HbA_{1c} > 8.0 for 41.5% of Maori or Pacific Islanders versus 23.8% of New Zealand Europeans; 95% confidence interval for the difference [CI]: 14.0, 21.1), and were less likely to have retinopathy screening (71.9% versus 77.9%; CI: -9.2, -2.6).[40] Maori and Pacific participation in the annual review programme made only small improvements in glycaemic control over two years, but significant improvements were made in all the ethnic groups in blood pressure and lipid management.[173]

Table 2-4. Clinical characteristics of diabetes patients

	Waikato Diabetes Clinic[169] 1992-95			South Auckland Survey 1996 [174 175 176]		
Metabolic Control	Type 1	Type 2	Type 2 - I*	European	Maori	Pacific
HbA_{1c} (%)[176]				7.4 ± 1.7	9.6 ± 2.6	9.2 ± 2.6
Random BG (mmol/L)				10.3 ± 5.0	11.8 ± 4.8	11.6 ± 5.8
Fructosamine (mmol/L)	376 ± 78	321 ± 73	360 ± 67			
Lipids						
Cholesterol (mmol/L)	5.2 ± 1.1	5.8 ± 1.2	5.8 ± 1.1	6.0 ± 1.3	6.2 ± 1.5	5.8 ± 1.3
HDL (mmol/L)	1.5 ± 0.5	1.1 ± 0.3	1.2 ± 0.5	1.1 ± 0.3	1.0 ± 0.3	1.0 ± 0.2
Triglycerides (mmol/L)	1.7 ± 1.4	3.1 ± 3.6	2.9 ± 3.8			
Renal Characteristics						
Albumin creatinine ratio† (mg/day)				2.18	9.06	4.38
Blood Pressure						
sBP (mmHG)				141 + 25	145 + 31	135 + 24
dBP (mmHG)				81 ± 12	84 ± 13	80 ± 13
% on anti-hypertensive medication[174]				44%	33%	33%
(complication free cohort)						
Physical Characteristics						
BMI (kg/m2)	25.6 ± 4.6	30.6 ± 5.8	29.8 ± 5.5	30.5 ± 6.6	33.3 ± 6.8	33.4 ± 5.8

Data are mean ± SD unless otherwise stated.
* Transferred from diet/pill to insulin.
† Data are geometric mean

Diabetes related mortality

Table 2-5. Diabetes Related Mortality & Complications

	European	Maori	Pacific	Asian
Mortality				
Five year mortality rates among Type 2 Diabetes patients aged 40-79 in 1991† [77]	16.3%	26.2%	16.8%	
For Ischaemic Heart Disease	5.7%	6.3%	4.6%	
For End Stage Renal Failure	0.8%	8.9%	2.9%	
Renal Complications				
Proteinuria in 1990 [175]	5.4%	30.2%	13.0%	
Microalbuminuria in 1990 [175]	22.1%	26.7%	33.3%	
End stage renal failure in 1990 [175]	0.3%	4.7%	3.3%	
Crude Incidence (per 100,000) of diabetes related renal disease in New Zealand in 2001*	1.5	18.2	19.8	3.8
Cardiovascular Complications				
Self-reported Known 'Heart Attack' in 1992-93‡ [174]	11%	11%	11%	
Previous cardiovascular disease among Type 2 [177]	25%	23%	15%	14%,9% §
First cardiovascular event during 5 year follow-up of Type 2 patients [177]	12%	12%	10%	7%, 6% §

(continued overleaf)

Table 2-5. (continued)

	European	Maori	Pacific	Asian
Eye Complications				
Blindness in 1992-93 [174]	2.0%	6.6%	7.7%	
Laser treatment in 1992-93 [174]	7.2%	19.2%	12.3%	
Cataract in 1992-93 [174]	6.2%	14.4%	16.0%	
Vision threatening retinopathy in 2002 [178]	2.5%	4.3%	4.9%	4.6%
Foot Complications				
Self-reported Leg/foot symptoms in 1992-93 [174]	37%	42%	29%	
Amputation in 1990 [179]	2.2%	2.8%	1.0%	
Foot ulcer in 1990 [179]	1.7%	2.7%	8.4%	
Prevalence of diabetes among cardiovascular and renal disease patients				
Among MI patients aged 40+ in 1992-93 [180]	14.7%	36%	37.9%	
Among patients with Congestive Cardiac Failure[68]	17%	34%	36%	
Among new renal disease patients in 2003 [181]	23%	65%	67%	50%

*Estimated from ANZDATA Registry 2001 and Census 2001. † Age and sex standardised.
‡ Age adjusted to total diabetes population. § Indo Asian and East Asian respectively.

The NZHIS mortality data attributed 3% of deaths in 2000 to diabetes.[182] In spite of 45%-55% under-coding of diabetes on death certificates[78 79 183], especially among non-insulin using (Type 2) patients, the standardised mortality rate for diabetes mellitus during 1999 were 62.5 per 100,000 in Maori versus 11 in non-Maori, especially from diabetes related conditions.[184] A 10-year follow-up of the predominantly European Type 2 diabetic cohort in Canterbury showed increased mortality [standardised mortality ratio (SMR) of 217], the cause of death being predominantly attributable to cardiovascular disease (CVD 69.8%).[185] The Canterbury insulin-treated diabetic registry has reported CVD related SMR of 448 for diagnosis age<30years, 2.05 for diagnosis age>=30 years among those who commenced insulin within 12 months of diagnosis.[186] The meta-analysis of studies from Asia Pacific region (including 10,326 subjects from New Zealand) revealed that the hazard ratio associated with diabetes was significantly higher for fatal cardiovascular disease (1.97), fatal coronary heart disease (2.19) and fatal cerebrovascular disease (2.0).[187] Table 2-5 shows the ethnic specific death rates from end stage renal disease (ESRD) and ischemic heart disease in the SADP cohort age 40-79.[183] The standardised mortality ratio for renal failure is 8.37%, estimated from the Canterbury insulin-treated Diabetic Registry.[186] This reflects the renal failure rate in insulin treated diabetes patients in a registry that has predominantly European patients (97.7%).

Cardiovascular and Cerebrovascular Diseases

Very few reports relating to heart disease exist (Table 2-5). A review of records from Middlemore Hospital has reported significant ethnic differences in the prevalence of diabetes among inpatients aged 40+ with acute myocardial infarction.[180] Five year follow up of Type 2 diabetes patients in New Zealand showed that Maori were at 30% higher risk of first cardiovascular event and East-Asian 27% lower risk compared with

European/Other, with no significant difference in risk for Pacific and Indo-Asian peoples.[177]

Diabetic Nephropathy

Among the 449 new renal disease patients entering the ANZDATA registry in 2003[181], 45% had diabetes (23% of European patients, 65% Maori, 67% Pacific, 50% Asian). Diabetic nephropathy (40%) was the most common cause of end stage renal disease in New Zealand, followed by glomerulonephritis (26%) and hypertension (10%). Type 2 diabetes (non-insulin and insulin requiring) was identified in 94% of diabetic nephropathic patients on the registry. From the prospective data from ANZDATA reports, the numbers of diabetes related ESRD in Maori population are the highest, but appear to have reached equilibrium (Figure 2-3, Figure 2-4). The incidence of diabetes related ESRD in Europeans while lower than other ethnic groups, has also doubled since 1992. The crude prevalence of proteinuria and ESRD were higher in Maori and Pacific people compared with Europeans in the SADS survey[175] in 1990 (Table 2-5). A familial predisposition to renal disease was suggested from one study showing that the predisposition to diabetic nephropathy in Polynesians was associated with a family history of renal disease (rather than a family history of diabetes) yet associated with diabetes through relative hypoinsulinaemia and hyperglycaemia.[188] Diabetic nephropathy among children and young adults with Type 1 diabetes was reportedly 19% in Waikato.[189] The predominantly European Southlink Health diabetes register has reported renal hospital admissions rates of 1.2% and 0.4% for 2000-2002 among Type 1 and Type 2 diabetes patients respectively.[190]

Figure 2-3. Number of dialysis patients with diabetic primary renal disease by ethnicity
Source: ANZDATA Reports 1998 to 2008[181 191-200]

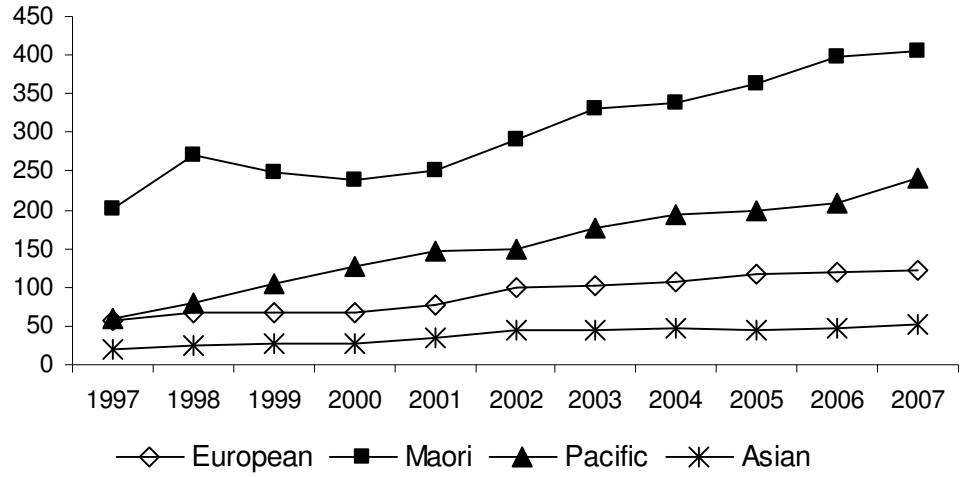
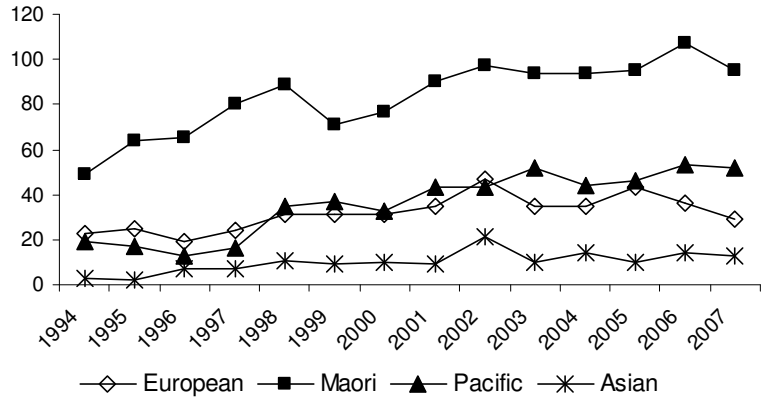


Figure 2-4. Number of new renal disease patients with diabetic primary renal disease
Source: ANZDATA Reports 2008[200]



Other diabetes related complications

Few studies of diabetic eye and foot disease have been undertaken. A summary is shown in Table 2-5. The SADP study in 1992/93 found significant ethnic differences in the rates of blindness, laser treatment and cataract among people with diabetes: Maori and Pacific people having double the proportions as those of European descent.[174] Retinopathy was present in 41% of a Type 2 diabetes cohort in Canterbury at baseline.[185] A decline in the rates of vision threatening diabetic retinopathy from 11.5%

in 1993 to 1.5% in 2002 has been reported in diabetes patients in Waikato area, but Maori had a high failure-to-attend-screening rate (32.3%) compared with the overall rate of 18.7%.[178] "Get Checked" results for 2004 indicated low eye screening rates of less than 70% overall with less than 60% for Maori and Pacific groups (Sandy Dawson, personal communication). The rate in those aged under 26 was 13%.[189]

The prevalence of hospital discharges for diabetic foot disease (per 100,000) in New Zealand increased from 13.56 in 1980 to 25.79 in 1993.[201] The total inpatient cost for the management of diabetic foot disease in New Zealand (population 3.3 million) for 1993 was estimated to be in the range of NZ$10-11 million (US$7-7.7 million). The SADP study found significantly higher numbers of Pacific peoples with major lesions (amputation or ulcer/blister) compared with European or Maori diabetes patients (Table 2-5).[179] The MoH estimated that Pacific people have more than double rate of lower limb amputation (43.6 per 100,000) in adults aged 25+ compared with the total New Zealand average (17.4)[202] in 2004. The Auckland Leg Ulcer Study in subjects aged 40+ years showed that 18% of cases had diabetes as a co-morbidity whereas only 5.5% of controls had diabetes.[203]

2.2.5 Access to Diabetes Care

Maori with diabetes face a range of structural and socio-economic barriers to diabetes care.[204] The most important barriers to diabetes care identified in a South Auckland survey were perceiving that the benefits of self-care were outweighed by the disadvantages (20% Europeans, 20% Maori, 29% Pacific Islanders, 16% others, $p<0.001$), lack of community-based services (13% Europeans, 27% Maori, 25% Pacific Islanders, 11% others, $p<0.001$) and the limited range of services available.[205] The most important barriers to diabetes care perceived by diabetes patients in Waikato were psychological and particularly related to the strictness of the regimen.[206]

Discordance between patients and different health professionals exists in the perception of the importance of different barriers to diabetes care.

In South Auckland, Maori and Pacific people with diabetes who attended a regular general practice had a higher average number of consultations than Europeans (5.7, 5.4, and 4.8 visits per year respectively).[171] They were as likely as Europeans to have undergone important regular examinations and investigations. Maori and Pacific people with Type 2 diabetes who attended the free "Get Checked" diabetes annual review in 2004 received similar high rates of appropriate CVD and renal preventive drug therapy to Europeans, but the prevalence risk factors in these groups (smoking, obesity, raised HbA_{1c} and albuminuria) were substantially higher.[39] There are also concerns over Maori adherence with prescribed medications.[207]

A Christchurch study has observed comparable levels of utilisation of a specialist diabetes complication screening clinic among Maori and Europeans.[208] Since the early nineties, virtually every community has had access to a health clinic and ESRD treatment services have been provided in all states and territories of New Zealand.[209] But indigenous people in general are less likely to receive a renal transplant prior to dialysis treatment, less likely to be on a transplant waiting list, and less likely to receive a well-matched transplant.[210]

2.2.6 Discussion

Prevalence varies widely between ethnic groups. Despite the ethnic diversity, a number of common themes can be found with regard to patterns of diabetes and prevalence rates among the non-European ethnic groups. Type 1 diabetes is relatively less common in these populations compared with Europeans and Type 2 diabetes is increasingly becoming common. The rise in prevalence rates reflect the genetic pre-

disposition added with lifestyle changes, urbanisation and in studies of known diabetes, improvements in diabetes detection rates.

While the diabetes epidemic continues to impact increasingly on New Zealanders and its health services, over the last five years, a growing number of Government and District Health Board funded initiatives are in place to prevent diabetes and its complications (e.g. Lets Beat Diabetes and Diabetes Projects Trust in Counties-Manukau, Ngati Porou Hauora Ngatai & Healthy Programme in Taiwawhiti, Te Wai o Rona: Diabetes Prevention Strategy in Waikato/Lakes). A number of district diabetes registers are in place or developing (e.g. in Otago, Canterbury, Waikato and South/West Auckland), and these are complemented by the "Get Checked" data. ANZDATA renal and the emerging Australasian Diabetes in Pregnancy Society diabetes in pregnancy registers, along with a number of eye screening registers also contribute to our understanding of diabetes in New Zealand. The "Get Checked" has been upgraded and the PHOs and practices now have the option to use the "Get Checked" database for diabetes reviews more often than annually, and for quality improvement initiatives for CVD risk assessment (in people without diabetes).[51] Work is now needed on how best to monitor the incidence and prevalence of diabetes, and the proportion with undiagnosed diabetes, impaired glucose tolerance and impaired fasting glucose. How else will we know that the growing resources directed towards lifestyle change are having an effect?

The data gathered to date relating to metabolic control and complications are patchy, yet suggest that New Zealand needs to do more to reduce the impact of diabetes on cardiovascular, renal, eye, foot and pregnancy related complications. This is particularly the case for Maori, Pacific people and Asians, whose metabolic control remains poorer than that for European New Zealanders.

The proportion of Asians in New Zealand is increasing rapidly, a large proportion being Chinese and Asian Indians. As with Asians living elsewhere in the world, there is an increasing prevalence of diabetes and its complications among Asians in New Zealand. Increasingly the risk of diabetes and its complications appear to be comparable with Maori and Pacific people. We need to align our planning and funding to these to address the increasing burden.

More aggressive blood pressure, glycaemic and lipid control would appear to be needed, and the development of ways to deliver this, within the context of New Zealand (i.e. its people and its health service), are urgently required. Such increases in medication use and services (in both primary and secondary care) are likely to cost more initially and yet little data exists to guide such development. PricewaterhouseCoopers estimated that Type 2 diabetes cost in 2001 approached NZ$400 million and predicted a rise to more than NZ$1,000 million by 2021.[211] They also estimated that the total cost of diabetes could be reduced over 20 years if existing services are increased as soon as possible (by $10 million each year in their enhanced services model). The models used are not perfect, yet more complete than the earlier Health Funding Agency report.[31] It is surprising that more detailed economic data are not available.

While there have been a relatively large number of publications relating to diabetes in New Zealand over the last five years, a significant proportion were from South Auckland in the 1990s and these data are now ageing. More importantly, while services are developing in primary and secondary care, evaluation has rarely been sufficiently robust to lead to publication in peer-reviewed journals. Indeed, funding for such "diabetes translational research" has been uncommon and fits poorly into the existing research funding paradigm. If we are to develop more complex models of care, and increase access to modern pharmaceuticals and devices, then it is also clear that we

need more research into the impact of such service developments on the incidence, prevalence and costs of diabetes and its complications. While this will not come cheaply, it will be cheaper than the alternative.

2.3 Diabetes Information Systems

> "Every is system perfectly designed to achieve exactly the results it gets. If you don't like the results, change the system".
>
> D Berwick, CEO of Institute for Health Care Improvements.

2.3.1 Background

The total number of people with diabetes worldwide is projected to rise from 171 million in 2000 to 366 million in 2030.[3] The severity of diabetes complications and the means required to control them make care costly, not only for patients and their family, but also for health services. For most countries, the largest single item of diabetes expenditure is hospitalisation for the treatment of long-term complications, such as heart disease and stroke, kidney failure, and foot problems.[4] Many of these complications are potentially preventable, given prompt diagnosis of diabetes, effective patient and professional education, and comprehensive long-term management. Availability of new technologies and information systems for monitoring and treating diabetes is critical to achieving recommended metabolic control, including HbA_{1c} levels.[212] The first step is to develop a registry, including a patient identifier that can link multiple data sources, which can then serve as a springboard to electronic mechanisms for practitioners to gain information on performance and results.[213 214] With the rapid advances in information technology in the last decade, various diabetes information systems have evolved in different parts of the world. This is a review of national and regional information systems for diabetes surveillance.

2.3.2 Materials and Methods

A comprehensive review was undertaken using Medline literature review with key words "diabetes and register", "diabetes and benchmarking", "diabetes and

"warehouse", "diabetes & information system", "diabetes & database", "diabetes & surveillance", "diabetes & audit", and "diabetes and record linkage". Internet search using the Google search engine and e-mail consultation with opinion leaders (identified thorough international diabetes organisations) have also been performed. Stand-alone diabetes databases (single source) and experimental intervention trials have been excluded.

2.3.3 National/Regional-Level Diabetes Surveillance Systems

The UK national diabetes audit was initiated in 2004, with annual data contribution from primary care trusts/GPs, hospitals, and paediatric units. The National Clinical Audit Support Programme provided sample MIQUEST (Morbidity Information Query and Export Syntax, a software tool to extract and aggregate comparable data from disparate general practice systems) queries and specification documents for data extraction. The 2003/04 data indicated that only 77% of the people predicted to have diabetes are actually recorded as having diabetes in general practices.[215] The recently approved Diabetes Continuing Care Reference Dataset[216] is expected to provide an agreed national standard for exchange extraction and analysis of the components. The National Paediatric Diabetes Register/Audit conducts analyses based on data collected once a year.[217] The General Practice Research Database[218] in the UK provides longitudinal anonymised patient data from general practices across the country and includes data on demographics, medical diagnoses and symptoms, prescriptions and hospital admissions. Data on patients' lifestyles such as smoking habit are also available. Researchers have been using this database extensively to study diabetes risk factors[219], complications[220 221] and mortality.[219 220] The introduction of the Quality Outcomes Framework, a pay for performance scheme introduced in the UK in 2004, was associated with improvements in quality of care in diabetes.[222]

The DIABCARE Q-Net project in Europe developed a complete and integrated information technology system to monitor diabetes care, according to the gold standards of the St. Vincent Declaration Action Program. Established in 1996, this was the first telematic platform for standardised documentation on medical quality and evaluation across Europe, which will serve as a model for other chronic diseases. Quality development starts from the comparison of diabetes services, based on the key data on diabetes care in the basic information sheet. This is a 141-field form, which is to be completed once a year for each patient under the care of the diabetes team. The system performs an analysis of the local data and compares the data with peer teams by means of telecommunication of anonymous data.[223] Denmark is leading the path with electronic health records[224] and information systems linking multiple data sources.[225]

National diabetes estimates in the United States are derived from various surveys of the Center for Disease Control and Prevention (CDC), the National Health Interview Survey, the National Health and Nutrition Examination Surveys, the National Hospital Discharge Survey, and surveys conducted through the Behavioral Risk Factor Surveillance System.[226] Other data sources include CDC's National Vital Statistics Systems, the outpatient database of the Indian Health Service, the US Renal Data System of the National Institutes of Health and published studies.

The National Diabetes Surveillance System[227] in Canada is a network of regionally distributed diabetes surveillance systems that compile administrative health care data relating to diabetes. Person-specific databases of health information remain within each participating province/territory, and an aggregate, anonymous dataset is transmitted by each province and territory to Health Canada. Tracking is possible because data are captured routinely in the provision of publicly funded, insured health services in the various jurisdictions and are stored in three major provincial/territorial

administrative databases: physician claims files, hospital files, and health insurance registries.

Five data collection projects were undertaken across specialist diabetes services in Australia between 1998 and 2004. The first collection was known as the "The National Clinical Diabetes Data Collection Project", while the next three were undertaken as "Australian National Diabetes Information Audit & Benchmarking" (ANDIAB). A modified version of the initial dataset has been incorporated in CARDIAB software, which is used as a general practice subset for monitoring the quality of diabetes care in the general practice setting, with two data audit collections undertaken in 1999-2000 and 2002-2003. ANDIAB is an important, now biennial, quality activity conducted by the National Association of Diabetes Centres, in specialist diabetes services across Australia, in all states and the Australian Commonwealth Territory. Participating specialist diabetes services (including diabetes centres and specialist endocrinologists in private practice) receive an individualised report comparing their diabetes practice processes, and patient outcome data, with their peers. The dataset is the Australian Diabetes Society National Diabetes Outcomes Quality Review Initiative minimum dataset for quality care in diabetes.[228] The dataset contains demographic, clinical, biochemical, and outcome data items that have standardised definitions, and has been promulgated for collection in all clinical practice settings. It is the first clinical dataset to be included in the National Health Data Dictionary. The participants in the ANDIAB 2002 survey completed a one-page scannable form (or provided data electronically by diskette or e-mail) containing these data items.

In New Zealand, the National Health Surveys[72 73 166] form the basis of national-level diabetes data collection. The Diabetes Care Support Service, an audit and feedback service[229] supported by the South Auckland Diabetes Project (now the Diabetes Projects Trust) in South and West Auckland, was one of the first such systems to be

set up in New Zealand in 1991. It uses manually and electronically extracted clinical data from paper and electronic general practice records and was validated against data from a concurrent household survey.[230] A national minimum diabetes dataset was agreed upon in 2000.[231] “Aotearoa Get Checked", the National Diabetes Screening Programme was initiated in 2001, and this database[232] stores data from free annual check-ups for diabetes patients. GPs send data on a standard form through their PHO. However, it is estimated that fewer than six out of 10 diabetes patients signed up in 2004.[233] In 2002, a data warehouse for diabetes (Integrated Care Server)[234] was set up in South Auckland alongside the Diabetes Care Support Service using electronic data. The server features e-mailed “alerts” providing doctors with guidelines on care of individual patients. At the outset of the Diabetes Integrated Care project in Counties Manukau in 2002, the percentage of patients with an elevated HbA_{1c} was reported to have been reduced by 25%. There has been an 80% reduction in wait time for statins for diabetes patients.[235] Many other countries have diabetes databases/registers, mostly with patients registered using a basic information sheet concept (Table 2-6).

The developing countries carry 90% of this world’s total diabetes burden, with India and China in the lead.[3] The Diabcare-Asia studies in 1998[236] and 2001[237] showed that more than 50% of diabetes patients have poor metabolic control. In many Asian countries this was the first attempt at stocktaking and quantifying metabolic control and clinical characteristics. Diabetes education programmes, interventions, and service developments are underway in Asian countries, but database system aided surveillance and audits are yet to be implemented. There is a growing recognition of the need for integrated care and database systems. The Framework for Information Technology Infrastructure for Health in India has addressed all information needs of different stakeholders (government, hospitals, insurance companies, patients, vendors, and others) in the healthcare industry and has recommended a Minimum Dataset for Diabetes.[238]

Table 2-6. National/Regional Diabetes Registers

Country	Register
United Kingdom	Royal College of Physicians of Edinburgh Diabetes Register,[239] Northern Wales Diabetes Register,[240] Yorkshire Regional Diabetes Register,[241] and Leicestershire Diabetes Register.[242] But the DARTS/MEMO Collaboration data linkage in Tayside, Scotland with its audits and research has created the most sophisticated system for diabetes management.[243 244]
United States	The University of Washington Physicians Network (UWPN) in Seattle diabetes registry linking nine clinics,[245] Minneapolis diabetes database,[246] Vermont Diabetes Information System in New York City[247 248]
Australia/ New Zealand	New South Wales Children's Diabetes Register,[249] the Diabetic Register of Perth and Osborne Divisions of General Practice,[250] Western Australian Diabetes Register,[251] Tasmanian Insulin-Treated Diabetes Register,[252] and Central Diabetes Register in Victoria.[253] Otago Diabetes Register[170 254], the Canterbury Insulin Treated Diabetes Register[186] in New Zealand. Diabetes Care Support Service[229], Southlink Diabetes Register in Dunedin[190]
Europe	The Black Sea Tele-Diab[255] and Sincrodiab[256] in the Black Sea area, Swedish Childhood Diabetes Register[257] and the National Diabetes Register in Sweden,[258] CroDiab NET in Croatia,[259] Audit Enhanced Monitoring System in The Netherlands,[260] the National Diabetes Register[261] and diabetes documentation software (DPV) in Germany,[262] Czech Childhood Diabetes Register,[263] National Type 1 Diabetes Register in Lithuania,[264] national Type 1 diabetes registers in Slovenian and Tuzla,[265] Viljandi Diabetes Register in Estonia,[266] National Diabetes Register in Finland,[267] Hungarian childhood diabetes register[268]
Asia	National Juvenile Diabetes Register in Israel,[269] Type 1 Diabetes Registry in Hong Kong[270]

The Health Ministry in China has recently launched a National Diabetes Management Project that aims to provide diabetes education and training to healthcare providers and establish state-of-art models of diabetes care in hospitals and community health centres throughout the country.[271]

2.3.4 Diabetes Information Systems

Networks of managed care organisations have been implementing various electronic management systems. A recently reported national survey in the United States[272] indicated that 40% of all physician organisations have diabetes registers. Among them, 64% were able to provide physician feedback on HbA_{1c} monitoring, compared with only 23% of those without a diabetes register. The National Diabetes Quality Improvement Alliance[273] formed in 2002 is a collaboration between private and public national organisations. It is dedicated to developing and maintaining a truly national performance measurement set for diabetes. A Diabetes UK-funded survey of primary care organisations and practices in 2001 indicated that 69% had a local diabetes register and 75% had carried out at least one diabetes audit in the previous five years.[274] However, an internet-based audit and feedback system requiring active physician interaction with technology was not successful in Boston.[275] This suggests that busy, practicing physicians cannot be expected to perform tasks which are not part of their daily routine and go out of their way to access technology for quality improvement efforts.

2.3.5 Critical Factors for Success of Diabetes Information Systems

Robust information systems with auditing and benchmarking tools supported by multifaceted interventions are vital for cost-effective diabetes surveillance.[276] A dynamic link between general practice systems and hospital systems eliminates long waiting

time for information update and provide decision support at point of care. Pharmacy data, lab measurements, retinal screening, and home blood glucose monitoring data are increasingly being linked into diabetes information systems. Access to this data can empower diabetes care teams with the ability to see the bigger picture.

In general, the success of the information systems depends upon effective integration of multiple sources of information, especially clinical record extracts and laboratory results while providing decision support for GPs and other clinicians and self-management support for patients (via reminders and summary profiles) supported by established clinical governance and dedicated maintenance (Table 2-7). Automated data extraction and minimum extra resource requirements are also critical. Associated diabetes translational researches add value by identifying diabetes management issues on an ongoing basis in order to constantly improve diabetes care.

2.3.6 Next Steps

Diabetes information systems are likely to continue to develop technically, and will become seen as critical and mandatory components for the delivery of safe and effective health care (Figure 2-5). Developing countries with high numbers of patients with diabetes will reap significant benefits with the implementation of diabetes management using diabetes information systems. There is likely to be increasing pressure for such integrated information to be accessible by patients, with linkage with self-management approaches. As scale and complexity grow, detailed measurements of the use, impact, and cost of such systems will be expected, but are yet to be undertaken. The cost-benefit analysis of one such system is currently under way in New York City.[277] How to extract maximal knowledge from the existence of such systems will also become increasingly important. There is clearly additional value in closely associating diabetes researchers, with the clinical “champions” and information

service staff. For example, the initial proposal for the Regional Diabetes Information Service of the Waikato DHB in New Zealand was written by a clinical researcher and then developed through collaboration with local primary and secondary care clinical managers and information technology staff. Researchers have been concurrently involved in understanding the data flows and likely business rules, along with methods for developing linkages with other stand-alone, or unlinked, clinical databases such as pharmacy systems. A fundamental frontier remains: how best to develop governance and guardianship over such data and associated systems once multiple organisations are involved.

Table 2-7. Diabetes Information Systems Linking Multiple Data Sources

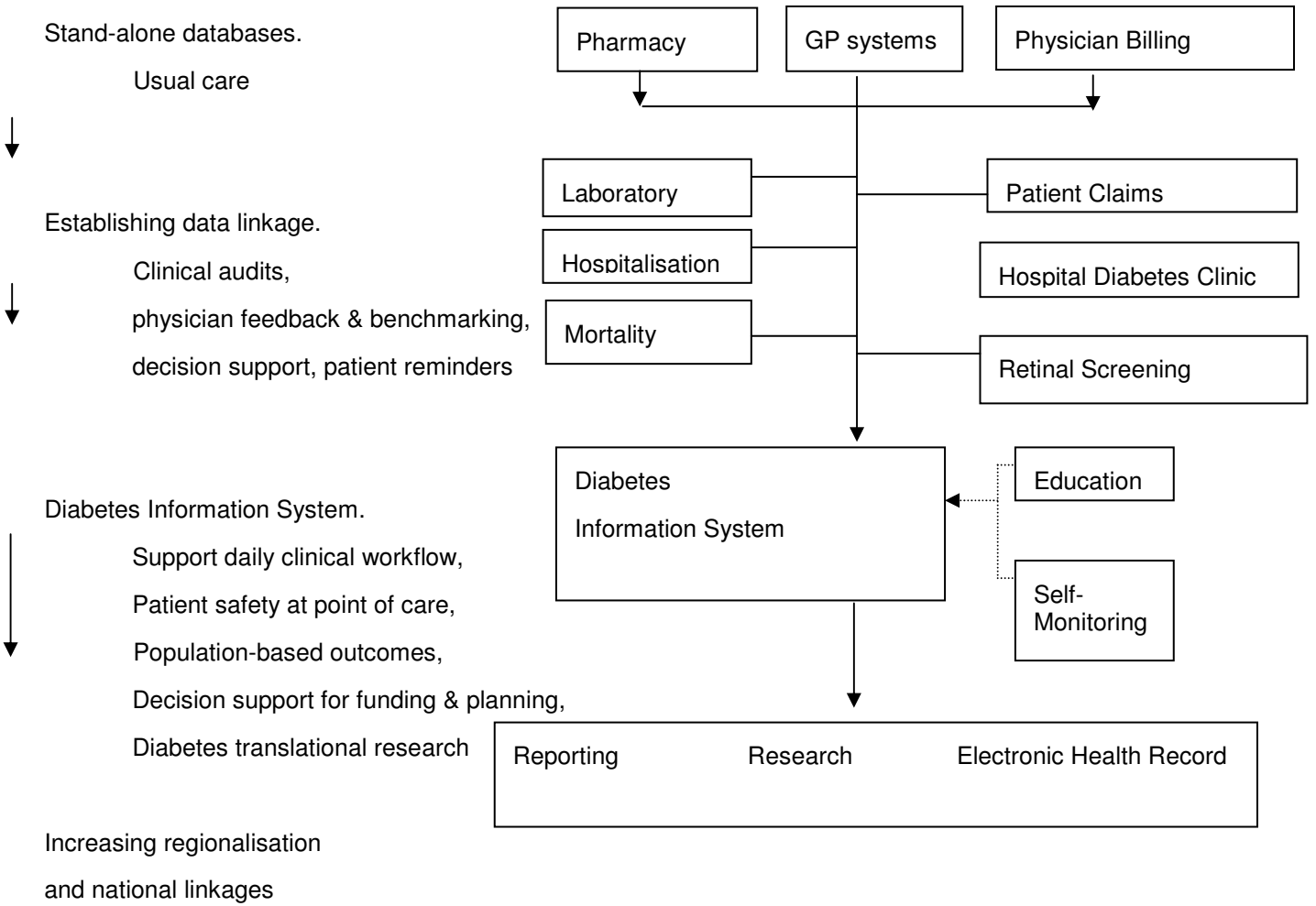
System	Description	Implementation issues	Key findings/achievements
DARTS database[244]	Developed by the diabetes record-linkage study in Tayside, Scotland. Links prescriptions, hospital diabetes clinics, mobile diabetes eye unit, regional biochemistry database, the Scottish morbidity record.	Required 12 full months of a full-time computer programmer and research nurse for creation of the register.	Record linkage using a unique patient identifier is more sensitive than general practice registers in identifying known diabetes patients.
Dialog Shared Care[225]	A Java solution based on service-oriented architecture and using web services and XML for integration to electronic patients' records, patient administrative systems, and lab systems. Operational in Funen County, Denmark.	Dialog is developed as a web-based service that has minimal requirements to the local infrastructure at the users and to information technology support.	Dialog contains information on lab results, treatment, use of insulin, eye status, foot status, self-care, latest contacts, and possible complications.
Diamond[278]	Currently operational in Ulster, Northern Ireland. Based within the acute hospital with access provided to primary and community service providers. Receives data from diabetes team, pathology, renal, community health, hospital administration, and emergency department. Directly interfaced with devices including insulin pumps, blood glucose meters, 24 blood pressure monitors, ECG machines (12 lead stress tests), etc.	Allows integration with existing systems including: patient administration system (PAS), pathology, retinopathy/screening, and surgery.	Supports clinical audits, GP decision support, and SMS text message reminders to patients.
MARS[253]	University of Pittsburgh Medical Center's clinical data repository, Medical Archival Retrieval System (MARS), captures patient demographics, laboratory results, visits, charges, health insurance information, medications, co-morbid conditions, and procedures.	Implementation of the chronic care model required implementing American Diabetes Association (ADA) standards of care to be able to claim reimbursements.	Integrating a multifaceted approach to improving diabetes care, including all elements of chronic care model resulted in significant improvement in provider practices and patient outcomes.

(continued overleaf)

Table 2-7 (continued)

System	Description	Implementation issues	Key findings/achievements
DEMS[279]	Diabetes Electronic Management System (DEMS)[280] implemented by the Mayo Health System Diabetes Translation Project in Wisconsin and Minnesota. A chronic disease management system used by physicians, nurses, dieticians, clinical assistants, educators, and specialists. Currently implemented in Greece, being installed in Texas, Ontario (Canada), and The Netherlands. Over 34,000 patients on the database.	Primary care providers and their team (nurses, clinical assistants, and diabetes educators) needed initial computer and DEMS training.	Addition of DEMS to planned care led to improvement in all performance measures.
Blue Care Network[281]	The Blue Care Network of South East Michigan, an organisation with nearly 1,100 GPs and 2,000 specialist providers, has linked pharmacy database and integrated clinical laboratory database at the patient level to augment physician decision-making and guidelines compliance through feedback.	A major challenge was developing the procedure for extracting, transmitting, receiving, and translating files containing laboratory test data.	This system is used to send reports to primary care physicians in an independent practice association model managed care setting to improve the care of diabetes patients.
DCMS[282]	Diabetes Care Management System, a multifaceted intervention and education approach interwoven with audit developed by Intermountain Health Care in Salt Lake City, UT. The system combines data from five different data sources: electronic laboratory, health plan claims, physician billing, clinical information system, and case mix (from hospital/facility billing data) and caters for over 25,000 patients.	(Not available)	A multifaceted approach in improving diabetes management has led to improved performance in clinical measures related to diabetes care.
Caritas Diabetes Registry[283]	Caritas Diabetes Registry in Boston has demonstrated the advantages of an internet-based information system linking data from multiple sources: hospitals, home care, physician practices, laboratories, claims data, and diabetes education data.	Contracted a health informatics internet company to establish the registry.	With repeated reminder letters sent to patients and providers, the frequency of the number of tests done (HbA_{1c}, cholesterol, microalbuminuria, and eye exam) increased progressively over time.

Figure 2-5. Natural evolution of diabetes information systems



2.3.7 Conclusion

Most of the developed countries have now implemented systems such as diabetes registers and audits for diabetes surveillance in at least some regions, if not nationally. The importance of having a unique identifier, which can link different datasets, and engines, which can link different electronic systems, cannot be understated. Developing nations are beginning to recognise the need for chronic disease management. With the advancements in information technology, the diabetes registers have the potential to rise beyond their traditional functions with dynamic data integration, decision support, and data access, as demonstrated by some diabetes information systems.

The success of the information systems depends upon integration of data from primary care and secondary care and system capabilities (automated data extraction, decision support for providers and self-management support for patients). Implementation would need substantial financial backing and support regarding governance and confidentiality issues. The importance of dedicated ongoing maintenance cannot be understated. Multifaceted interventions supported by such robust systems could bring the spiralling cost of diabetes care down and reduce diabetes-related complications. With the rapid pace of development in electronic health records and health information technology systems, countries that are beginning to build their health information technology infrastructure could benefit from planning and funding along these lines.

2.4 Conclusions of the Literature Review

While the diabetes epidemic continues to impact increasingly on New Zealanders and its health services, over the last five years, a growing number of Government and District Health Board funded initiatives are in place to prevent diabetes and its

complications. A nationally agreed strategic plan is now urgently needed on how best to monitor and control the increasing incidence and prevalence of diabetes, and the proportion with undiagnosed diabetes, impaired glucose tolerance and impaired fasting glucose.

With the rapid advances in information technology in the last decade, various diabetes information systems have evolved in different parts of the world. The first step is to develop a registry, including a patient identifier that can link multiple data sources, which can then serve as a springboard to electronic mechanisms for practitioners to gain information on performance and results.

CHAPTER 3 METHODS

The thesis uses eight studies which demonstrate the use of NHI linkage to monitor diabetes care: three general practice based diabetes prevalence studies (Hamilton, Rotorua and Taumarunui), three diabetes outcome studies (hospital admissions, renal progression and mortality), patient retention on "Get Checked" and an audit. In each of these studies, existing databases are linked to estimate diabetes prevalence, access to diabetes care or complications. Sometimes, only parts of studies are used in the thesis. This chapter summarises the studies and audits used in the thesis, their rationale, methodology and contributions to thesis.

Table 3-1. Summary of thesis methodology

Study	*NHI Linkage Used*	*Contribution to Thesis*
Taumarunui	GP ↔ WRDS ↔ GC	Coverage of databases, data agreement, diabetes care
Hamilton	GP ↔ WRDS ↔ GC	Coverage of databases, data agreement, prevalence, diabetes care
Rotorua	GP ↔ GC	Coverage of database, prevalence, diabetes care
Audits	WRDS ↔ PMS	Data agreement, Coverage
Hospital Admissions	WRDS ↔ PMS	Diabetes outcome
Renal progression	WRDS ↔ PMS	Diabetes outcome
Mortality	WRDS ↔ Mortality	Diabetes outcome
"Get Checked" Retention	GC ↔ Mortality	Diabetes care

GP: General Practice database, WRDS: Waikato Regional Diabetes Service database,
GC: "Get Checked" database, PMS: Waikato DHB patient management system

3.1 Integrated Diabetes Care Initiative (IDCI) in Taumarunui

3.1.1 Background

An integrated diabetes care initiative planned to include nine interventions was introduced in a rural Waikato town, Taumarunui, in 2005. The area includes a population of 5136, including, 43% Maori according to the 2001 census. The approach included a diabetes specialist clinic, primary care decision support and training, and novel, tailored strategies for identifying and addressing psycho-social barriers to self-care. Information on barriers to diabetes was collected as part of the baseline data collection.

The initial plan was to implement the new services, systems and approaches in Taumarunui to form the intervention limb of a prospective, non-randomised, controlled, clinical trial over 18-24 months. The proposed control group was the corresponding population in a matched town, Te Kuiti, which was supposed to continue with existing diabetes services. Unfortunately, the study had to be terminated as funding was not secured for the main trial or for the additional services required. It was not feasible to continue the specialist interventions with available resources. However, the baseline data collection with linkage of data from multiple data sources, serves as a pilot for the proposed RDIS (as intended). Later studies have demonstrated the importance of integrated care for improved clinical care, managing acute demand and cost effectiveness internationally[284 285] and in New Zealand.[286]

The area has three general practices: one private, one run by a community trust and one run by a Maori Health Provider. Each practice is computerised with a recall system in place. A single pharmacy services the town. The local hospital, run by the Waikato DHB, has an emergency department staffed by Medical Officers and a few visiting specialist services (e.g. general medicine). As with all districts in the Waikato,

Taumarunui has a community-based Waikato DHB diabetes service educator, thought to have seen most local diabetic patients. The diabetes educator leads a bi-monthly "support group", with attendances ranging between 12 and 30. There is a visiting dietitian and a visiting podiatrist. A visiting retinal photography service reviews most diabetic patients.

3.1.2 Methods

A "Barriers to Care" postal survey was sent out to all known diabetes patients in the town, starting from March of 2005 to December 2006. All patients with diagnosed diabetes in the town and surrounding area were identified via list matches. We used patient lists from the three general practices in the area, patient list from the secondary diabetes services based WRDS database and the local diabetes educator's patient list. A letter was sent out to these patients starting from March 2005 explaining the rationale for the study. The "Barriers to care" tick list was included along with a self-addressed envelope and informed consent form. Patients who did not return the forms after two weeks were followed up with a reminder letter, and then by telephone reminders, as per Dillman's guidelines.[287]

The "Barriers to care" survey questionnaire included 27 closed questions based on educational, psychological, psycho-social, external physical and internal physical barriers (Table 3-2). This framework for barriers has been used in Australia[288] and the US[289] and has been validated for use in New Zealand.[205] A description of the framework is given below. The tick list used in the survey has been included in the Appendix 4.

Table 3-2. Barriers to diabetes care framework based on psychological, educational, internal physical, and external physical and psycho-social barriers

Source: Simmons et al.[205]

Psychological	
Public health belief	Believes the public should bear more financial responsibility for health care
Self factors – motivation	Psychological – motivation, attitudes, 'laziness', denial
Self factors – self-efficacy	No confidence, external locus of control, low self-efficacy
No symptom cue	No physical symptoms
Priority setting	Others needs priority over own (e.g. children, elders)
Negative perceptions of time	Not enough time (education provided too quickly)
Emotional	Fear, shame, emotion, anxiety, worry
Precontemplative	Strictness of the regimen, giving up things I enjoy
Educational	
Low diabetes knowledge	Lacks general/specific diabetes knowledge
Low knowledge of services	Unaware of services available
Internal physical	
Self factors/other health conditions	Diabetes related and non-diabetes related
Physical effects of treatment	Pain of glucose monitoring, drug side-effects

(continued overleaf)

Table 3-2. (continued)

External physical	
Personal finance	Income in relation to costs
Service/physical access	Transportation, wheelchair entry
Limited range of services	Timing or format of services (e.g. evening clinics, home visits)
Appointment system/staffing levels	Insufficient staffing for adequate service
Lack of community-based services	No local clinic that is identified as 'own' services
Unhelpful health professionals in the past	Past encounter with health professional leading to conflict or without expected communication or clinical expertise
Psycho-social	
Unsatisfactory/ inappropriate diabetes care or education	Wrong information provided or information provided in inappropriate way
Group pressure	Pressure from others not to adhere to advice
Prejudice	Impression of discriminatory practice due to diabetes or for other reasons
Lack of public awareness of diabetes	Others behave without adequate knowledge or acceptance of diabetes
Lack of family support	Family consumes diabetic food, resists change of lifestyle
Family demands	Pressure to spend time/money on the family rather than their diabetes
Unsupportive macro-environment	Feeling of lack of support in the community, e.g. access to low fat foods
Communication	Language differences (translation)
Inappropriate cultural messages	Attitude, ethnicity of workers, appropriateness of communication

Demographic information on consenting patients (age, ethnicity, gender, and diabetes duration) was extracted from the existing databases. Patients were considered eligible if they were diagnosed with diabetes and remained resident in the town and surrounding area. Patients with gestational diabetes, impaired glucose tolerance, who were mentally incapable of giving informed consent and who claimed not to have diabetes were excluded from the study. The local pharmacy database covering a three month period was used to access the medication costs of those patients who filled in the survey. Patients under treatment for non-glycaemic risk factors and cardiovascular diseases (treated with ACE inhibitors, anti-hypertensive drugs, anti-angina drugs, beta blockers, Ca channel blockers, diuretics, hypolipidaemic agents and vasodialators) were identified using the prescription data. Patients under drug treatment for diabetes (insulin and oral hypoglycaemic agents) were also identified. Results from the "Get Checked" free annual diabetes review programme in New Zealand were linked using the WPH's "Get Checked" database.

Ethical approval for this study was granted by the Waikato Ethics Committee (Reference WAI/04/11/106).

Statistical Analysis

Data were analysed using SAS® Version 9.1. All tests were two-tailed using 5% significance level. Case ascertainment using list matches was estimated using capture-recapture method (log-linear model).[290] Comparisons of the total number of barriers were made using the non-parametric Kruskal-Wallis test. Chi-square test was used to compare proportions.

3.1.3 Contribution to Thesis

Linking datasets:

- To access the difficulties and advantage of linking primary care and secondary care databases in identifying diagnosed diabetes patients (Section 4.4.1).
- To assess the agreement between databases as a pilot for the proposed RDIS (Section 4.5).
- To assess the completeness of the "Get Checked" data (Section 4.3.2), coverage of the "Get Checked" programme and compare the profile of diabetes patients registered with the "Get Checked" free annual diabetes review programme with those who are not (Section 4.6.1).

Monitoring diabetes care and outcomes:

- To study the barriers to diabetes care among diabetes patients (Section 5.2.2).

3.2 Retention Analysis Using Waikato Primary Health's "Get Checked" Database

3.2.1 Background

The "Get Checked" annual diabetes review data could potentially function as a powerful monitoring tool for diabetes care in New Zealand. But there are concerns about drop out from the programme and the problem of interpreting data through the use of repeated cross sectional rather than longitudinal analysis. This study investigates the patient retention in this programme using data from the local primary healthcare organisation.

WPH is the largest PHO in the Waikato area with a registered population of 294,510 in 2006. It covers 90% of the 328,510 Waikato DHB population enrolled with a PHO[86 87], with an estimated 10,604 people diagnosed with diabetes.[88]

3.2.2 Methods

This research was a retrospective review of WPH registered patients who had at least one “Get Checked” review between 1 July 2000 and 30 Jun 2006, using the demographic variables from the “Get Checked” database (age, gender, latest recorded ethnicity and type of diabetes). Year of diagnosis of diabetes was not available for analysis. Mortality data were obtained from the NZHIS and were linked to WPH patient register using the NHI numbers. Some patients left WPH after their initial review and were not available for further reviews. The WPH registrations were recorded on a quarterly basis for each patient.

Ethical approval for this study was granted by the Northern Y Regional Ethics Committee (Reference NTY/06/04/031).

Statistical Analyses

Survival analysis was employed to analyse the time to second review from the initial review. In order to look at continued participation beyond the second review, time to third review from second review, time to fourth review from third and time to fifth review from fourth were also analysed in a similar fashion.

Those who died or left WPH before a second review and were considered “censored” for the analysis of time to second review. Those who did not return for a second review during follow up time were censored on 30 June 2006. A similar approach to censoring was also used for the analysis of time to subsequent reviews. For censored patients, the time to event was the start date to date of death, migration date or end of follow-up, which ever was the earliest. Migration date was defined as 45 days after the last quarter of registration with WPH.

Kaplan-Meier survival curves for time to reviews are presented. Allowing a six month window to the ideal one year of interval between reviews, review rates at 1.5 years were examined. Survival curves for time to second review are presented by ethnicity, age group at first review, gender and type of diabetes. Hazard ratios for the likelihood of a second review were estimated using Cox's proportional hazard model. A stratified Cox's proportional hazards model for recurrent events (Conditional model 2)[291] was used to analyse subsequent reviews following initial review. This model, assumes that time until the second review does not influence the risk set for a third or later reviews.

Potential predictors were identified by running a series of regression analyses. Ethnicity, age group at first review, gender and diabetes type were included as predictors in a Cox's regression analysis. Proportionality assumption was verified by testing the correlation between Schoenfeld's residuals for a particular co-variate and individual failure times. All Statistical analyses were performed using SAS® Version 9.1.

3.2.3 Contribution to Thesis

Linking datasets:

- To study the demographics profile diabetes patients in the "Get Checked" database and extent of missing data (Section 4.3.1).

Monitoring diabetes care and outcomes:

- To characterise the retention of patients in the "Get Checked" free annual diabetes review programme in New Zealand (Section 5.2.1). (How good is the "Get Checked" database as a data source for cohort studies?)

3.3 Diabetes Prevalence Survey in Rotorua

3.3.1 Background

The Rotorua General Practice Group (RGPG) provides services to 65,940 people living in and around Rotorua, New Zealand. These patients are registered with 15 practices. There are a high proportion of Maori people living in the Rotorua district; 36.4% Maori, compared to 14.6% Maori in New Zealand's total population.[292]

There is interest in reducing inequalities for people who are economically disadvantaged.[293] As in the UK[13 294 295], the prevalence of diabetes has been shown to be inversely related to socio-economic status in New Zealand.[72 73] But it is not known whether the trend is similar across ethnic groups. Maori and Pacific people are over represented in the most deprived categories. Diabetes risk factors such as obesity, reduced physical activity and smoking are also more prevalent among most deprived groups.[296 297] There is significant association between deprivation index and hospital discharge rates for diabetes among New Zealand Europeans, but no such relationship has been found for Maori.[298] The impact of socio-economic deprivation on diabetes prevalence among Maori is not clear.

Primary care physicians have been encouraged to test for macro and micro albuminuria and to estimate the albumin-creatinine ratio (ACR). It has also been suggested that estimating the glomerular filtration rate (eGFR) is a more sensitive method of identifying early renal failure.[299] The eGFR, calculated by using the MDRD equation (named after the US Modification of Diet in Renal Disease Study[300]), detects chronic kidney disease more accurately than does the serum creatinine level alone. The eGFR rate also is used for disease staging. Using the MDRD equation, laboratories are now able to routinely report eGFR derived from the serum creatinine concentration, age and gender. It does not require body surface-area measurements.

In their position statement, the Australasian Creatinine Consensus Working Group, recommended that an eGFR based on the abbreviated MDRD formula be reported with every request for serum creatinine in patients over the age of 18 years.[301] Over 69% of New Zealand laboratories report eGFR results with most requests for serum creatinine in patients aged >18 years.[302] New Zealand Guidelines Group[49] recommends calculating the eGFR using the Cockcroft-Gault (CG)[303] method which uses age, serum creatinine, gender, body weight and height or using the MDRD formula.[300] There is concern over the validity of either method in Maori. The MDRD calculation makes an adjustment for ethnicity in the case of black Americans, but no such adjustment factor has been developed for other non-European ethnicities including Maori. Consequently, we wanted to investigate the prevalence of chronic kidney disease (CKD) in a population of New Zealand patients with diabetes and measure the agreement between the MDRD and CG formulae in identifying CKD among both Europeans and Maori in New Zealand.

Key indicators of quality treatment in patients identified with early CKD include good glycaemic control, management of blood pressure to agreed targets, the use of ACE inhibitors to reduce progression of renal disease and use of statins to reduce the risk of cardiovascular disease.[49] [304] This study reviewed the management of diabetes in patients with evidence of CKD by comparing blood pressure control, glycaemic control, the use of ACE and the use of statins among patients with or without evidence of renal disease.

3.3.2 Methods

A cross sectional survey was conducted on all patients registered with any one of the 10 RGPG practices that took part in this study. The survey identified all patients registered with the practices on 1 July 2007. Patients with diabetes were initially

identified by searching the practice electronic data systems for all those with a diagnostic code for diabetes or diabetes annual review (DAR) as part of the "Get Checked" programme. Further case identification was sought by identifying all patients with a prescription of anti-diabetic medications (Insulin, Sulphonylureas, Acarbose, Glitazones) who did not have a diagnosis of diabetes and then manually checking the notes in patient records and verifying with the general practitioner to confirm whether the patient should be on the register. The laboratory records of all RGPG patients were then checked to identify any patient with an HbA_{1c} greater than 6.5% and similar additional validation was performed by manually checking the patient records and review by the GP. Only validated cases were included in the study. Identification of undiagnosed diabetes was not attempted in this study. A previous survey by RGPG had been carried out in 2006 linking the local retinal screening register with the diabetes register – this further check was therefore not repeated. Thus a very sensitive search was used for identifying patients by looking for diagnostic codes, prescriptions, laboratory tests and records of retinal screening. Specificity was ensured by review of the patient's charts in conjunction with the relevant general practitioner in cases where there was no diagnosis code in the record but other evidence suggesting diabetes. A comprehensive diabetes register was formed.

Ethnicity data recorded at Level 2 of the Statistics New Zealand Ethnicity Classification, which is the standard for health sector data collections in New Zealand, were aggregated for analysis into ethnic groups. NZDep2001 quintiles were used as the key indicators of socio-economic status. NZDep2001 is a "small area-based" index of socio-economic deprivation that measures the level of deprivation for each meshblock, according to a combination of Census 2001 variables (i.e. income, transport (access to car), living space, home ownership, employment status, qualifications, support (sole-parent families) and access to a telephone).[69] Meshblocks are geographical units defined by Statistics New Zealand, containing a median of approximately 90 people in

2001. In NZDep2001 quintile categories, quintile 1 represents the least deprived and quintile 5 the most deprived. RGPG has assigned NZDep2001 scores to patients based on their address.

Information on metabolic control, body measurements and treatments (Statin or ACE prescription) were extracted either from the DAR database or from patient records where it was not otherwise available. We excluded newly diagnosed patients (diagnosed in 2007) as they may not have had time to be fully assessed or optimum treatment to be instituted.

Estimates of eGFR could only be made in patients where age, gender, ethnicity, weight and serum creatinine were all available.

$$\text{MDRD eGFR} = 186 \times \left[\frac{\text{Serum Creatinine}}{88.4}\right]^{-1.154} \times \text{Age}^{-0.203} \times (0.742 \text{if female})$$

$$\text{CG eGFR} = \frac{(140 - \text{Age}) \times \text{Weight} \times 1.04 \text{ x } 1.73}{\text{Serum Creatinine}} \div (0.007184 \times \text{Weight}^{0.425} \times \text{Height}^{0.725}) \text{ if female}$$

$$= \frac{(140 - \text{Age}) \times \text{Weight} \times 1.23 \text{ x } 1.73}{\text{Serum Creatinine}} \div (0.007184 \times \text{Weight}^{0.425} \times \text{Height}^{0.725}) \text{ if male}$$

Both MDRD and CG formulas were used to calculate eGFR. Those with missing data in any of these categories have been excluded from this analysis. Microalbuminuria (ACR 2.5-29.9 mg/mmol creatinine (men), 3.5-29.9 (women)) and proteinuria (ACR > 30) were defined as per local guidelines.[49] Ethnic and gender specific prevalence of clinically significant CKD (eGFR <60 ml/min/1.73m^2) has been calculated.

Ethical approval for this study was granted by the Northern Y Regional Ethics Committee (Reference NTY/07/11/117).

Statistical analyses

All patients registered with the practices as of 1 July 2007 were included in the denominator for prevalence calculation. Prevalence of diagnosed diabetes among general practice registered patients by ethnicity, age group, gender and NZDep2001 quintiles has been calculated. Pacific Islanders and Asians have been excluded from further analysis by deprivation and gender due to small patient numbers. It was not possible to track patient migration and changing providers within this cross sectional study. Adjusted odds ratios for the risk of diabetes have been obtained from logistic regression analysis.

Chi-square test was used to test differences in proportions and ANOVA was used to test differences in means. Agreement between the two eGFR formulas in identifying patients with eGFR <60 ml/min/1.73m^2 was tested using McNemar's chi-square test. Kappa statistics for agreement has also been reported. Logistic regression model was used to identify predictors of clinically significant CKD.

All statistical analyses were performed using SAS® Version 9.1 (SAS Institute, Cary, NC, USA).

3.3.3 Contribution to Thesis

Linking datasets:

- To access the completeness of the "Get Checked" data (Section 4.3.2) and coverage of the "Get Checked" programme using general practice databases (Section 4.6.2).

Monitoring diabetes care and outcomes:

- To estimate the prevalence of diagnosed diabetes among Maori and New Zealand Europeans and the influence of deprivation on diabetes prevalence (Section 5.1.2).
- To estimate the prevalence of chronic kidney disease (CKD) among diabetes patients in New Zealand, using eGFR (Section 5.3.2).
- To measure the agreement between the Modification of Diet in Renal Disease (MDRD) and Cockcroft-Gault (CG) equations in identifying CKD among Europeans and Maori (Section 5.3.2).

3.4 Diabetes Prevalence Survey in Hamilton

3.4.1 Background

There is concern that the "Get Checked" programme in Waikato is only reaching 69% of the estimated number of patients and that only 35% of Maori are receiving a review.[76] One of the barriers to the "Get Checked" programme is that DHBs do not have comprehensive diabetes registers and so have difficulty ascertaining exactly what proportion of patients with diabetes have attended a "Get Checked" review.[38] The aim of this study was to create a comprehensive diabetes register for the study practices using general practice data systems and to measure government targets for diabetes[83] across ethnic groups, which include proportion of diabetes patients receiving "Get Checked" diabetes annual review, proportion of people on the diabetes register who have satisfactory diabetes management (HbA_{1c} < 8%) and proportion of people on the diabetes register who have had retinal screening in the preceding two years. The prevalence of diabetes in three large general practices by age, gender and ethnicity has been estimated. Quality of diabetes care and disparities in diabetes care has been investigated.

3.4.2 Methods

A cross sectional study in three general practices in Hamilton, New Zealand in November 2007. It was necessary to develop a comprehensive register of patients with diabetes. The study identified patients aged 20 years or over and those with Type 2 diabetes. All three practices managed their patient files through the MedTech-32 programme. Through the query builder search we found our total practice population to be 36,387. The practice's computer system search facility was used to identify:

- Patients under the Read Codes 'C108' (insulin-dependent diabetes mellitus) and 'C109' (non-insulin-dependent diabetes mellitus). This represents all the patients coded with diabetes.
- Patients who have in the past 12 months (between 15/11/2006 and 15/11/2007) been on any of the following drugs: Insulin, Metformin, Sulphonylureas, Acarbose, Glitazones. This represents all patients who have been prescribed diabetic medication in the past 12 months, some of whom may not have been coded with diabetes.
- Patients registered under the "Get Checked" programme with their demographic and clinical information.
- Patients who have had an HbA_{1c} test ordered in the past two years (between 15/11/2005 and 15/11/2007). This represents all patients who have had an HbA_{1c} test requested by their GP but who may not have been coded with diabetes (or been prescribed with diabetic medication). This also included tests ordered for diabetes screening purpose and GP confirmation was needed for verification.
- The records were checked against the WRDS database using patient NHI numbers to see if there were any patients known to the hospital service not identified using our search strategy.

The data collected from the first stage was collated using Microsoft Excel. NHI numbers were collated to form a single list of all potential patients with diabetes for each practice. Patients with a diagnostic code for diabetes, who were also recorded on the WRDS database as having diabetes and had a record of a "Get Checked" review in the last year, were presumed to be true cases. No further verification of the diagnosis was carried out in these patients. Patients who had a diagnostic code but no evidence of a diabetes annual review or a relevant prescription had their written records reviewed and had to meet the WHO diagnostic criteria for diabetes[49] or have a letter from a specialist confirming the diagnosis before being accepted as validated cases. Those with a diagnostic code but where the diagnosis could not be confirmed were excluded. Similarly we reviewed the case records of patients without a diagnostic code for diabetes but with either a prescription for a hypoglycaemic agent or a record of an $HbA_{1c} \geq 6.5\%$. Again these patients had to have evidence that they met the diagnostic criteria for diabetes or have a letter from a specialist before being included. A cut off of 6.5% was chosen as evidence from unpublished local data suggested this was a relatively specific cut off point. This is also consistent with evidence from another New Zealand study.[305] For those who were not registered under the "Get Checked" programme, missing data were retrieved from individual patient records. The completed list consisted of all patients with confirmed diabetes, with demographic, clinical and laboratory information.

The demographic and clinical data that was collected included age, gender, ethnicity, height, weight, latest HbA_{1c} and any record of retinal screening. Ethnicity was that recorded on the practice system. A GP name search was carried out on the WRDS database, including names of practices studied under the Hamilton GP based prevalence study, and aggregate data were compared.

Ethical approval for this study was granted by the Northern Y Regional Ethics Committee (Reference NTY/07/66/exp)

Statistical Analysis

Prevalence of diabetes was estimated by age-group and ethnicity for Type 2 diabetes. Agreement between prioritised ethnicity on the practice system and the single ethnicity recorded on the WRDS database has been studied. Marginal logistic regression model was used to analyse retinal screening rates and glycaemic control, adjusting for the correlation between patients from the same practice. Data were analysed using SAS® Version 9.1. As retinal screening is only carried out every two years in the Waikato patients who had been diagnosed in the last two years were excluded from the analysis of retinal screening uptake.

3.4.3 Contribution to Thesis

Linking datasets

- To evaluate the coverage of the WRDS (Section 4.7.1) and the "Get Checked" databases (Section 4.6.3).
- To access the advantage of linked datasets in identifying diagnosed diabetes patients (Section 4.4.1).
- To quantify the agreement between the single ethnicity on the WRDS database and the prioritised ethnicity on general practice system (Section 4.5.1).

Monitoring diabetes care and outcomes:

- To estimate the prevalence of diabetes in Hamilton by age, gender and ethnicity (Section 5.1.1).
- To investigate disparities in care (difference in HbA_{1c} or uptake of retinal screening) between ethnic groups (Section 5.1.1).

3.5 Progression of Renal Disease Using the WRDS Database

3.5.1 Background

Population rates of renal failure with concurrent diabetes (aged 15+) were 9.4 times higher in Maori compared with non-Maori.[73] While some of this difference can be attributed to the higher prevalence of diabetes among Maori, the disproportionately higher rate would suggest that Maori with diabetes are more likely to develop renal failure than non-Maori with diabetes.[306]

The proportion of Maori on dialysis with diabetes co-morbidity is much higher than that for New Zealand Europeans (55% versus 14%).[307] Maori with Type 2 diabetes are fifteen times more likely to die from diabetic nephropathy than Europeans.[77] But the rate of progression of renal disease among Maori is not clear. Population level incidence rates and hazard ratios for renal failure among Maori diabetes patients have not been previously estimated. Available studies on nephropathy among Maori diabetes patients have limitations because they were cross sectional in nature looking at prevalence rates [39 175 308], included dialysis and transplant registry patients only [210 309-311] or included existing renal disease patients only. [312]

3.5.2 Aim

To estimate the incidence of chronic renal failure, incidence of end stage renal failure (ESRD) and renal mortality rates among European and Maori patients with Type 1 and Type 2 diabetes; to estimate the ethnic difference in the risk of developing renal failure.

3.5.3 Methods

We identified the cohort of patients registered with the WRDS, diagnosed with diabetes before 2003. Patients without a history of renal disease (no renal event from 2000-2003) were retrospectively followed from 1 January 2003 until death or end of 2006. None of the 146 patients aged below 18 years at the start of follow up experienced a renal event and were excluded from analysis. The sample population was therefore adults 18 years or above.

Three events were included in the follow up: renal admission (defined as hospital admission for chronic renal disease, renal clinics attendance or contact with home dialysis unit), start of dialysis or kidney transplant and death coded with renal disease. Hospital admissions based on primary diagnosis codes and outpatient visit codes from 2000-2006 were obtained from the local Waikato DHB. Hospitals used ICD-10 codes. The codes used to identify renal outcomes are included in the Appendix 5. Mortality data were obtained from the National Health Information Service, including causes of death. National mortality database captures deaths throughout the country including deaths outside of hospitals. Start date of dialysis or transplant was obtained from the Australia and New Zealand Dialysis and Transplant (ANZDATA) registry through the Waikato Regional Renal Unit. The Waikato Regional Renal Unit provides dialysis and transplant care with support in both the community and secondary/tertiary setting for those patients in the Midland Region with diseases of the kidney.

The study was approved by Northern Y Regional Ethics Committee (NTY/08/34/EXP).

Statistical analyses

Incidence of renal hospital admission, ESRD and death from renal disease were calculated for NZ Europeans and Maori patients with diabetes. New Zealand's total population from the 2006 census was used for age standardisation. Cox's proportional

hazards model was employed to analyse the time to first renal event. Data were analysed using SAS® Version 9.1.

3.5.4 Contribution to Thesis

Monitoring diabetes care and outcomes:

- To estimate the ethnic difference in the incidence of renal disease (Section 5.3.1).

3.6 Hospital Admissions Using the WRDS Database

3.6.1 Background

The Health Needs Assessments[76] conducted by all DHBs are carried out using mortality records and hospital admissions records from the NZHIS. Hospital admissions for diabetes (primary diagnosis codes E10-E14) are routinely analysed to assess the morbidity levels among diabetes patients and their service utilisation (Table 3-3).

With the whole spectrum of diabetes complications, diabetes patients are often admitted for complications (like renal disease and cardiovascular disease). An analysis involving only E10-E14 codes misses out many of the admissions for diabetes related complications. For example, hypertensive diseases (I10-I15), ischaemic heart diseases (I20-25), pulmonary heart disease and diseases of pulmonary circulation (I26-28), other forms of heart disease (I30-52), cerebrovascular diseases (I60-69) or related procedure codes would not be captured using this approach. A comprehensive study of service utilisation among diabetes patients is not feasible without a robust denominator of diabetes patients.

Table 3-3. ICD-10 codes routinely used to access morbidity levels among diabetes patients

Codes	***Description***
E10	Insulin-dependent diabetes mellitus
E11	Non-insulin-dependent diabetes mellitus
E12	Malnutrition-related diabetes mellitus
E13	Other specified diabetes mellitus
E14	Unspecified diabetes mellitus
Sub-codes	***Description***
.0	With coma
.1	With ketoacidosis
.2+	With renal complications
.3+	With ophthalmic complications
.4+	With neurological complications
.5	With peripheral circulatory complications
.6	With other specified complications
.7	With multiple complications
.8	With unspecified complications
.9	Without complications

3.6.2 Methods

An audit of hospital admissions in 2005 among diabetes patients registered with the WRDS was carried out. A 2005 snapshot of the database was used to estimate hospital admissions. Waikato DHB admissions database was linked using NHI number. Although this analysis does not capture private hospital admissions or admissions outside of the DHB hospitals, the estimates serve as a proxy for service utilisation among diabetes patients with worse diabetes control, complications and co-morbidities. Primary diagnosis codes (ICD-10) were extracted from the inpatient management system and were classified admissions related to renal disease, cardiovascular disease

or cerebrovascular disease. The full list of the codes and classification are included in the Appendix 6. Grouping of codes were validated by the local endocrinologist. Logistic regression analysis was used to estimate the risks of hospital admission.

3.6.3 Contribution to Thesis

Linking datasets:

- To access the advantage of estimating service utilisation with the help of a diabetes register (Section 4.4.2).

Monitoring diabetes care and outcomes:

- To study the disparities in hospital admissions among diabetes patients (Section 5.3.3).

3.7 Mortality Study Using the WRDS Database

3.7.1 Background

For health planning purposes, substantial importance is attached to mortality statistics as an indicator of the prevalence of diabetes and the potential health burden associated with it.[79] Waikato DHB's Health Needs Analysis Report 2008 highlights gaps in mortality outcome analysis for diabetes patients. The NZHIS mortality records are routinely analysed, looking at deaths coded with diabetes as the primary cause of death. This approach misses out important information on deaths due to diabetes related complications among diabetes patients. Routine mortality analysis is further hindered by the under-coding of diabetes on death certificates when diabetes patients die of complications.[77-79] It is not clear whether there are ethnic differences in the level of under-coding. A comprehensive mortality analysis is not possible without a population based diabetes register.

The aims of this study were:

1. To estimate the mortality rates among people with diabetes in Waikato by ethnicity and gender.
2. To examine the differences in risk factors for all cause and cause specific mortality among people with diabetes in Waikato.

3.7.2 Methods

Retrospective cohort study of diabetes patients registered with the WRDS database in 2008. Patients diagnosed before 2003 where identified and retrospectively followed until end of 2005. Causes of death information for deaths from 2003-2005 was obtained from the NZHIS and linked using NHI number. The NZHIS Mortality Collection classifies the underlying cause of death for all deaths registered in New Zealand, using the ICD-10-AM 2nd Edition and the WHO Rules and Guidelines for Mortality Coding. Deaths registered in New Zealand from 1988 onwards are held in this national mortality database. Patient status information (alive/deceased) is also available from the WRDS database. Patient records were searched with the help of a summer student. In case of mismatch between the national mortality data and the WRDS data, deaths were verified by manually reviewing patient records and then by contacting the diabetes educators and general practitioners. Causes of death were classified into cardiovascular disease (CVD), cancer, renal, cerebrovascular, gastro intestinal, respiratory, diabetes/complications and other. Two people coded the data independently and the two sets of codes were compared to minimise coding errors. A full list of codes and classifications are included in the Appendix 6.

Statistical analyses

Crude mortality rates per 1000 person-years were calculated by ethnicity and gender. Segi world population, used in national mortality reports, was used to standardise

mortality rates. The 95% confidence intervals for age-standardised mortality rates have been calculated using the Keyfitz method.[313] Mortality rates for Type 1 and Type 2 diabetes patients were age-adjusted using direct standardisation to the corresponding study population structure. SMRs in relation to the national death rates were calculated using the 2004 national data from the MoH.[314] National ethnicity specific death rates were available for Maori population. SMRs for Maori diabetes patients in relation to national age and gender specific rates for Maori have been calculated. Confidence intervals for SMRs were calculated using the Boice-Monson method.[315] Fisher's exact test was used to determine whether diabetes was more likely to be recorded on NZHIS coding for Maori compared with Europeans. Cox's proportional hazards model was employed to identify the risk factors for all cause and cause-specific mortality. Data were analysed using SAS® Version 9.1.

3.7.3 Contribution to Thesis

Linking datasets:

- To access the agreement in ethnicity between the WRDS database and the national mortality database (Section 4.5.1).

Monitoring diabetes care and outcomes:

- To study mortality among diabetes patients (Section 5.3.4).

3.8 Audits Using the Waikato DHB Hospital IT Systems

The WRDS database is a stand-alone system. Key questions regarding the WRDS database, which are not answered by the studies presented in this thesis, are:

- Are the demographic variables recorded in the database in agreement with the data recorded secondary service patient management system which is the source data for NMDS? (Validity of data, Section 4.5.1)
- What proportion of the WRDS registered patients is from the Waikato DHB area? (Geographic profile, Section 4.2.3)
- How complete is the database in capturing diabetes patients with secondary service contact? (Missing diabetes patients, Section 4.7.2)

Two audits were conducted in March 2009 using the Waikato DHB hospital IT systems, with the help of the Waikato DHB audit team.

3.8.1 Audit of Demographic Details

Diagnosed diabetes patients on the WRDS database were identified using a 2008 snapshot of the database. Demographic details of patients (date of birth, prioritised ethnicity, gender and domicile DHB) were extracted from the Waikato DHB hospital IT systems via NHI linkage. This audit was used to compare the demographic details recorded on the WRDS database with that on the hospital systems (Section 4.2, 4.5).

3.8.2 Audit of Case Ascertainment Using Hospital System and the WRDS Database

All Waikato DHB hospital discharges in the calendar year 2005 with a discharge diagnosis of diabetes (using primary and secondary codes) were identified. This was compared against the WRDS database to identify patients not registered with the secondary diabetes service. The NHI list of patients registered with the WRDS was used to make the comparison. Summary of the profile of patients with diabetes related hospital admissions, but not registered with the WRDS database, were obtained from the Waikato DHB audit team.

3.8.3 Contribution to Thesis

Linking datasets:

- To assess the agreement between the single ethnicity in the WRDS database and ethnicity on the hospital PMS (Section 4.5.1).
- To assess the coverage of the WRDS database by identified diabetes related hospital admissions among patients not registered with the WRDS database (Section 4.7.2).

CHAPTER 4 LINKING DATABASES TO CREATE A REGIONAL DIABETES REGISTER

4.1 Introduction

Validity and completeness of a regional register linking datasets would depend upon the quality of data and completeness of the contributing data sources. This section presents a closer look at two of the major data components: the WRDS database and the "Get Checked" database. Missing data, data agreement and database coverage have been investigated.

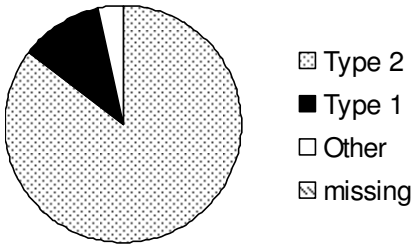
4.2 The WRDS Database: a Descriptive Summary

This section summarises the profile of patients from a 2008 snapshot of the WRDS database. Patients with either the type of diabetes or the year of diagnosis of diabetes recorded on the WRDS database were considered as diagnosed diabetes patients. 14,948 diagnosed diabetes patients were identified. Audit results, using Waikato Hospital IT system, are used to compare demographic details.

4.2.1 Type of Diabetes and Year of Diagnosis of Diabetes

The WRDS database snapshot had 85% Type 2 diabetes patients and 11% Type 1 diabetes patients (Figure 4-1). 95% of Type 2 and 97% of Type 1 patients had year of diagnosis of diabetes recorded.

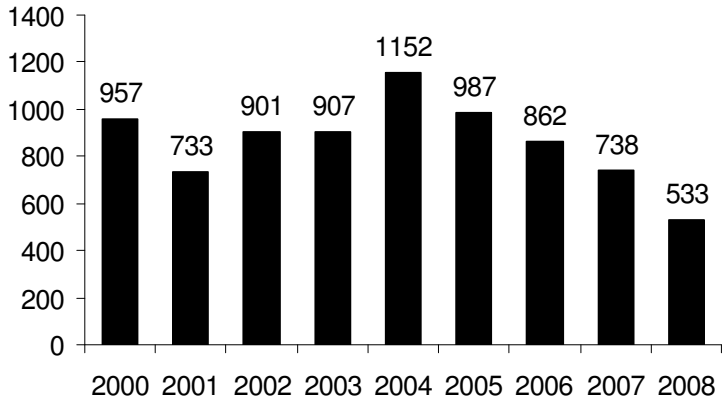
Figure 4-1. The WRDS database (2008): Type of Diabetes



Type of diabetes	n	%
Type 2	12749	85%
Type 1	1700	11%
Other	481	3%
missing	18	0.1%
Total	14948	

588 (3.9%) patients had a missing year of diagnosis. 6590 (44%) were diagnosed before 2000. 7770 (51.9%) were diagnosed since 2000 (Figure 4-2).

Figure 4-2. The WRDS database (2008): Number of patients diagnosed with diabetes since 2000



4.2.2 Gender and Ethnicity

All patients had gender and ethnicity recorded. 218 patients had ethnicity classified as "Not Known" (Table 4-1).

Table 4-1. The WRDS database (2008): Ethnicity and Gender

Ethnicity	n	%	Male	Female
European	10107	67.61	5235	4872
Maori	3189	21.33	1563	1626
Indian	402	2.69	234	168
Pacific Island	378	2.53	177	201
Asian	268	1.79	135	133
Other	386	2.58	201	185
Not Known	218	1.46	123	95
Total	14948		7668	7280

4.2.3 Domicile Code

The majority of patients (89%) had a domicile DHB code of Waikato (Table 4-2). 876 (5.8%) were from other DHB areas. Domicile DHB could not be extracted for 724 (4.8%) patients who were not on the Waikato DHB IT system.

Table 4-2. The WRDS database (2008): Domicile DHB extracted from Waikato DHB system

Domicile DHB		n	%
D031	Waikato	13328	89.16
D047	Bay of Plenty	251	1.68
D042	Lakes	212	1.42
D023	Counties Manukau	117	0.78
D021	Waitemata	41	0.27
D022	Auckland	35	0.23
D011	Northland	27	0.18
D091	Capital and Cost	26	0.17
D071	Taranaki	24	0.16
D081	MidCentral	22	0.15
D121	Canterbury	21	0.14
D051	Tairawhiti	20	0.13
D061	Hawkes Bay	17	0.11
D082	Whanganui	14	0.09
D092	Hutt	12	0.08
D141	Southland	11	0.07
D131	Otago	9	0.06
D101	Nelson Marlborough	7	0.05
D123	South Canterbury	5	0.03
D111	West Coast	4	0.03
D093	Wairarapa	1	0.01
n/a		20	0.13
not known		724	4.84
Total		14948	

4.2.4 Deceased Patients on the Database

Data of deaths up to end of 2007 were obtained as part of the mortality study. NHI search on the mortality database indicated that 1089 (7%) patients were deceased as of 2007 (Table 4-3).

Table 4-3. The WRDS database (2008): Deaths up to 2007

Year of death	n
Before 2001	44
2001	32
2002	35
2003	96
2004	171
2005	228
2006	304
2007	179
Total	1089

4.2.5 Retinal Screening

1170 (8%) of patients were indicated on the WRDS database were recorded as attending the secondary services eye clinic due to eye complications and were no longer attending retinal screening (Table 4-4).

Table 4-4. The WRDS database (2008): patients attending retinal screening and those under the care of secondary eye clinic

Year of diagnosis of diabetes	Year of last retinal screening				Attending eye clinic	Total
	2006-08	2003-05	before 2003	never		
missing	210	145	24	147	61	587
<2003	5443	1307	461	953	1017	9181
2003	679	187	0	20	21	907
2004	866	202	2	48	34	1152
2005	795	110	0	59	23	987
2006	790	0	0	63	9	862
2007	624	0	1	112	1	738
2008	323	0	0	207	4	534
Total	9730	1951	488	1609	1170	14948
	(65%)	(13%)	(3%)	(11%)	(8%)	

A further 11% had never attended a retinal screening. It is not clear whether they represented non-attendance, patients booked to attend screening in the future, patients with eye complication not needing retinal screening or patients attending eye-clinic but not recorded as eye-clinic patients on the WRDS database.

4.2.6 Conclusion of this Section

The WRDS database is a good data source for diabetes patients in the region, with high levels of recording of type of diabetes and year of diagnosis of diabetes. The database includes deceased patients and patients under the care of specialist eye services. The majority of patients are from Waikato DHB area. Although a proportion of patients have unknown ethnicity and gender, there is the possibility of populating these missing data items with the help of a regional diabetes register, created by linking databases.

4.3 The "Get Checked" Database: an Epidemiological Perspective

This section is a descriptive summary of the "Get Checked" data using the different studies where "Get Checked" review data was obtained, with focus on completeness of the database and missing data.

4.3.1 Patient Profile Using WPH's "Get Checked" Database

WPH's "Get Checked" database was obtained as part of the retention analysis. 10,919 distinct patients were reviewed at least once between 1 July 2000 and 31 June 2006. Only demographic data (ethnicity, gender, date of birth and type of diabetes) were provided. Demographic profile of patients and missing data are summarised below.

- All patients had their date of birth recorded.
- 86% had gender recorded. 4761 (44%) were male, 4651 (43%) were female.
- 95% had ethnicity recorded. 5% had ethnicity coded as "unknown". 69% European, 18% Maori, 3% Pacific Islanders and 4% Asian.
- All patients had type of diabetes recorded. 87% had Type 2 diabetes and 8% had Type 1 diabetes. 482 (4%) had type recorded as "Other".

4.3.2 Completeness of "Get Checked" Database

The completeness of "Get Checked" data as found in three studies are summarised below (Table 4-5).

Table 4-5. Completeness of "Get Checked" database: number of patients (%) with data available

	Rotorua Study	***Hamilton Study***	***Taumarunui Study[@]***
Number of patients with "Get Checked" review	1353	982	151
Type of diabetes	1241 (92%)	975 (99%)	151 (100%)
Year of diagnosis of diabetes	707 (52%)	895 (91%)	151 (100%)
HBA_{1c}	1352 (99.9%)	926 (94%)	151 (100%)
Serum creatinine	1267 (94%)	-	-
Total cholesterol	1336 (99%)	915 (93%)	151 (100%)
HDL cholesterol	1317 (97%)	910 (93%)	150 (99%)
LDL cholesterol	1264 (93%)	-	-
Systolic blood pressure	1345 (99%)	924 (94%)	151 (100%)
Diastolic blood pressure	1345 (99%)	922 (94%)	151 (100%)
Height	1083 (80%)	745 (76%)	148 (98%)
Weight	1081 (80%)	804 (82%)	142 (94%)
Smoking status	1353 (100%)	926 (94%)	151 (100%)

[@] Patients with "Get Checked" review only

4.3.3 Conclusion of this Section

Completeness of the general practice systems vary between providers. Year of diagnosis of diabetes and physical measurements (height and weight) in particular are poorly recorded.

4.4 Advantages of Linking Databases

4.4.1 Case Ascertainment

Taumarunui study

The Taumarunui study used three sources to identify diagnosed patients (Table 4-6).

Table 4-6. Identification of diagnosed diabetes patients in the Taumarunui study from three lists

Source:	*Educator List*	*GP List*	*WRDS database*	*Number of patients*
	N	N	C	6
	N	C	N	2
	C	N	N	16
	C	N	C	60
	C	C	N	21
	C	C	C	198
	N	C	C	0
Total captured	295	221	264	303

C – Captured, N – Not captured

Log-linear model without interaction terms yielded an estimate of 0.2914 (0.13, 0.64) for the number of patients not captured in any list, producing an estimate of 303.29 potential diabetes patients in the area. Identification process using the three lists has been quite comprehensive.

Hamilton Prevalence Survey

1251 potential patients with diabetes were identified from record searches in the Hamilton prevalence study. 1207 patients were coded as having diabetes on the general practice database (Table 4-7). Of these 198 had no record of “Get Checked” in the last 12 months and after review of their notes, 10 were excluded because they did

not meet the diagnostic criteria for diabetes. Another 10 potential patients were identified from prescriptions for hypoglycaemic medications and of these three were confirmed as having diabetes. Of 17 extra patients identified from laboratory results with an HbA_{1c} result >6.5%, four were confirmed as having diabetes. Eighty-six percent of patients with diabetes identified in the practices were also present on the WRDS database. Seventeen patients were found on the WRDS database, who were not found through searches on the general practice systems for either diabetes codes or other evidence such as prescriptions. Thus a search of the three general practice computer systems for diagnostic Read Codes for diabetes had a sensitivity of 98.0% and a specificity of 99.9%.

Table 4-7. Identification of diabetes patients from existing databases

Database Source	Diabetes patients identified	
	1221	
Diabetes code on GP database	1207	99%
with “Get Checked” review	1009	83%
without “Get Checked” review	188	15%
Not coded with diabetes on GP database	28	2%
Prescription only	7	1%
HbA_{1c} test only	4	0%
WRDS only	17	1%

GP: General Practice

4.4.2 Event Identification: Estimating Service Utilisation

The 9936 WRDS registered diabetes patients in 2005 had a total of 6275 admissions in 2005 (Table 4-8 to Table 4-11). The extent of underestimation of the service utilisation using discharge diagnosis codes alone is demonstrated in Figure 4-3 and Figure 4-4.

Figure 4-3. Number of WRDS registered diabetes patients with Waikato DHB hospital admissions in 2005 by primary diagnosis category

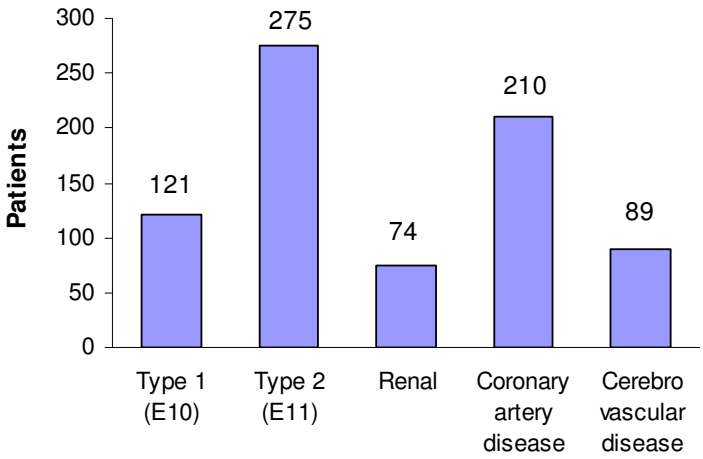


Figure 4-4. Number of Waikato DHB hospital admissions in 2005 among WRDS registered diabetes patients by primary diagnosis category

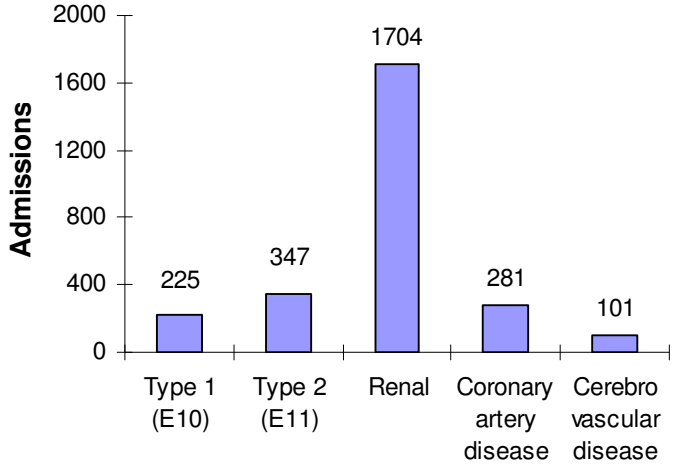


Table 4-8. Number of patients and number of admissions for diabetes (E10-E14)

Code	*Description*	*# Patients*	*# Admissions*
Codes E10-E14			
E1011	Type 1 diabetes mellitus with ketoacidosis without coma	29	37
E1022	Type 1 diabetes mellitus with established diabetic nephropathy	1	1
E1023	Type 1 diabetes mellitus with end-stage renal disease [ESRD]	3	3
E1029	Type 1 diabetes mellitus with other specified renal complication	2	2
E1031	Type 1 diabetes mellitus with background retinopathy	2	6
E1033	Type 1 diabetes mellitus with proliferative retinopathy	1	2
E1036	Type 1 diabetes mellitus with diabetic cataract	1	1
E1039	Type 1 diabetes mellitus with other specified ophthalmic complication	2	5
E1043	Type 1 diabetes mellitus with diabetic autonomic neuropathy	1	5
E1051	Type 1 diabetes mellitus with peripheral angiopathy without gangrene	1	1
E1052	Type 1 diabetes mellitus with peripheral angiopathy with gangrene	1	1
E1061	Type 1 diabetes mellitus with diabetic musculoskeletal and connective tissue complication	1	1
E1064	Type 1 diabetes mellitus with hypoglycaemia	15	21
E1065	Type 1 diabetes mellitus with poor control	23	25
E1071	Type 1 diabetes mellitus with multiple microvascular complications	5	10
E1073	Type 1 diabetes mellitus with foot ulcer due to multiple causes	3	3
E109	Type 1 diabetes mellitus without complication	46	101
E1111	Type 2 diabetes mellitus with ketoacidosis without coma	6	6
E1112	Type 2 diabetes mellitus with ketoacidosis with coma	1	1
E1113	Type 2 diabetes mellitus with lactic acidosis without coma	1	1
E1122	Type 2 diabetes mellitus with established diabetic nephropathy	4	4
E1123	Type 2 diabetes mellitus with end-stage renal disease [ESRD]	13	16
E1129	Type 2 diabetes mellitus with other specified renal complication	11	13
E1131	Type 2 diabetes mellitus with background retinopathy	1	1

(continued)

Table 4-8. (continued)

Code	*Description*	*# Patients*	*# Admissions*
E1132	Type 2 diabetes mellitus with preproliferative retinopathy	1	1
E1133	Type 2 diabetes mellitus with proliferative retinopathy	4	4
E1134	Type 2 diabetes mellitus with other retinopathy	4	4
E1135	Type 2 diabetes mellitus with advanced ophthalmic disease	4	4
E1136	Type 2 diabetes mellitus with diabetic cataract	1	1
E1139	Type 2 diabetes mellitus with other specified ophthalmic complication	98	109
E1140	Type 2 diabetes mellitus with neuropathy unspecified	1	1
E1141	Type 2 diabetes mellitus with diabetic mononeuropathy	1	1
E1142	Type 2 diabetes mellitus with diabetic polyneuropathy	5	8
E1143	Type 2 diabetes mellitus with diabetic autonomic neuropathy	12	12
E1151	Type 2 diabetes mellitus with peripheral angiopathy without gangrene	33	35
E1152	Type 2 diabetes mellitus with peripheral angiopathy with gangrene	6	7
E1153	Type 2 diabetes mellitus with diabetic ischaemic cardiomyopathy	1	1
E1161	Type 2 diabetes mellitus with diabetic musculoskeletal and connective tissue complication	1	1
E1162	Type 2 diabetes mellitus with skin and subcutaneous tissue complication	1	1
E1164	Type 2 diabetes mellitus with hypoglycaemia	23	23
E1165	Type 2 diabetes mellitus with poor control	17	17
E1169	Type 2 diabetes mellitus with other specified complication	7	8
E1171	Type 2 diabetes mellitus with multiple microvascular complications	7	8
E1172	Type 2 diabetes mellitus with features of insulin resistance	1	1
E1173	Type 2 diabetes mellitus with foot ulcer due to multiple causes	33	47
E119	Type 2 diabetes mellitus without complication	11	11
E1465	Unspecified diabetes mellitus with poor control	1	1
G459	Transient cerebral ischaemic attack unspecified	28	31

Table 4-9. Number of patients and number of admissions for coronary artery disease

Code	*Description*	*# Patients*	*# Admissions*
I200	Unstable angina	72	84
I208	Other forms of angina pectoris	1	1
I209	Angina pectoris unspecified	29	30
I210	Acute transmural myocardial infarction of anterior wall	8	9
I211	Acute transmural myocardial infarction of inferior wall	15	16
I214	Acute subendocardial myocardial infarction	92	116
I219	Acute myocardial infarction unspecified	4	4
I229	Subsequent myocardial infarction of unspecified site	2	2
I240	Coronary thrombosis not resulting in myocardial infarction	1	1
I2510	Atherosclerotic heart disease of unspecified vessel	1	1
I2511	Atherosclerotic heart disease of native coronary artery	15	16
I259	Chronic ischaemic heart disease unspecified	1	1

Table 4-10. Number of patients and number of admissions for cerebrovascular disease

Code	*Description*	*# Patients*	*# Admissions*
I611	Intracerebral haemorrhage in hemisphere cortical	1	1
I618	Other intracerebral haemorrhage	1	1
I619	Intracerebral haemorrhage unspecified	4	4
I632	Cerebral infarction due to unspecified occlusion or stenosis of precerebral arteries	3	3
I635	Cerebral infarction due to unspecified occlusion or stenosis of cerebral arteries	1	1
I638	Other cerebral infarction	3	3
I639	Cerebral infarction unspecified	18	19
I64	Stroke not specified as haemorrhage or infarction	28	29
I652	Occlusion and stenosis of carotid artery	6	6
I653	Occlusion and stenosis of multiple and bilateral precerebral arteries	2	2
I672	Cerebral atherosclerosis	1	1
G459	Transient cerebral ischaemic attack unspecified	28	31

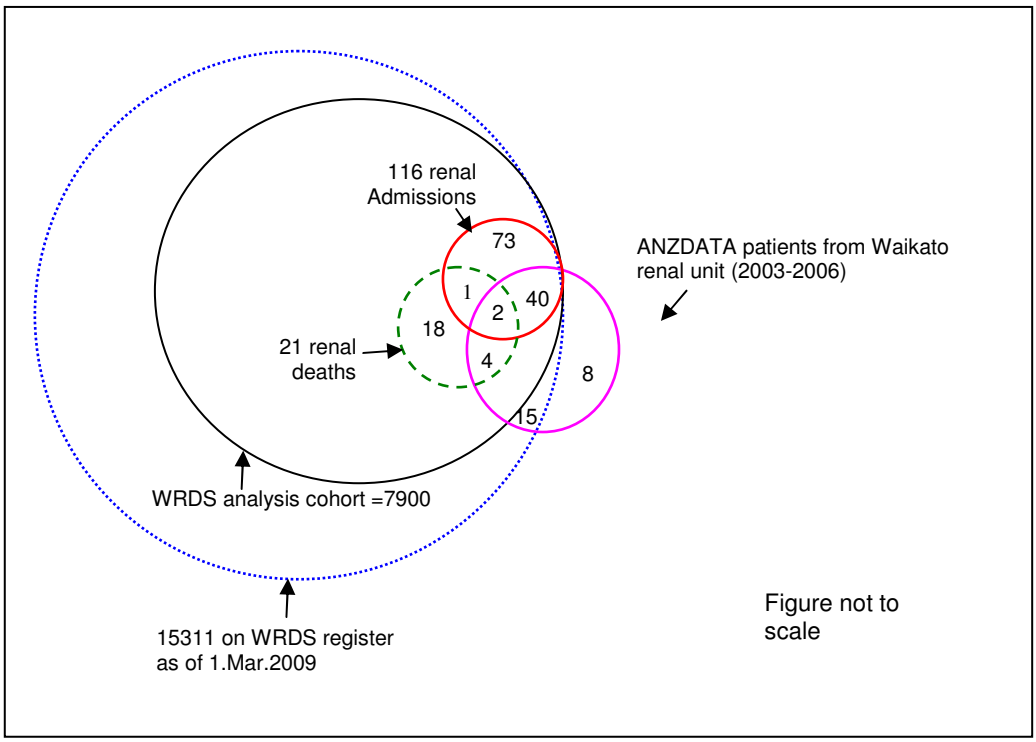
Table 4-11. Number of patients and number of admissions for renal disease

Code	*Description*	*# Patients*	*# Admissions*
N179	Acute renal failure unspecified	1	1
N1891	Chronic renal impairment	1	1
T824	Mechanical complication of vascular dialysis catheter	1	2
T8571	Infection and inflammatory reaction due to peritoneal dialysis catheter	16	19
Z490	Preparatory care for dialysis	22	33
Z491	Extracorporeal dialysis	36	1535
Z492	Other dialysis	19	79

4.4.3 Follow up Using Cohort Studies: The Example of Renal Progression Study

The Waikato Renal Unit provides renal services for the wider Midlands Region including Waikato and Lakes DHB areas. Of the 304 new dialysis/transplant patients entering the ANZDATA register through Waikato Renal Unit from 2003-2006, 61 were registered with the WRDS database. Of the 243 who were not registered with the WRDS database, only eight patients were Waikato residents with diabetes primary renal disease (Figure 4-5). Upon further verification, they were found to be diagnosed after 2002 and were excluded from the cohort for analysis. It is feasible to track diabetes complications using diabetes registers.

Figure 4-5. NHI linkage of the WRDS database, the ANZDATA register and the NZHIS mortality data



4.4.4 Conclusion of this Section

Most patients in the Hamilton study were identified from diagnosis codes alone. Looking for patients identified from prescriptions or laboratory data produced only another seven cases, whilst combining the register with a hospital database found another 17. This suggests the completeness of the general practice data can be high (98%) and in these practices is better than the 90% quoted in other studies.[10] Case identification in the Taumarunui study proved very different, with the majority of diabetes patients identified from the diabetes educator's and the WRDS database. This indicates that good IT systems and diagnosis coding practices are essential for case identification using general practice systems. A 2004 survey involving all New Zealand general practices (with 80% response rate) showed that almost all practices used PMS software and 72% used it to store full clinical notes.[44] But GPs expressed concerns over time involved and ongoing costs to meet the IT requirements.

In the Hamilton study, 86% of diabetes patients identified from general practice records were registered with the WRDS; the majority of missing patients being newly diagnosed who had not been referred for retinal screening or other assessments. This figure is similar to findings from the Taumarunui study where the WRDS database had 91% of patients.

Both the Hamilton and Taumarunui studies demonstrate the advantage of linking primary care systems and the WRDS database to create a combined diabetes register. It is possible to estimate under-counting of cases on the combined register using capture-recapture methods[316], as demonstrated using the Taumarunui example. It will then be possible to estimate the number of diagnosed diabetes patients in the region, which can in turn be used as a reliable denominator for rate calculations.

Up-to-date and reliable data on utilisation rates and costs of health services and treatments for people with diabetes, especially Type 2 diabetes, is needed to monitor the implications of diabetes.[27] A systematic review of the literature measuring the accuracy of discharge coding suggests that perhaps policy makers and researchers should interpret hospital database records with caution.[317] Estimating secondary service utilisation among diabetes patients using primary discharge diagnosis codes are limited by inaccuracies in coding of diagnoses[67 318] and changes to coding practices.[66] A regional diabetes register, linking primary care and secondary care data, would be a useful tool to evaluate service utilisation. It would not only provide a reliable denominator, but also minimise the impact of coding inaccuracies.

4.5 Agreement Between Datasets in Common Data Items

4.5.1 Ethnicity

Concordance between single ethnicity recorded on the WRDS database and ethnicity recorded on other database in the different studies are summarised in Table 4-12. Although the general practice and hospital systems are capable of recording up to three ethnicities, such detailed recording is rarely carried out. A single ethnicity is commonly recorded. An audit of Waikato DHB hospital inpatient management system found 14,224/14,949 WRDS registered patients. Ethnicity on the hospital system could be compared with ethnicity recorded on the WRDS database. As part of the mortality study, causes of death information on 581 deaths among the WRDS registered patients were obtained from the NZHIS. Ethnicity on the mortality database matched with the single ethnicity recorded on the WRDS database for 388 (94.9%) Europeans and 136 (98.5%) Maori. Ethnicity on "Get Checked" database was matched with the WRDS database ethnicity for 134 patients in the Taumarunui who had "Get Checked" data available. From the Hamilton study, 1132 patients with ethnicity recorded on general practice systems are compared with ethnicity recorded on the WRDS database.

Table 4-12. Concordance between the single ethnicity recorded on the WRDS database and ethnicity on other databases

	European	Maori	Pacific	Asian	Kappa statistic
Waikato DHB hospital IT system (n=14224)	8800 (90%)	2655 (90%)	290 (85%)	500 (82%)	0.76 (0.74, 0.77)
Get Checked Taumarunui (n=134)	83 (97%)	36 (92%)	1 (100%)	1 (50%)	0.92 (0.85, 0.99)[†]
NZHIS Mortality (n=581)	388 (96%)	100 (98%)	5 (100%)	5 (100%)	0.91 (0.87, 0.96)
Hamilton general practices (n=1132)	831 (97%)	133 (95%)	18 (86%)	73 (90%)	0.92 (0.90, 0.95)

Data are number of patients with same ethnicity on both databases (percentage out of WRDS Patients in that ethnic group). [†]Including European and Maori only.

4.5.2 Year of Diagnosis of Diabetes

95 patients in the Taumarunui study had year of diagnosis recorded on the "Get Checked" database. Only 36 (38%) had the same year recorded on both the "Get Checked" and the WRDS databases. 27 (28%) had a later year recorded on Get Checked. 32 (34%) had an earlier year recorded on Get Checked. The differences ranged from 20 years earlier to 13 years later on Get Checked.

4.5.3 Conclusion of this Section

Concordance between ethnicity on the WRDS database and ethnicity collected as part of a Waikato mail survey has been previously compared.[63] The study which compared prioritised ethnicity (Maori vs. non-Maori) with ethnicity on the WRDS database showed that 71% of people who identified as Maori in the survey were recorded as Maori on the WRDS database. 99% of non-Maori in the mail survey were recorded as non-Maori on the WRDS database.

Current results indicate that ethnicity recorded on the WRDS database has good agreement with ethnicity on other data systems. A diabetes register linking datasets would make it feasible to conduct outcomes analysis using prioritised ethnicity or sole/combination ethnicity groups.

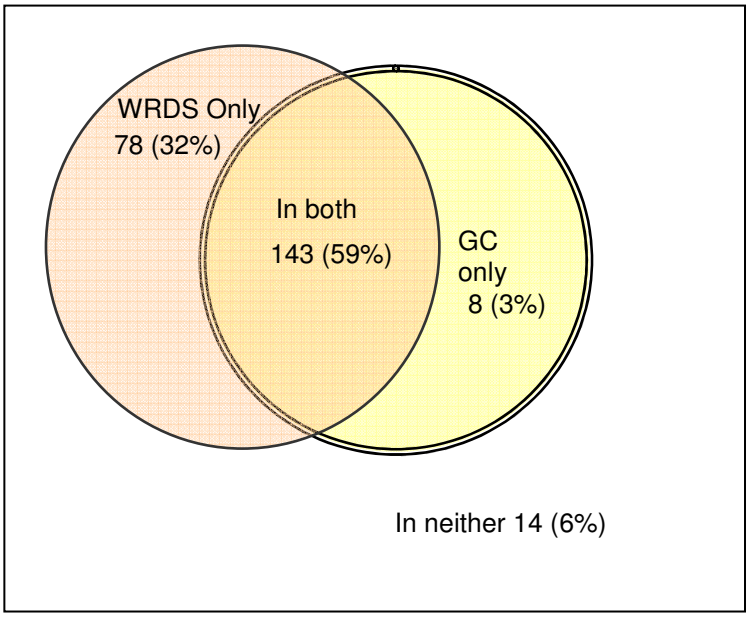
Problems with the recording of year of diagnosis of diabetes are not only limited to missing data but also extend to major non-concordance. It would be possible to populate one database and also match data using a probabilistic approach (see the discussion section).

4.6 Validity of the "Get Checked" Database: Who is Not Represented?

4.6.1 Coverage of the "Get Checked" Programme in Taumarunui

Among the 303 diabetes patients identified, 243 (80%) patients signed informed consent and completed the barriers survey. The "Get Checked" data for the 243 consenting patients were obtained from the local "Get Checked" administrator, WPH. Of the 243 diabetes patients who participated in the Taumarunui study, 221 (91%) were registered with the WRDS. 151 (62%) had at least one "Get Checked" review in the past (Figure 4-6). Among those with "Get Checked" reviews, 84 (35%) were reviewed in 2005/06.

Figure 4-6. Coverage of the “Get Checked” database in Taumarunui



The 243 participants were of mean age 65 ±12 years, 45% male, 61% European & 31% Maori, 78% low income financial support card users. 161 (62%) were registered with the “Get Checked” programme, which started in June 2000. 84 (35%) of patients attended a review in 2004/05. Only 24 (10%) patients did not have a GP name recorded on the WRDS database. But 61 (25%) were not found on any of the diabetes patient lists obtained from the three general practices in the town.

There were significant differences in presence on GP lists of diabetes patients, ethnicity, age group, treatment for hypertension and treatment for non-glycaemic risk factor and cardiovascular disease between the “Get Checked” attendees and non-attendees (Table 4-13). The uptake of the “Get Checked” programme seems to be governed by factors beyond financial barriers. No differences in “Get Checked” reviews were shown by reporting of financial barriers to diabetes care or lack of symptoms as a barrier to diabetes care.

Table 4-13. Profile of "Get Checked" attendees and non-attendees in Taumarunui

	Not registered with "Get Checked"	Registered with "Get Checked"	χ^2 p-value
Overall	92 (38%)	151 (62%)	
Ethnicity			
European	37 (29%)	90 (71%)	0.0113*
Maori	38 (46%)	44 (54%)	
Gender			
Male	37 (34%)	72 (66%)	0.2670
Female	55 (41%)	78 (59%)	
Age			
40-65	43 (42%)	60 (58%)	0.0363*
65+	35 (29%)	88 (71%)	
Treatment			
Diet Only	60 (53%)	53 (47%)	
OHA (Non-insulin)	20 (23%)	66 (77%)	<0.0001*
Insulin	12 (27%)	32 (73%)	
Treated for hypertension			
Yes	9 (24%)	29 (76%)	0.0498*
No	83 (40%)	122 (60%)	
CVD or risk factor medication			
Yes	48 (27%)	129 (73%)	<0.0001*
No	44 (67%)	22 (33%)	
Reported financial barrier to diabetes care			
Yes	68 (39%)	105 (61%)	0.1938
No	15 (29%)	36 (71%)	
Reported lack of symptoms as a barrier to diabetes care			
Yes	76 (38%)	126 (62%)	0.4750
No	10 (31%)	22 (69%)	
Present on general practice list of diabetes patients			
Practice 1	11 (20%)	43 (80%)	<0.0001*†
Practice 2	26 (21%)	98 (79%)	
Practice 3	4 (100%)	0	
Not present	51 (84%)	10 (16%)	

*Chi-square test significant at 5% level. †Test combining practices

4.6.2 Get Checked Programme in Rotorua

Of the 1819 (3.74%) diabetes patients identified in the Rotorua study, 1353 (74%) had a "Get Checked" review in the last two years. 342 (19%) patients did not attend a review. 124 (6.8%) were newly diagnosed (36 Maori, 74 NZ European, 14 Others). Review rates were significantly higher among older patients (age 60+), those with longer duration of diagnosed diabetes and those with better metabolic control (Table 4-14)

Table 4-14. "Get Checked" reviews among Rotorua general practice patients in the past 2 years

Variable	Category	Total	GC review (%)	$\chi 2$ p-value
Age	<40	90	80 (89%)	
	40-60	477	435 (91%)	<0.001*
	60+	849	838 (99%)	
Duration	2-<5	267	242 (91%)	
	5-<10	393	371 (94%)	<0.001*
	10+	346	338 (98%)	
Gender	Female	641	611 (95%)	
	Male	775	742 (96%)	0.7014
Race	Asian	51	41 (80%)	
	European	981	793 (81%)	0.4723
	Maori	599	469 (78%)	
HbA_{1c} (%)	≤ 8	920	901 (98%)	
	> 8	483	451 (93%)	<0.001*

4.6.3 Get Checked Programme in Hamilton

Of all the patients found to have diabetes 79.9% had a "Get Checked" annual review in the last 12 months. Maori and Asian patients were just as likely to have had a "Get Checked" as NZ Europeans (Table 4-15). NZ Europeans 726/910 (79.8%), Maori 121/147 (82.3%), Asian 89/115 (77.4%) (p = 0.61). Older patients (age>60 years) and those with Type 1 diabetes were less likely to have attended.

Table 4-15. "Get Checked" reviews among Hamilton general practice patients in the past 12 months

Variable	Category	Total	GC review (%)	χ^2 p-value
Age	<60yrs	505	389 (77)	0.033*
	>60yrs	716	587 (82)	
Gender	Female	599	483 (80.6)	0.549
	Male	622	493 (79.3)	
Ethnicity	NZ Euro	910	726 (79.8)	0.610
	Maori	147	121 (82.3)	
	Asian	115	89 (77.4)	
Type DM	Type 1	110	71 (64.6)	<0.001*
	Type 2	1111	905 (81.5)	
WRDS registration	Not on the WRDS database	168	119 (70.8)	<0.002*
	On the WRDS database	1053	857 (81.4)	

4.6.4 Conclusion of this Section

As pointed out by the recent audit report[38] it is usually difficult to draw detailed conclusions about the coverage of the "Get Checked" programme, since patient level information on all people with diabetes is routinely not available. The Taumarunui, Hamilton and Rotorua studies have demonstrated the utility of diabetes registers in

estimating programme coverage. The practices involved in the Hamilton study had provided “Get Checked” review for 80% of their patients with diabetes in the last 12 months. 74% of patients in Rotorua had attended a review in the past two years. This demonstrates that a high uptake of “Get Checked” can be achieved if practices have good systems. Furthermore, an equal proportion of Maori and Asian patients were attending “Get Checked” compared with NZ Europeans which indicated that involvement of patients from ethnic minorities was not a problem in these practices. This suggests that the low uptake of “Get Checked” in Maori patients with diabetes in the Waikato maybe a function of how individual practices work. Rather than blaming Maori patients for the poor attendance rates perhaps we could look at ways of improving the systems in our practices where the overall uptake is poor.

In Taumarunui, with a high number of community services card users, the uptake of the “Get Checked” programme seems to be governed by factors beyond financial barriers. The “Get Checked” attendees were less likely to be present on the practice list of diabetes patients, indicating non-practice registered patient and/or under-coding of diabetes on the PMS. Practice registration is a pre-requisite for the free “Get Checked” review. Information on practice registration was not obtained in the Taumarunui study. It was not possible to determine what proportion of patients was practice registered. Unregistered patients have been shown to have a different age and gender profile from registered patients, with fewer holders of community service cards and high user health cards than registered patients.[30] Maori diabetes patients and younger patients and patients who were asymptomatic when diagnosed are more likely to have no ongoing care.[319]

The three practices in Taumarunui do not come under one PHO umbrella. It is evident from the Waikato DHB’s Health Needs Analysis report[76] that there are PHOs who do not have any information available on their patients’ “Get Checked” utilisation.

Differences in PHO procedures may have an impact on “Get Checked” data entry and reporting, while variations in practice systems and patient recall procedures could affect the uptake of reviews.

In conclusion, the patients not found on the “Get Checked” database form a distinct subpopulation of diabetes patients, with different profile and needs from patients attending review. Studies using “Get Checked” database alone would be severely biased. It is necessary to utilise general practice diagnosis codes and the WRDS database to minimise this bias in a regional diabetes register.

4.7 Validity of the WRDS Database: Who is Not Represented?

4.7.1 Comparison with General Practice

Based on results from the general practice based summer studentship project estimating the prevalence of diabetes in Hamilton, the number of patients aged 60+ seem to be around 20% more than those registered with the WRDS.

Table 4-16. Comparison of the WRDS Database with the General Practice Register

Age Group	WRDS	GP	Difference as % of WRDS
0-9	11	3	-73%
10-19	39	21	-46%
20-29	54	28	-48%
30-39	106	75	-29%
40-49	209	141	-33%
50-59	300	258	-14%
60-69	260	310	19%
70-79	204	245	20%
80+	63	152	141%
	1246	1233	

GP: General practice

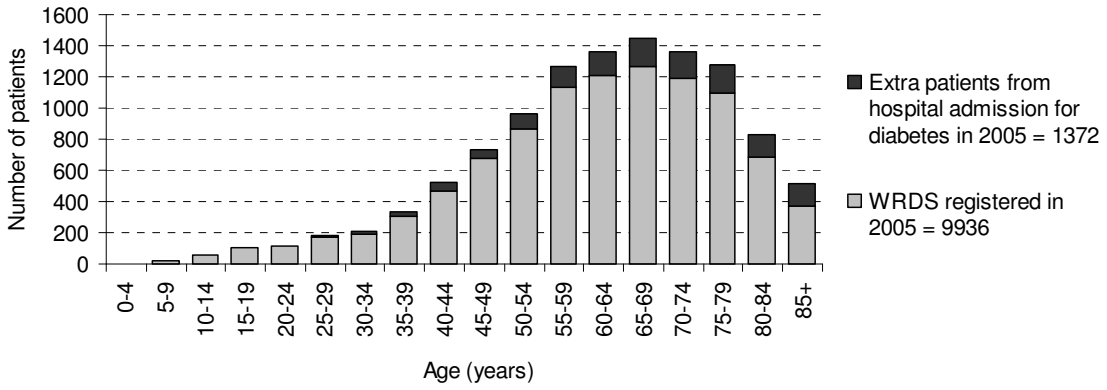
Patients with visual loss or known eye disease are not referred for retinal screening. This may explain the loss of older patients in the WRDS database. But the WRDS database is much better in capturing younger patients (Table 4-16). Recent changes to GP registration are not reflected here.

4.7.2 An Audit of Hospital Admissions

While looking at hospital admissions for the 9936 diabetes patients registered with the WRDS in 2005, hospital admissions for coded with diabetes among non-WRDS registered patients were also audited. There were 1372 patients who were not registered with the WRDS in the 2005, but were admitted to hospital with a primary diagnosis code of diabetes. They accounted for a total of 5055 hospital admissions for diabetes. 50% of admissions (231 patients) were due to Type 2 diabetes with ESRD. 18% of admissions (684 patients) were due to Type 2 diabetes without complication.

921 (67%) of them were from the Waikato DHB area. 404 (29%) patients were from outside of Waikato DHB area, including seven patients were overseas residents. Domicile could not be matched for 47 (3%) patients. 298 (32%) patients from the Waikato DHB area registered with the WRDS by 2008. The remaining 623 (68%) patients did not register with the WRDS until Jan 2008, although 58% of them survived beyond 2007. Since information on the year of diagnosis of diabetes is not available for these patients from hospital records, it is not clear what proportion represents previously undiagnosed diabetes. A high proportion of the extra diabetes patients identified were aged over 60 years (Figure 4-7).

Figure 4-7. Extra diabetes patients identified from Waikato DHB hospital admissions



4.7.3 Conclusion of this Section

The Hamilton study shows that a major limitation of the WRDS database is the time lag between the diagnosis of diabetes and referral to retinal screening, which could be 1-2 years. Hospital system audits point to another issue of hospital admission among non-WRDS database registered patients. Unpublished results from the Waikato diabetes education study[320] indicate that the majority of the newly diagnosed diabetes patients are asymptomatic and diagnosed through routine screening tests. So the extra diabetes patients found in hospital system audits are more likely to represent a sub-population of diabetes patients with severe diabetes and complications, but not needing retinal screening or other secondary diabetes care services. This could also include patients with late diagnosis of diabetes with complications. A proportion of patients with diabetes are diagnosed at the time of a major event like stroke, myocardial infarction or renal disease.[321] [322] It has been estimated that for every two European diabetes patients in New Zealand, there is one in the community with undiagnosed diabetes.[134]

Since access to secondary services in New Zealand is through GP referrals, and hospital diagnoses are communicated to GPs, a regional diabetes register linking

primary care PMS would be capable of minimising the bias of newly diagnosed, patients not needing retinal screening and patients first diagnosed in secondary care.

4.8 Discussion

An important goal in the MoH's Diabetes Strategy[121] adopted in 1997 was to establish information systems to collect data to enable identification of people with diabetes and to monitor the care provided. Guidelines for the set up of the "Get Checked" database as was outlined in Diabetes 2000[31], but necessary IT support was not provided.[38] In 2001, the New Zealand MoH prepared a five-year, broad, strategic directive for information and technology developments, referred to as The WAVE Report.[54] The report which was produced by means of collaboration among health sector participants, including system vendors, clinicians, government representatives and health care managers, calls for integration of health information systems. Subsequently, the New Zealand Health Information Strategy introduced in 2005 had its focus on making gains in linkages between primary and secondary care in the next 3-5 years, as well as improving the overall level of information sharing and collaboration across the sector.[323] An excellent example of such data linkage is the "Known Diabetes Project" undertaken in Counties Manukau DHB towards the end of 2007.[324] The project identified a "super set" of Counties Manukau DHB residents with diabetes from multiple databases, such as inpatients and outpatients, diabetes waitlist, diabetes referrals, diabetes chronic care management enrolees, "Get Checked" enrolees and retinal screening patients.

The pilot studies in this thesis have demonstrated that it is possible to successfully link existing data systems using NHI numbers in the Waikato. New Zealand has a significant national asset in the current NHI. Many of the developed nations have yet to achieve a single identifier with the level of coverage that has been obtained here or have yet to even develop an identifier system.[325]

The different studies linking existing databases to monitor diabetes care and outcomes have all also brought out several issues around data linkage into focus. While there are huge potential benefits in linking primary and secondary care systems to create a regional diabetes register, there are critical issues which need to be addressed before a complete and reliable register can become functional. A recent review of diabetes registries identified the following registry capabilities for successful implementation:[326]

- Identification of patients with diabetes
- Capture data elements electronically (avoiding extra work load on providers)
- Real-time availability ensuring completeness and accuracy of data
- Searchable (to identify subgroups of high risk patients)
- Web-based system linked to diabetes guidelines (for decision support)
- Feedback to providers to facilitate benchmarking and improve processes
- Generate patient letters to support clinical care.

Some of the key issues around linking records and their use are discussed in this section. Full implementation protocol is beyond the scope of this thesis.

Many of the barriers[327] found in the implementation of electronic health records in New Zealand may also hold true in the implementation of diabetes registers. Barriers to implementation of regional diabetes registers may include (but not limited to):

- Divergence among stakeholders
- Lack of consensus on priorities
- Lack of leadership
- Privacy and security issues
- Inadequate funding for implementation and ongoing support
- Governance of the register.

4.8.1 Issues Around Linking Records

Case ascertainment: identification of diagnosed diabetes patients

The foremost challenge is ascertaining the diagnosis of diabetes and identifying all diagnosed diabetes patients from existing medical records. The Hamilton prevalence study indicates that using GP diagnostic Read Codes for diabetes (sensitivity of 98.0% and a specificity of 99.9%) is one of the best approaches. The WRDS database alone identifies 86-90% of diabetes patients, but may not include newly diagnosed patients (as seen from the Hamilton prevalence study) due to the time lag between diagnosis of diabetes and first retinal screening. Unpublished results from the Waikato Diabetes Education Study[320] identified that 80% of new diagnoses are through routine blood tests ordered by GPs, not due to symptoms of diabetes. Although this indicates improved detection of diabetes, the profile and needs of these newly diagnosed patients are quite different from those who are first diagnosed with diabetes during a secondary service contact (example: hospital admission surgery, emergency department contact for cardiac event). It is important to distinguish between primary care and secondary care diagnosis for newly diagnosed patients.

Although current advice does not support the use of HbA_{1c} as a screening test for diabetes[50 328 329], its use as a potential screening tool has been under discussion[330 331], and there is anecdotal evidence of such use. The option of using HbA_{1c} for screening has already been recognised in the update [in press] of the 2003 guideline for assessment and management of cardiovascular risk.[50] So, identification of cases using HbA_{1c} tests would require further decision rules (for example at least three such tests in a year) or further verification using medical records. Anti-diabetes medications such as metformin may be used for prevention of diabetes[332-334] or even in people without diabetes.[335] As a result, identification of diabetes cases using prescription for diabetes medication could result in some misclassification.

Patients who are not registered with any general practice would form a distinct subset of diabetes patients[30], who are not represented in the "Get Checked" review (which is meant for practice registered patients). The use of GP Read Codes would help with the identification of these patients.

Hospital system audits indicate that some diabetes patients in more advance stages of complications may be using tertiary services alone. But they may not benefit from retinal screening and may not be represented on the WRDS database. Secondary service utilisation also includes patients from other parts of the country and overseas patients treated at Waikato DHB hospitals. When patients coded with diabetes are picked up through hospital system contacts without past history of retinal screening or "Get Checked" review, it is difficult to determine whether they are newly diagnosed without access to GP Read Codes.

Waikato DHB provides secondary services primarily to people living within the Waikato DHB area, but also to some patients living in the nearby regions. A small proportion of people from other parts of the country and overseas residents also access the service provisions. Patient addresses are coded using domicile codes in hospital systems and PHO systems. Domicile codes could be used to filter patients by DHB region. Some addresses (example P.O. Box and Private Bag addresses, c/o Marae addresses, some rural addresses, rest home names without street address) may not be readily coded.

The WRDS database linked with primary care (Get Checked database and GP Read Codes) and secondary care (hospital admissions) data sources could minimise the underestimation seen in cohort analyses using the WRDS database alone.

Variable definition: the example of ethnicity

Prioritised ethnicity reporting is commonly used in official reports health and census reports.[336] General practice systems follow this principle and use the prioritised ethnicity, but not without issues of accuracy.[60] The differing definitions of ethnicity pose a problem in comparing local estimates with national figures. Once the WRDS database is linked with other data systems, prioritised ethnicity would also be available.

Data agreement: the example of year of diagnosis diabetes

Diabetes complications worsen with longer duration of diabetes. Time since diagnosis of diabetes is an important covariate in analyses of outcomes among diabetes patients.[337] [338] Year of diagnosis of diabetes is a data item on the "Get Checked" database as well as the retinal screening register. But agreement between these two databases in the recorded year of diagnosis is very poor, as seen in the Taumarunui study. WPH was not confident enough about the quality of the year of diagnosis on the "Get Checked" database to use it in the retention analysis. The reliability of this variable is under question.

4.8.2 Issues Around Using the Regional Register for Surveillance and Research

Tracking patient migration

It is difficult to estimate the number of cases lost to follow up using existing records. Retinal screening records are updated only once in two years. For those not attending retinal screening, it is hard to distinguish between non-attendance due to migration from non-attendance due to choice. General Practice registrations are maintained by PHOs in the age/sex registers, which are updated on a quarterly basis. Unregistered patients may be receiving GP care, but are not reflected on the age/sex registers. Patient registrations become more complex when they are registered with multiple practices serviced by different PHOs. Tapping into pharmaceutical claims and claims

for laboratory investigation could help with tracking of patient migration, as shown by the estimation of diabetes and its impact using the reconstructed diabetes population for Counties Manukau DHB.[339]

Adjusting for under ascertainment: Capture-recapture method

Record linkage using multiple sources underestimates prevalence estimates of diabetes and would benefit from adjustment for under ascertainment using capture-recapture methods.[340] Capture-recapture methods[341] [342] are frequently used in epidemiology to estimate population prevalence by correcting for underestimation of cases.[294] [343] While calculation of capture-recapture estimates using two sources of data can be easily calculated, log linear modelling can be employed when more than two sources of data are involved.[290] Such models are capable of adjusting for dependency between data sources as well.

4.8.3 Privacy and Confidentiality Issues

Based on the legislative requirement set out in the Privacy Act 1993 and the Privacy Code[344], the Health Information Code of Practice[345] regulates agencies in New Zealand that use and disclose health information. The Privacy Act is based on the notion of careful consideration in collection, storage, use and disclosure of personal information and maximum transparency in this area. The obligation of openness in information collection can raise practical issues given time constraints around a typical general practice consult.[346] There is also a tension between the need to obtain informed consent for services provided and GPs' discretion to refuse to share their patients' information where they are unsure of how or where it is to be used, in the context of real or perceived obligations under the Code. Clinicians may also have ethical concerns about a lack of informed consent, leading them to veto the use of their patients' information in shared repositories even where such use might be legally

permissible.[346] Clinicians, health care agencies and individuals are likely to support data sharing willingly, once they have confidence in the privacy and ethical standards.

There is current focus on health information sharing and collaboration across the continuum of care, as expressed in the Health Information Strategy for New Zealand[323], and integrated care.[286] The Health Intranet security requirements[347] are an example of the practical implementation of the privacy code and the relevant legislation (Table 4-17).

Table 4-17. The Health Intranet security requirements

Principles	***Description***	***Health Intranet implementation***
Confidentiality	Assuring the message is not readable by unauthorised parties, whilst in transit	Strong data encryption using digital certificates and associated procedures and policies
Integrity	Knowing the message was not damaged or altered whilst in transit	The use of secure private networks and digital signatures
Authenticity	Assurance that the user is a trusted party by virtue of having been issued a digital certificate by an authorised certification authority	User ID/password and/or digital certificates
Non-repudiation	Providing assurance that the sender cannot claim the message is counterfeit or deny the fact that the message was sent or received	The use of secure private networks and digital signatures
Auditing	Recording of user connectivity and site access	Logging is undertaken at sites and by the network provider, and can be made available for audit
Accountability	Identification of clear responsibilities of organisations and individual users	Through compliance with legislation and the Health Intranet security policies

With policy support from the government, patient consent would be better handled by an “opt-off” process rather than an ”opt-on” process[286 348], although potential risks to provider-patient relationship, privacy breaches and discrimination fears would need to be addressed prior to implementation.[349]

CHAPTER 5 MONITORING DIABETES CARE AND OUTCOMES USING LINKED DATA

5.1 Prevalence of Diabetes, Social Deprivation and Quality of Care

5.1.1 Disparities in Prevalence of Diabetes and Quality of Diabetes Care

The three Hamilton practices that participated in the study had a total population of 36,321. Patients were 79% European, 10% Maori, 2% Pacific Islanders, 4% Asian, 3% Other and 2% Indian. 1235 diabetes patients were identified: 920 European, 149 Maori, 26 Pacific, 49 Asian, 67 Indian & 22 Other (Table 5-1).

Table 5-1. Diabetes patients identified in the Hamilton study by age group and ethnicity

Age	European	Maori	Pacific	Asian	Other	Indian	Total
<10	2	1	0	0	0	0	3
10-19	18	2	0	1	0	0	21
20-29	21	3	0	1	1	2	28
30-39	40	24	2	3	1	5	75
40-49	87	23	3	10	4	14	141
50-59	158	48	14	13	6	20	259
60-69	247	29	6	8	6	14	310
70-79	204	16	1	11	3	11	246
80+	145	3	0	2	1	1	152
Total	920	149	26	49	22	67	1235

Age and ethnicity specific prevalence of diabetes estimated from the Hamilton study are given below. Results show that prevalence rates vary widely across subgroups of age and ethnicity. In the 40-70 age groups, prevalence rates among all the non-European ethnic groups are two-seven times higher than that among Europeans. Of

particular note are high rates among Asians, who were previously thought to have a prevalence profile similar to that among Europeans, and Indians who have the highest rates among all (Table 5-2).

Table 5-2. General practice based prevalence of diabetes in Hamilton in 2007 by ethnicity, type of diabetes and age group

	Diabetes Type 2						Type 1
Age	European	Maori	Pacific	Asian	Indian	Total	Total
0-9	-	-	-	-	-	-	0.6
10-19	0.1	0.0	0.0	0.0	0.0	0.1	3.4
20-29	0.1	0.6	0.0	0.4	1.8	0.3	3.5
30-39	0.6	4.3	1.9	0.9	2.4	1.1	4.1
40-49	1.7	4.9	3.6	4.5	10.1	2.3	3.0
50-59	3.2	15.0	21.0	7.7	24.7	4.7	6.4
60-69	7.8	19.7	25.0	16.7	29.5	8.9	4.5
70-79	11.7	41.0	20.0	30.6	45.8	13.2	5.6
80+	14.8	15.8	0.0	20.0	33.3	14.7	1.0
Total*	1.9	7.8	6.5		12.8[@]	3.0	3.6

*Age standardised to 2006 NZ population.
[@]Indians included with Asians for age standardised prevalence. Denominator data was not available for separate estimation.
Prevalence rates are per 100 for Type 2 and per 1000 for Type 1.

The quality of diabetes care among patients categorised as having Type 2 diabetes in the Hamilton study was assessed. The proportion of patients with satisfactory glycaemic control as per government targets (i.e. $HbA_{1c} \leq 8\%$) and retinal screening rates; overall and within subgroups of age, gender, ethnicity and the years since diagnosis (Table 5-3) was looked at.

Table 5-3. Glycaemic control and retinal screening rates among patients with Type 2 diabetes in the Hamilton study

	n	HbA_{1c} recorded	$HbA_{1c} \leq 8\%$	Retinal screening recorded	Retinal screening in the last 2 yrs	
					All patients	Excluding newly diagnosed[†]
	1111	1012 (91.1%)	763 (75.4%)	967 (87.0%)	708 (63.7%)	65%
Ethnicity						
European	811	758 (93.5%)	604 (79.7%)	726 (89.5%)	547 (67.4%)	69%
Maori	141	123 (87.2%)	74 (60.2%)	112 (79.4%)	71 (50.4%)	54%
Asian	111	90 (81.1%)	62 (68.9%)	87 (78.4%)	61 (55.0%)	53%
Age (years)						
20-40	64	49 (76.6%)	33 (67.3%)	45 (70.3%)	31 (48.4%)	45%
40-60	356	316 (88.8%)	212 (67.1%)	301 (84.6%)	213 (59.8%)	61%
60+	691	647 (93.6%)	518 (80.1%)	621 (89.9%)	464 (67.1%)	69%
Gender						
Male	566	521 (92.0%)	369 (70.8%)	496 (87.6%)	369 (65.2%)	68%
Female	545	491 (90.1%)	394 (80.2%)	471 (86.4%)	339 (62.2%)	62%
Year diagnosed						
last 2 yrs	127	126 (99.2%)	99 (78.6%)	97 (76.4%)	67 (52.8%)	
last 3-5 yrs	272	270 (99.3%)	228 (84.4%)	249 (91.5%)	188 (69.1%)	69%
before 5 yrs	554	549 (99.1%)	385 (70.1%)	545 (98.4%)	389 (70.2%)	70%
missing	158	67 (42.4%)	51 (76.1%)	76 (48.1%)	64 (40.5%)	41%
Practice						
1	330	284 (86.1%)	218 (76.8%)	283 (85.8%)	165 (50.0%)	52%
2	467	444 (95.1%)	330 (74.3%)	424 (90.8%)	324 (69.4%)	70%
3	314	284 (90.4%)	215 (75.7%)	260 (82.8%)	219 (69.7%)	71%

[†] excluding those diagnosed in the last 2 years.

Odds ratios for unsatisfactory glycaemic control, adjusting for age, showed that patients of Maori ethnicity, male gender and those diagnosed more than five years before were at increased risk (Table 5-4). Adjusted odds ratios from a similar logistic regression model (excluding patients diagnosed in the last two years) suggested that patients of Maori or Asian ethnicity or female gender were more likely to have problems with access to retinal screening. Year of diagnosis was not a predictor for access to retinal screening and was dropped from the model.

Table 5-4. Adjusted odds ratios (95% C.I) for unsatisfactory glycaemic control and poor access to retinal screening in the Hamilton Study

	HbA_{1c}>8%	No retinal screening in the last two years†
Ethnicity		
Maori	1.78(1.33-2.39)*	1.31 (0.96-1.79)
Asian	1.53(1.33-1.76)*	1.20 (0.97-1.47)
Other	2.73(2.15-3.49)*	1.29 (0.92-1.81)
European	1	1
Gender		
Male	1.78(1.33-2.39)*	1
Female	1	1.31 (0.96-1.79)
Diagnosed		
Within last 5 years	1	-
Before 5 years	2.71(2.41-3.06)*	-

* $p<0.05$
† excluding those diagnosed in the last 2 years.

Discussion

The three practices involved in this study were larger than average, had a smaller proportion of Maori patients than is the norm for Hamilton City (Census 2001), but had a substantial number of patients of Asian origin. Indeed at the last census almost 10% of Hamilton City identified themselves as Asian. Thus, whilst acknowledging the special place of Maori as tangata whenua, it is also important to recognise the growing needs of Asian patients. Asian

people in New Zealand are not a single cultural entity, but made up of distinct communities, each with its own unique health needs.[12] The MoH has recognised the diversity that exits within the ”Asian” population by separating Chinese, Indian and ”Other Asian” ethnic groups in the Asian Health Chart book.[13] In particular the risks for South Asians has been identified because they have similar rates of diabetes to Maori and are prone to the increased risk of macrovascular disease.[14] The prevalence of diabetes in the Hamilton Asian population was similar to that found in Maori, although it is a heterogeneous group including Chinese, Indian and other ethnicities. In future, it would be better to identify South Asian patients separately from Asians of Chinese, Japanese, Korean and related ethnic background, as recommended by the MoH.

It should be acknowledged that there are problems with the completeness and accuracy of ethnicity recording within the health services in general.[47] [61] If the nationally instituted diabetes annual review is to report its outcomes for different ethnic groups then attention will be needed to the accuracy and completeness of ethnicity recording in general practice. Because of the nature of the practices and the Hamilton population structure, the results of this study may not be directly generalised to New Zealand as a whole. However, its advantages are that the sample size is greater than most other studies from which the prevalence of diabetes has been derived, like the New Zealand household survey. Age, gender and ethnic specific data allows comparisons with populations with different demographic characteristics.

The Hamilton study results suggested that there are disparities in access to retinal screening. i.e. Maori and Asian patients seemed less likely to access screening. The Waikato DHB has had a long standing and well organised retinal screening programme that was first piloted in the early nineties.[20] The programme recalls patients on a two yearly cycle (although sometimes this can stretch a little over the two years depending on the workload). It was noted in 2003 that Maori were less likely to be screened than NZ Europeans.[21] Results from

the “Get Checked” programme indicates that Maori and Pacific islanders are less likely to access retinal screening.[40] We know from this study that over 85% of patients had ever been screened, but in the last two years only 67% of NZ Europeans, 50% of Maori and 55% of Asian had attended for retinal screening. This suggests that there are continuing disparities for Maori and strategies are needed to try to address this if disparities in blindness due to diabetic eye disease are to be avoided for Maori and Asian patients.

Good practice management systems can ensure equal uptake of the “Get Checked” annual review but that more effort is needed in trying to ensure equitable management of glycaemic control and retinal screening – two of the government’s key targets. This is an interesting finding to all general practices in channelling their efforts to meet the demands of the “Get Checked” programme including the reporting of data for different ethnic groups. A regional diabetes register, linking primary care and secondary care data, would help to evaluate the coverage of the programme and characterise patients who are not using the free check.

5.1.2 Influence of Ethnicity and Social Deprivation on Prevalence of Diabetes

There were 45,500 patients registered with 10 general practices within the Rotorua General Practice group network. Patients were 61% European, 33% Maori, 3% Asian and 1.6% Pacific Islander. 49% were male and 41% were above 40 years of age. From the registered patients, 2027 were identified through record searches with some evidence of diabetes. 208 patients, identified from laboratory results or prescriptions could not be validated as having diabetes and were excluded from the study. Following validation, 1819 patients with previously diagnosed diabetes were included in the study (Table 5-5). All patients had gender and date of birth recorded. 13 (0.7%) had ethnicity recorded as “unknown”. Diabetes patients included 1055 (58%) Europeans, 635 (35%) Maori, 41 (2.3%) Pacific Islanders, 60 (3.3%) Asians and 15 (0.8%) other ethnicities. 1001 (55%) were male. 248 (14%) were in the least deprived NZDep2001 quintile 1 and 688 (38%) were in the most deprived quintile 5.

Table 5-5. Diabetes patients identified in the Rotorua study by age group and ethnicity

Diabetes	European	Maori	Pacific	Asian	Other	Not Known	Total
<10	7	2	0	0	0	0	9
10-<20	11	6	0	0	1	0	18
20-<30	20	20	1	2	0	0	43
30-<40	41	37	5	5	1	2	91
40-49	96	119	10	14	2	5	246
50-59	203	185	10	18	3	2	421
60-69	288	160	9	11	2	4	474
70-79	237	90	4	9	5	0	345
80+	152	16	2	1	1	0	172
Total	1055	635	41	60	15	13	1819

Prevalence of diabetes by age group varied widely across the ethnic groups (Table 5-6). In the 40+ age groups, Maori and Pacific people have around three times the prevalence compared with NZ Europeans. Asians have around twice the prevalence than Europeans in these age groups.

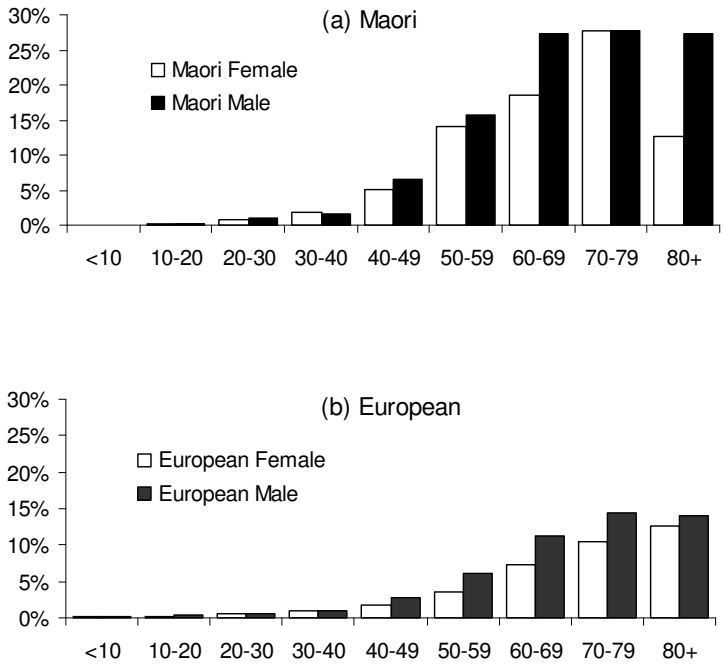
Table 5-6. Prevalence of diabetes (%) by age group and ethnicity in Rotorua

	European	Maori	Pacific	Asian
0-9	0.2%	0.1%	0.0%	0.0%
10-19	0.3%	0.2%	0.0%	0.0%
20-29	0.6%	0.9%	0.7%	0.8%
30-39	1.0%	1.8%	4.6%	1.8%
40-49	2.2%	5.8%	10.6%	5.9%
50-59	4.8%	14.9%	19.2%	13.3%
60-69	9.3%	22.6%	27.3%	19.3%
70-79	12.3%	27.8%	-	-
80+	13.1%	18.2%	-	-
Age standardised prevalence (95% C.I)	3.06% (3.06,3.06)	7.00% (6.99,7.01)	8.90% (8.87,8.93)	6.71% (6.69,6.73)

standardised to NZ national population 2006

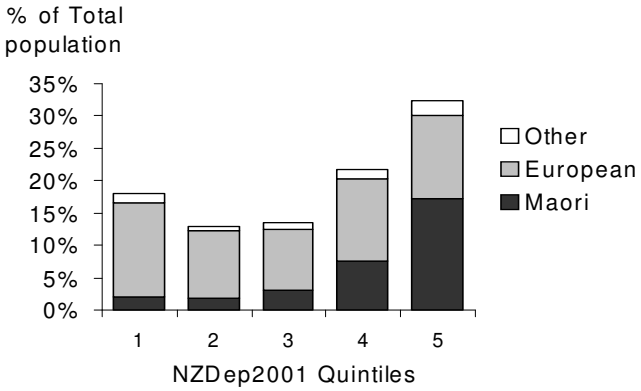
Prevalence rates were consistently higher for male than female among Maori and NZ Europeans (Figure 5-1).

Figure 5-1. Prevalence (%) of diabetes by 10 year age bands and gender among Maori (a) and European (b)



Age standardised prevalence of diabetes was significantly higher among males than among females [prevalence and 95% C.I: Maori female 6.32% (6.31-6.32), Maori male 7.87% (7.86-7.88), NZ European female 2.532% (2.530-2.535) and NZ European males 3.609% (3.606-3.612)]. The distribution in NZDep2001 quintiles 1-5 were 18% (least deprived), 13%, 13%, 22% and 32% (most deprived) respectively, with over-representation of Maori in the most deprived quintiles (Figure 5-2).

Figure 5-2. Ethnic composition of the study practice patients by NZDep2001 quintiles



With increasing deprivation, the age standardised prevalence of diabetes increased among European male (2.7% to 5.0%) and female (2.1% to 3.1%), (Table 5-7). However, the prevalence of diabetes was highest among least deprived Maori male (9.7%). Among Maori female, the prevalence of diabetes among the least deprived was higher (6.2%) than that for quintiles 2-4.

Table 5-7. Age standardised prevalence of diabetes (%) and 95% C.I across NZDep2001 deprivation quintiles, stratified by gender and ethnicity

NZDep2001	European		Maori	
Quintiles	Female (d=454/n=14887)	Male (d=585/n=14191)	Female (d=290/n=7720)	Male (d=312/n=7611)
1	2.12 (2.11,2.12)	2.72 (2.71,2.72)	6.21 (6.18,6.24)	9.75 (9.75,9.75)
2	2.41 (2.40,2.41)	3.25 (3.24,3.25)	4.27 (4.25,4.30)	6.29 (6.26,6.32)
3	2.08 (2.08,2.09)	3.25 (3.24,3.26)	4.46 (4.43,4.48)	6.61 (6.59,6.64)
4	2.88 (2.87,2.88)	4.13 (4.12,4.14)	5.89 (5.87,5.90)	8.15 (8.12,8.17)
5	3.11 (3.10,3.12)	4.95 (4.95,4.96)	7.21 (7.20,7.22)	7.87 (7.86,7.89)

d – number of diabetes patients. n – number of patients.

Table 5-8. Adjusted odds ratios (95% confidence intervals) for the risk for diabetes

	European	Maori
Male (vs. Female)	1.6 (1.36 , 1.8) *	1.3 (1.07 , 1.6) *
Quintile 5 (vs. 1)	1.7 (1.37 , 2.1) *	1.2 (0.79 , 1.7)
Quintile 5 (vs. 2)	1.7 (1.31 , 2.1) *	1.9 (1.23 , 3.1) *
Quintile 5 (vs. 3)	1.8 (1.40 , 2.2) *	1.6 (1.09 , 2.3) *
Quintile 5 (vs. 4)	1.2 (0.95 , 1.4)	1.2 (0.94 , 1.5)
Age	1.1 (1.06 , 1.1) *	1.1 (1.09 , 1.1) *

* Significant at 5% level.
Quintile 5=most deprived, Qintile1=least deprived
Adjusted for age, gender and NZDep2001 quintile.

After adjustment for age and gender, most deprived (quintile 5) Europeans have nearly twice the risk of having diabetes compared with Europeans in quintiles 1-3 (Table 5-8). The adjusted risk of diabetes for most deprived Maori is not significantly different from least deprived Maori. However, most deprived Maori have significantly higher risk of diabetes compared with Maori in quintiles 2 & 3.

Discussion

The Rotorua study has looked at the prevalence of diagnosed diabetes by ethnicity and socio-economic deprivation in a general practice population. The observed prevalence of diagnosed diabetes among Europeans and Maori in New Zealand are similar to official estimates derived from other sources.[28] The finding that diabetes prevalence rises with increasing deprivation among Europeans is similar to results from national[72 73] and international studies.[294 350 351] The trend among Maori seems to be different where the least deprived are equally at risk of diabetes. National survey results regarding the influence of social deprivation on diabetes prevalence have not been adjusted for the over-representation of Maori in quintiles 4 & 5. Using ethnicity specific analyses, this study has confirmed the association between social deprivation and prevalence of diabetes among Europeans. It has been shown that a similar trend does not hold true for Maori.

Although Rotorua has a high proportion of Maori, those living in Rotorua are similar to Maori living elsewhere in New Zealand, with respect to their levels of obesity, lifestyle and other risk factors for diabetes. It is reasonable to generalise the present findings to the nation's Maori population.

Age, obesity, sedentary lifestyle and smoking are the main risk factors in the progression from the pre-diabetes state to Type 2 diabetes.[160-162] Generally, the association between socio-economic status and diabetes has been attributed to the differences in risk factors, with the rates of obesity, poor diet, sedentary lifestyle and smoking being higher among people living in more deprived areas.[352 353]

Analysis of the 2002/03 Health Survey data, where deprivation quintiles 1 & 2 were merged to form the least deprived category, revealed that Maori males exhibit an inverse relationship between BMI and deprivation.[354] That is, least deprived Maori males tend to be heavier and of wider girth (median BMI 29.3 kg/m^2) than their less advantaged counterparts (median BMI 28.5 kg/m^2). Maori females by contrast show a direct relationship: increasing BMI/waist circumference with increasing deprivation. But even the least deprived Maori females had a median BMI of 25.6 kg/m^2. This trend is quite different from New Zealand's non-Maori population where the median BMI of the least deprived categories are much lower (25.7 for males and 23.9 for females) than the most deprived (26.3 for males and females). In this study, the impact of BMI on diabetes risk could not be assessed since it was not available for non-diabetes patients, but obesity might be important contributor to the differences seen between Maori and Europeans in New Zealand.

In developing countries like India [355], Bangladesh [356], China [357], Malaysia [358] and Africa [359], the prevalence of diabetes is lower among those with a low income than among more affluent groups. This trend is consistent with lower BMIs among low income groups in these countries. But developed countries experience higher rates of obesity and diabetes prevalence in more deprived areas. After adjustment for body size, the relationship between

socio-economic status and diabetes among indigenous Australians [73] and African Americans [360] is consistent with the patterns observed in Europeans.

Another postulated explanation for the finding that the least deprived Maori have a higher prevalence is that it is a detection issue. i.e. the least deprived are more likely to visit the doctor and therefore are more likely to be diagnosed. In the UK, undiagnosed diabetes is more prevalent among the poorest than the richest women.[306] Maori in general are less likely than Europeans to visit a doctor and are more likely to report an unmet need for a GP.[296 349] But it is not clear whether diabetes detection rates vary with social deprivation among Maori. There is evidence that the rates of doctor consultations increases with socio-economic deprivation among Maori and Europeans in New Zealand general practices.[332 333 360] So it is possible that diabetes detection is not compromised in the most deprived groups.

Higher proportions of Maori live in the most deprived geographical areas. In 2001, 39% of Maori lived in the most deprived quintile 5 areas (compared with 15% of non-Maori), while only 6% of Maori lived in the least deprived quintile 1 areas (compared with 16% of non-Maori). The modifiable risk factors (obesity, smoking and reduced physical activity) are more prevalent in populations of low socio-economic status.

There is strong evidence that the progression of Type 2 diabetes can be delayed or prevented with lifestyle programmes that promote a healthy diet and physical exercise. New Zealand Europeans will benefit from diabetes prevention programmes targeting socio-economically deprived groups. But for Maori, interventions should be tailor-made to include the least deprived groups as well. More research is needed into the role of obesity in the observed differences in diabetes prevalence across deprivation quintiles among Maori.

5.2 Access to Diabetes Care

5.2.1 Are Patients Coming Back for Review? Retention in the "Get Checked" Programme

A total of 10,919 patients were reviewed at least once during the five year period (Table 5-9). Ethnicity was recorded for 95% of patients, showing 69% Europeans, 18% Maori, 3% Pacific Islanders and 4% Asians. Of the reviewed patients 87% had Type 2 diabetes, 8% had Type 1 diabetes and 5% had other or unclassified diabetes.

Table 5-9. Patient characteristics at first "Get Checked" review by ethnicity

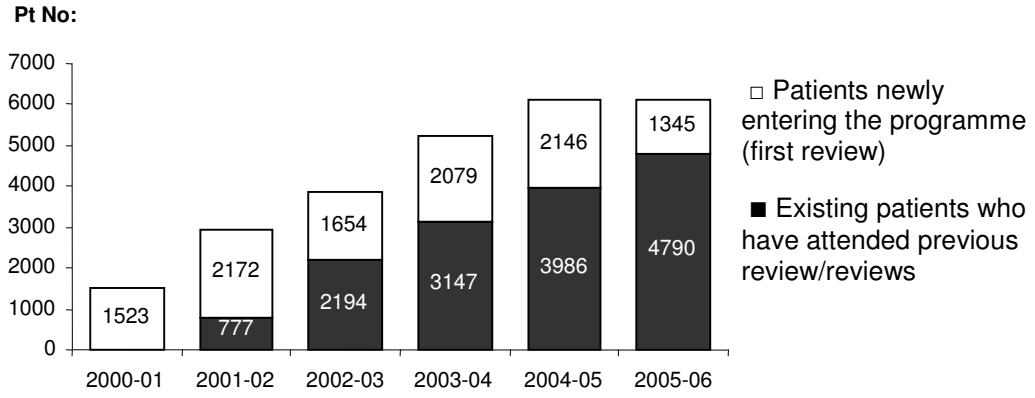
	European	Maori	Pacific Islander	Asian	Overall
Total of all years	7582 (69%)	1958 (18%)	309 (3%)	394 (4%)	10919 (100%)
Year of first review					
2000-01	1136 (75%)	244 (16%)	17 (1%)	53 (3%)	1523 (14%)
2001-02	1379 (63%)	364 (17%)	60 (3%)	49 (2%)	2172 (20%)
2002-03	1135 (69%)	281 (17%)	69 (4%)	56 (3%)	1654 (15%)
2003-04	1451 (70%)	390 (19%)	69 (3%)	84 (4%)	2079 (19%)
2004-05	1509 (70%)	431 (20%)	54 (3%)	94 (4%)	2146 (20%)
2005-06	972 (72%)	248 (18%)	40 (3%)	58 (4%)	1345 (12%)
Age at first review, years					
	65.1	55.8	56.0	55.4	62.6
	(64.8 - 65.4)	(55.2 - 56.4)	(54.6 -57.3)	(54.2 - 56.7)	(62.4 - 62.9)
Gender					
Male	3330 (44%)	814 (42%)	132 (43%)	157 (40%)	4761 (44%)
Female	3185 (42%)	876 (45%)	133 (43%)	160 (41%)	4651 (43%)
Diabetes Type					
Type 1	687 (9%)	106 (5%)	13 (4%)	22 (6%)	890 (8%)
Type 2	6549 (86%)	1752 (89%)	286 (93%)	353 (90%)	9547 (87%)

Data are N (%) or Mean (95% confidence interval).
Row wise percentages for the four ethnic groups are presented for each cohort.
Percentages may not add up to 100 because of missing data.

At first review, European patients were on average a decade older (65.1 ± 14.1) than other ethnic groups. In 2005/06, 6135 patients attended a review, including 933 (15%) Maori. Of these, 1345 were new patients, attending their first review.

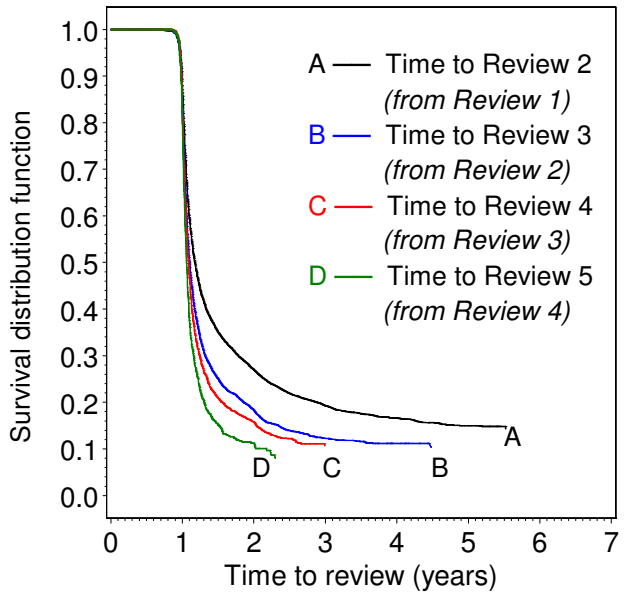
During each year of this study, between 1300-2100 patients attended their first "Get Checked" review (Figure 5-3). The proportion of newly diagnosed patients among those attending their first review is unclear.

Figure 5-3. Uptake of Patients in the "Get Checked" Programme from 2000/01-2005/06



Survival analysis shows that 7142 patients returned for a second review within a median time of 1.17 years after initial review (Figure 5-4, Table 5-10).

Figure 5-4. Kaplan-Meier Survival Curves for the Time to “Get Checked” Reviews (from the Previous Review, Conditional that Patients Attended the Previous Review)



The survival distribution function at a time represents the proportion of patients who have not returned for a review up to that time. At one and a half years after initial review (allowing a six month window to the ideal one year time frame), 35% of eligible patients were yet to return for a second review. At five years after the first review, 15% had not returned for a second review. Those who continued participating in the programme after second review returned for subsequent reviews on a much more regular basis. At one and a half years after second review 75% of eligible patients had returned for a third review. High proportions of patients (35%-46%) were censored for each review. The proportion of patients censored due to death and migration were relatively small (Table 5-10). Patients of Maori or Asian origin, younger patients and those with Type 1 diabetes took a significantly longer time to return for a second review.

Table 5-10. Censoring in the Analysis of Time to "Get Checked" Review

Analysis variable	Reviewed	Censored			Median time to review (inter quartile range)	Review rates at 1.5 years
		Total	Death	Migration		
Time to Review 2 (from Review 1*)	7140 / 10919	3779 (35%)	262 (2%)	736 (7%)	1.17 (1.0 , 2.1)	65.0%
Time to Review 3 (from Review 2*)	4183 / 7140	2957 (41%)	182 (2%)	281 (4%)	1.10 (1.0 , 1.5)	74.8%
Time to Review 4 (from Review 3*)	2352 / 4183	1831 (44%)	139 (3%)	110 (3%)	1.09 (1.0 , 1.3)	79.1%
Time to Review 5 (from Review 4*)	1070 / 2352	1282 (46%)	46 (2%)	29 (1%)	1.06 (1.0 , 1.2)	84.8%

* Conditional that patient attended this review.

Survival curves for time to second review were significantly different for subgroups of ethnicity, type of diabetes and age at first review (Figure 5-5 to Figure 5-7). No significant gender difference was found (Figure 5-8).

Figure 5-5. Kaplan-Meier Survival Curves for Time to Second Review (from Initial Review) by Ethnicity

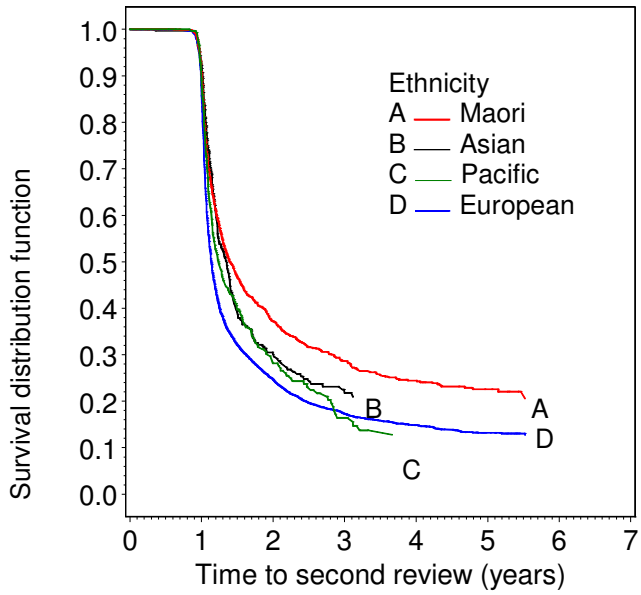


Figure 5-6. Kaplan-Meier Survival Curves for Time to Second Review (from Initial Review) by Age

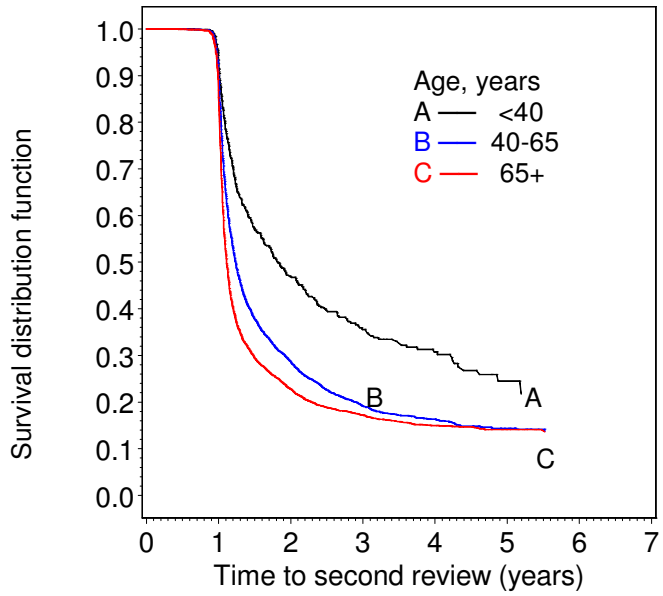


Figure 5-7. Kaplan-Meier Survival Curves for Time to Second Review (from Initial Review) by Type of Diabetes

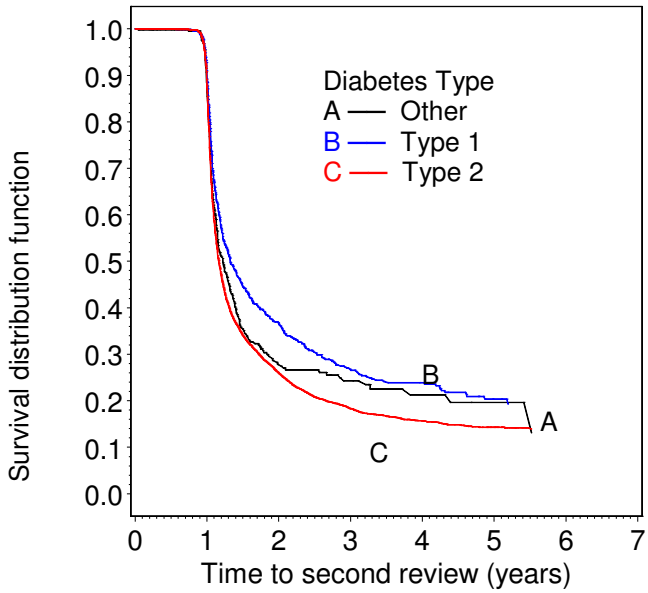
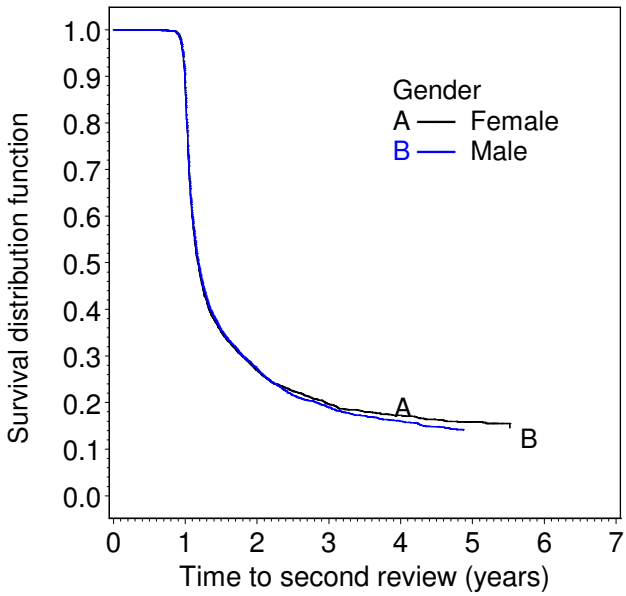


Figure 5-8. Kaplan-Meier Survival Curves for Time to Second Review (from Initial Review) by Gender



After co-variate adjustment for age, ethnicity and type of diabetes, younger patients aged<40 years were less likely to return for a second review compared with those aged 65+. Maori

and Asian patients were less likely to return for a second review compared with Europeans, and those with Type 1 diabetes were less likely to return for a review compared with Type 2 patients (Table 5-11, Table 5-12). Pacific ethnicity and gender were not found to be significant predictors of return for a second review.

Table 5-11. Hazard Ratios (95% Confidence Intervals) for a Second Review

	Univariate Hazard Ratio	Multivariate Hazard Ratio
Age, years (OR=1 for 65+ years)		
< 40 years	0.508 (0.45 , 0.57)	0.565 (0.50 , 0.64)
40-65 years	0.804 (0.76 , 0.85)	0.862 (0.82 , 0.91)
Ethnicity (OR=1 for Europeans)		
Maori	0.690 (0.65 , 0.74)	0.728 (0.68 , 0.78)
Asian	0.739 (0.65 , 0.85)	0.786 (0.69 , 0.90)
Diabetes Type (OR=1 for Type 2)		
Type 1	0.729 (0.66 , 0.80)	0.868 (0.81 , 0.93)

Hazard ratios from Cox's Proportional Hazards Model.
The multivariate model included age group (<40, 40-65, 65+), ethnicity (European, Maori and Asian), and type of diabetes (Type 1 and Type 2).
Gender and Pacific ethnicity were found to be non-significant predictors in the multivariate analysis and were excluded from the final model.

Table 5-12. Hazard Ratios (95% Confidence Intervals) for Subsequent Reviews, Following the Initial Review

	Univariate Hazard Ratio	Multivariate Hazard Ratio *
Age, years (1=65+)		
< 40 years	0.48 (0.44 , 0.52)	0.535 (0.49 , 0.59)
40-65 years	0.766 (0.74 , 0.79)	0.815 (0.79 , 0.84)
Ethnicity (1=Europeans)		
Maori	0.696 (0.66 , 0.73)	0.747 (0.71 , 0.79)
Pacific Islanders	0.836 (0.76 , 0.92)	0.896 (0.81 , 0.99)
Asian	0.719 (0.65 , 0.79)	0.778 (0.71 , 0.86)
Diabetes Type (1=Type 2)		
Type 1	0.787 (0.74 , 0.84)	0.868 (0.81 , 0.93)
Other	0.894 (0.81 , 0.99)	0.902 (0.82 , 1.00)

Hazard ratios from Stratified Cox's Proportional Hazards Model (Conditional model 2) for recurrent events, assuming that time until the second review does not influence the risk set for a third or later reviews.
* Covariates include age, ethnicity and type of diabetes.

Discussion

Disparities are not limited to uptake of the "Get Checked" programme, but also extend to retention of patients who enter the programme. The WRDS database had 9936 patients registered in year 2005, with 2006 (21%) patients being Maori.[109] WPH estimated that in 2005/06 there should be 10,600 patients with known diabetes within the organisation network. Yet in 2005/06 only 6135 WPH patients turned up for a free diabetes check, of which 933 (15%) were Maori. Data from the "Get Checked" programme is underestimating the number of people with diabetes in the region.

It is likely that there are some differences between the total population of people diagnosed with diabetes in Waikato and those who attended "Get Checked" review in any one year. Between 1300-2100 new patients were recruited into the "Get Checked" programme each year between 2000 and 2006. These patients coming for their first check in any one year include:

1. newly diagnosed diabetes patients,
2. existing diabetes patients who have been diagnosed for some time but new to the programme and,
3. existing diabetes patients who recently moved in to the Waikato region and are newly registered with a WPH practice.

The incidence of Type 1 diabetes had been increasing in many countries and the prevalence is higher among Europeans. Overall, the number of new Type 1 diabetes patients diagnosed each year is small and will only make a small contribution to the total number. Incidence of Type 2 diabetes is variable and may be influenced by screening. For instance between 2003-2005, Te Wai o Rona Diabetes Prevention Strategy identified 262 new cases of Type 2 diabetes among Maori. This might explain the increase in new reviews among Maori in these years and the subsequent reduction in numbers in 2005/06. The WRDS estimates that there are 800-1000 new cases of diabetes in the Waikato each year. Consequently, a significant

proportion of new patients in the “Get Checked” programme are likely to be in categories 2 & 3 (as defined above). Although the cohort of 10,919 patients is not typical of diabetes patients registered with WPH, this study is looking at what happens to patients after their first “Get Checked” review. WPH was not confident about the quality of the data on year of diagnosis of diabetes data collected as part of the “Get Checked” programme. Consequently, this information was not released for analysis. So the proportion of newly diagnosed diabetes patients is unclear.

Despite this programme being free to patients, a significant proportion of patients did not return for a second review within 1.5 years after initial review. The profile of patients who were retained in the programme with regular reviews was quite different from the irregular attendees and those who dropped out. Younger patients aged <40 years, those of Maori or Asian origin and those with Type 1 diabetes were less likely to be retained in the programme with regular checks, as indicated by the longer time to second review and lesser likelihood of returning for a second review. In the UK, predictors of attendance for review in general practice were: older age, less co-morbidity and being of European ancestory.[19] A South Auckland study in the early nineties showed that patients who defaulted from diabetes care were younger, diagnosed at a younger age, more likely to be in paid employment, knew less about diabetes and were less likely to require medication.[20] Out-of-pocket expenses also impede diabetes self-care in New Zealand.[19 206]

Maori, Pacific and Asian people have considerably higher rates of diagnosed diabetes compared with European people (European/Other 2.9%, Maori 8%, Pacific 10.1%, Asian 8.4%).[73] They also have an earlier onset of Type 2 diabetes and higher rates of diabetes complications.[23] Overall, the finding that Maori and Asians were less likely to attend a second review is a concern and it indicates these diabetes patients still have problems with access to appropriate health care. In order to minimise this inequality, remedial measures are needed to increase the uptake of this free review among ethnic minorities.

The findings regarding irregular reviews among younger patients were interesting but not unexpected. Older patients are known to be adherent with medications. So their adherence with diabetes follow up care is not surprising. Younger Type 1 patients with complications may be visiting the WRDS regularly and may not deem it necessary to go to their GP for a separate annual check. In 2005, there were 1338 (13%) Type 1 patients registered with the WRDS[109], but only 890 (8%) of the patients who had had a "Get Checked" review had Type 1 diabetes. Of the patients reviewed in 2005-06, 405 had Type 1 diabetes. Thus these patients may in fact be receiving good follow up care, although the results from this study indicate that these patients may have difficulty accessing their health services. However, a high proportion of younger patients are likely to be in the workforce and patients in paid employment are known to be less likely to access care.[319] They are also more mobile and could be getting treated elsewhere (perhaps managed by the WRDS) but still registered with WPH.

It was outside the scope of the retention study to track continued participation of patients who migrated and changed to a different PHO, after completing their initial "Get Checked" review with WPH. A national diabetes register will be needed to make cross regional comparisons. Migrations were censored in the survival analysis and were not a major issue. Unavailability of data concerning year of diagnosis of diabetes is another major limitation. It would have been of considerable interest as the participation rates of those newly diagnosed with diabetes may differ from that of others. Similarly, data concerning geographical location of residence was not available. Physical access to care including transportation has been identified as a barrier to care in a previous study.[205]

The "Get Checked" programme provides a beneficial service for many people with diabetes, but use of these data for policy purposes could be significantly biased. The longitudinal analysis reveals concerns regarding retention rates in the "Get Checked" programme, especially for Maori and patients with Type 1 diabetes. Further research aimed at

understanding the lower retention rates for these groups may help to improve health outcome disparities.

5.2.2 Patient Perceived Barriers to Diabetes Care

303 diabetes patients were identified as eligible in March 2005, 243 (80%) returned the barriers survey. Patients were aged 65 ±12 years, 45% male, 61% European and 31% Maori, 78% community services card users (low income financial support card). 17% were diagnosed since 2002. 91% were registered with the WRDS database. 62% had attended a free “Get Checked” annual diabetes review since 2001 (35% in 2004/2005).

99% of patients reported at least one barrier. There was a median of four barriers per patient. The maximum number of barriers was 22. Patients of Maori ethnicity, male gender or younger age reported significantly higher number of barriers (Table 5-13). Psychological barrier group was the most frequently reported in all subgroups of ethnicity, duration of diabetes, gender, insulin treatment and age.

Table 5-13. Type of Barriers Reported and Comparison of the Number of Barriers

	Number of Patients	% of patients reporting at least one barrier in the following groups						Total no: of barriers	
		Any Barrier	PS	P	E	IP	EP	Median [Q1-Q3]	p-value
Overall	243	99	77	96	44	48	78	4 [3 - 7]	
Ethnicity									
European	148	97	73	93	43	44	73	4 [2 - 6]	0.0089*
Maori	88	100	85	99	43	55	85	5 [4 - 7]	
Duration of diabetes									
<5	60	100	75	95	50	40	83	5 [3 - 7]	
5-<10	68	99	78	97	46	49	81	5 [3 - 7]	0.3765
10+	107	98	77	95	37	53	72	4 [3 - 6]	
Gender									
Male	109	98	78	95	53	53	80	5 [4 - 7]	0.0166*
Female	134	99	75	96	36	43	77	4 [3 - 6]	
Insulin Treatment									
Yes	31	100	77	97	32	58	81	5 [3 - 6]	0.4148
No	211	99	76	96	45	46	78	4 [3 - 7]	
Age									
<40	5	100	80	100	40	60	100	5 [4 - 6]	
40-49	15	100	80	100	47	33	93	7 [4 - 10]	
50-59	49	100	84	98	51	55	90	6 [4 - 8]	0.0032*
60-69	77	99	79	94	45	48	82	4 [3 - 6]	
70-79	69	97	68	94	39	49	70	4 [2 - 6]	
80+	28	100	75	100	36	36	57	3 [3 - 5]	

PS: Psycho-Social, P: Psychological, E: Educational, IP: Internal Physical, EP: External Physical.
* p-value from Kruskal Wallis test < 0.05

Table 5-14 shows the frequency of each barrier overall and by ethnicity. Psychological (no symptoms cue and priority setting), psycho-social (poor public awareness), external physical (personal finance) and internal physical (other health conditions) barriers prevent patients from taking care of their diabetes. The most common barriers were the lack of a symptom cue in diabetes and personal finance. The five most frequently reported barriers are the same for Maori and Europeans. Maori are significantly more likely to report “priority setting” and “public health belief” as barriers to diabetes care. No other significant ethnic differences were found. Access to care was not commonly reported as a barrier in this study (16% Europeans, 13% Maori). After covariate adjustments, Maori were 2.8 (5.1-1.5) more likely to report having diabetes as a low priority and 2.9 (5.8-1.5) fold more likely to report “public health belief” (not having their health care paid for) as barriers to care. After adjusting for age, diabetes duration, gender and ethnicity, males were 2.4 (1.4-4.4) more likely to report low diabetes knowledge and 2.4 (1.2-4.6) more likely to report “public health belief” as barriers.

Table 5-14. Most Frequently Reported Barriers to Diabetes Care

Barriers ranked by frequency of reporting	All Patients N=243	Europeans N=148	Maori N=88
1. No Symptoms Cue	201 (86.3%)	119 (85.0%)	74 (88.1%)
2. Personal Finance	173 (77.2%)	97 (72.9%)	69 (83.1%)
3. Lack of Public Awareness	165 (69.9%)	94 (66.7%)	69 (80.2%)
4. Priority Setting *	141 (58.0%)	73 (49.7%)	62 (71.3%)
5. Self Factors-Other Health Conditions	112 (48.9%)	62 (45.3%)	47 (56.6%)
6. Appropriateness of Venue of Services	77 (33.8%)	39 (27.9%)	33 (41.3%)
7. Public Health Belief *	61 (28.2%)	27 (20.9%)	31 (39.2%)
8. Low Diabetes Knowledge	78 (33.1%)	50 (35.5%)	27 (31.4%)
9. Low Knowledge of Services	70 (29.2%)	42 (29.2%)	24 (27.6%)
10. Service-Physical Access to Care	36 (15.3%)	23 (16.1%)	11 (13.1%)
11. Lack of Family Support	34 (14.5%)	21 (15.0%)	13 (15.3%)
12. Unsupportive Macro-environment	28 (12.1%)	15 (10.9%)	13 (15.3%)
13. Emotional	33 (13.7%)	22 (15.1%)	11 (12.8%)
14. Communication	28 (12.1%)	15 (10.7%)	12 (14.3%)
15. Not enough time	25 (11.0%)	16 (11.7%)	9 (10.8%)
16. Physical Effects of Treatment	21 (9.5%)	15 (11.6%)	6 (7.2%)
17. Lack of Community Based Service	24 (10.4%)	15 (10.8%)	7 (8.5%)
18. Unsatisfactory Diabetes Care/Education	20 (8.7%)	12 (8.6%)	8 (9.8%)
19. Self-Efficacy	22 (9.4%)	15 (10.5%)	7 (8.5%)
20. Organisation of Service	19 (8.4%)	12 (8.9%)	6 (7.4%)
21. Unhelpful Health Professionals	15 (6.4%)	8 (5.6%)	7 (8.3%)
22. Family Demand	18 (7.4%)	11 (7.5%)	7 (8.0%)
23. Group Pressure	15 (6.3%)	9 (6.3%)	6 (7.0%)
24. Services-Inappropriate Culturally	10 (4.3%)	4 (2.9%)	6 (7.1%)
25. Prejudice	11 (4.6%)	8 (5.6%)	3 (3.4%)
26. Willingness to Take Responsibility	10 (4.3%)	3 (2.2%)	5 (5.9%)
27. Self-Motivation	1 (0.4%)	0 (0%)	1 (1.2%)

* Significant difference between Europeans and Maori. p-value from Chi-square test < 0.05

Discussion

The Taumarunui study shows that almost all patients have barriers to diabetes care. The ranking of barriers were comparable between Maori and non-Maori, except in priority setting

(giving priority to others things over own health care) and public health belief (the belief that public should bear more responsibility). This is consistent with earlier findings[205] using open qualitative questions based on the same barrier frame work, which found that the top 10 barriers to diabetes care were also similar between ethnic groups in spite of major differences in culture and socio-economic status. Barriers were different, perhaps reflecting the different era and different area. In the barriers study in Waikato,[205] the most important barriers were belief that benefits of self-care were outweighed by their disadvantages, lack of community based services and a limited range of services. In 2001, a report by PricewaterhouseCoopers[26] in New Zealand summarised the main barriers as personal cost of items required to manage diabetes, lack of skilled services in many regions, lack of strategic workforce planning for workforce and language barriers. Financial barriers are still important for patients, but access to care and language barriers were not common in this community, which could be either a geographical or temporal phenomenon. Personal finance and other health conditions are common barriers for all patients but they may have an increased impact on Maori due their higher risk of complications and over-representation amongst socio-economically disadvantaged groups.[361] The Waikato barriers survey in 2004, using open questions on the same barrier frame work, found that psychological barriers were most important to diabetes patients.[206] Taumarunui study has not only confirmed this, but showed that psychological barriers rank highly for all subgroups of ethnicity, age, gender, duration of diabetes and insulin treatment.

Diabetes-related distress and psycho-social problems appear to be common among diabetes patients worldwide and are associated with worse outcomes.[362-364] Results from the DAWN study showed that patients with fewer socio-economic resources and more diabetes complications had lower access (and/or higher barriers) to care and a lower quality of patient-provider collaboration.[365] While there have been many different interventions trialled to address psychological barriers, to date these remain of limited use.[366]

The Taumarunui study has several strengths including the population based approach, the high response rate to the barriers survey and the heterogeneity of the sample. The barriers tool used is based upon a well validated framework now used across three countries and many different ethnic groups. The major weakness is that the provision of a closed list of barriers (rather than the usual open questions used[205]) could minimise the number of barriers identified and does not allow them to be prioritised by patients. This contrasts with the open tool[206] which provides richer responses, but only captures those barriers thought about at the time of the interview. This study using a closed questionnaire shows similar results to previously reported studies using open qualitative questions on the same barrier framework. The closed questionnaire is a simple tool which does not require substantial resources for classifying and coding the open responses, as in the case of open barriers to care questions. Intervention for psychological barriers is needed, especially among Maori who are more likely to report them.

5.3 Diabetes Complications and Mortality

5.3.1 Progression of Renal Disease

7900 adult diabetes patients registered with the WRDS database, diagnosed before 2003 and free of renal complications prior to 2003, were identified and retrospectively followed up for up to three years. The cohort included 69% NZ Europeans and 1664 (21%) Maori (Table 5-15). Duration of diabetes was similar for both NZ Europeans and Maori but Maori were on average seven years younger. Maori patients were more likely to have Type 2 diabetes (95% vs. 84% among NZ Europeans). During follow up, 116 (1.5%) patients had a renal admission, 42 (0.5%) started dialysis/transplant and 21 (0.27%) patients died due to renal disease. Eight more new dialysis/transplant patients with diabetes primary renal disease, residing in the Waikato region, were identified from the ANZDATA register. Since they were not registered with the WRDS, patient records were manually searched for the year of

diagnosis of diabetes. All of them were diagnosed after 2003 and were excluded from the analysis.

Table 5-15. Characteristics of diabetes patients at start of follow up

	European	Maori	Total
N	5476	1664	7900
Age	62 ± 15	55 ± 12	60 ± 14
Duration of diabetes	9 ± 9	9 ± 8	9 ± 8
<10 years	65%	67%	66%
≥ 10 years	35%	33%	34%
Male	2853 (52%)	799 (48%)	4062 (51%)
Type 2	4609 (84%)	1586 (95%)	6906 (87%)
Type 1	862 (16%)	77 (4.6%)	988 (12.5%)

The crude incidence of ESRD in this cohort with established diabetes was 1.37 per 1000 patient years. Rates of all three renal events increases with increasing age and duration of diabetes. Maori diabetes patients with both Type 1 and Type 2 diabetes have significantly higher incidence of dialysis or transplant, rates of renal admission and renal death (Table 5-16 to Table 5-22). Crude incidence for dialysis/transplant among Type 1 Maori (17.3 per 1000 person years) is eleven-fold higher than that among Europeans (Table 5-20). Although incidence rates for dialysis/transplant among Type 2 Maori is much lower (4.57 per 1000 person years), it is 41 times higher than that among Europeans (Table 5-19).

Table 5-16. Incidence of renal events by among Maori and European diabetes patients

	European	Maori	Total
Renal admission	46 (0.84)	64 (3.85%)	116 (1.47%)
Rate / 1000 person-years	2.2 (1.6,2.9)	10.1 (7.9,12.8)	3.8 (3.2,4.6)
Dialysis or transplantation	7 (0.13%)	33 (1.98%)	42 (0.53%)
Rate / 1000 person-years	0.33 (0.16,0.69)	5.14	1.37 (1.02,1.86)
Deaths from renal disease	12 (0.22%)	7 (0.42%)	21 (0.27%)
Rate / 1000 person-years	0.75 (0.4,1.3)	1.43 (0.7,2.99)	0.9 (0.6,1.4)

Primary diagnosis codes for renal admissions included E1023, E1123, I120, I130, N179, N1891, Z490 and Z491.
Causes of death from renal disease included E1023, E1121, E1122, E1123 and E1423.

Table 5-17. Renal admission among European and Maori with Type 2 diabetes

	European	Maori	Total
Type 2	30 (0.65%)	57 (3.59%)	91 (1.32%)
Age (years)			
<40	1 (0.88%)	3 (1.91%)	4 (1.18%)
40-59	5 (0.39%)	28 (3.28%)	36 (1.44%)
60-79	23 (0.82%)	26 (4.64%)	50 (1.38%)
80+	1 (0.24%)	-	1 (0.23%)
Duration of diabetes			
10+ years	14 (1.11%)	32 (6.69%)	47 (2.48%)
<10 years	15 (0.46%)	23 (2.24%)	41 (0.85%)
Gender			
Female	10 (0.46%)	25 (3.04%)	37 (1.11%)
Male	20 (0.83%)	32 (4.19%)	54 (1.52%)
Rate / 1000 person-years	1.69 (1.2, 2.4)	9.4 (7.2,12.2)	3.4 (2.8,4.2)

Table 5-18. Renal admission among European and Maori with Type 1 diabetes

	European	Maori	Total
Type 1	16 (1.9%)	7 (9.1%)	25 (2.5%)
Age (years)			
<40	3 (0.86%)	1 (2.33%)	4 (0.98%)
40-59	6 (1.87%)	2 (9.52%)	8 (2.20%)
60-79	7 (3.87%)	4 (30.8%)	12 (5.88%)
80+	-		1 (7.14%)
Duration of diabetes			
10+ years	15 (2.42%)	5 (11.1%)	22 (3.19%)
<10 years	-	2 (6.25%)	2 (0.73%)
Gender			
Female	6 (1.42%)	2 (4.76%)	10 (2.05%)
Male	10 (2.28%)	5 (14.3%)	15 (2.99%)
Rate / 1000 person-years	4.8 (2.9,7.8)	24.6 (11.8,51.7)	6.5 (4.4,9.7)

Table 5-19. Dialysis or transplantation among European and Maori with Type 2 diabetes

	European	Maori	Total
Type 2	2 (0.04%)	28 (1.8%)	32 (0.46%)
Age (years)			
<40			
40-59	1 (0.08%)	16 (1.88%)	19 (0.76%)
60-79	1 (0.04%)	12 (2.14%)	13 (0.36%)
80+			
Duration of diabetes			
10+ years	1 (0.08%)	16 (3.35%)	18 (0.95%)
<10 years	1 (0.03%)	10 (0.97%)	12 (0.25%)
Gender			
Female	2 (0.09%)	11 (1.34%)	14 (0.42%)
Male	-	17 (2.23%)	18 (0.51%)
Rate / 1000 person-years	0.11 (0.05,0.45)	4.57 (3.2.,6,6)	1.2 (0.85,1.7)
Age-adjusted rate (age 40+)	0.11 (0.03,0.45)	4.39 (2.9, 6.5)	-

Table 5-20. Dialysis or transplantation among European and Maori with Type 1 diabetes

	European	Maori	Total
Type 1	5 (0.58%)	5 (6.49%)	10 (1.01%)
Age (years)			
<40	1 (0.29%)	1 (2.33%)	2 (0.49%)
40-59	4 (1.25%)	2 (9.52%)	6 (1.65%)
60-79		2 (15.4%)	2 (0.98%)
80+			
Duration of diabetes			
10+ years	5 (0.81%)	5 (11.1%)	10 (1.45%)
<10 years	-	-	-
Gender			
Female	-	2 (4.76%)	2 (0.41%)
Male	5 (1.14%)	3 (8.57%)	8 (1.60%)
Rate / 1000 person-years	1.5 (0.6,3.6)	17.3 (7.2, 41.5)	2.6 (1.4,4.8)
Age-adjusted rate	1.27 (0.5, 3.3)	19.35 (8.5, 44.3)	-

Table 5-21. Deaths from renal disease among European and Maori with Type 2 diabetes

	European	Maori	Total
Type 2	10 (0.22%)	4 (0.25%)	16 (0.23%)
Age (years)			
<40	1 (0.64%)	1 (0.30%)	-
40-59	1 (0.12%)	4 (0.16%)	1 (0.08%)
60-79	2 (0.36%)	9 (0.25%)	7 (0.25%)
80+		2 (0.45%)	2 (0.49%)
Duration of diabetes			
10+ years	4 (0.84%)	9 (0.47%)	4 (0.32%)
<10 years	-	7 (0.15%)	6 (0.19%)
Gender			
Female	3 (0.36%)	8 (0.24%)	4 (0.18%)
Male	1 (0.13%)	8 (0.22%)	6 (0.25%)
Rate / 1000 person-years	0.74 (0.4,1.4)	0.86 (0.3,2.3)	0.79 (0.48,1.29)
Age-adjusted rate (age 40+)	0.45 (0.2,1.0)	0.92 (0.3, 2.5)	-

Table 5-22. Deaths from renal disease among European and Maori with Type 1 diabetes

	European	Maori	Total
Type 1	2 (0.23%)	3 (3.9%)	5 (0.5%)
Age (years)			
<40	-	-	-
40-59	2 (9.52%)	2 (0.55%)	-
60-79	1 (7.69%)	3 (1.47%)	2 (1.10%)
80+	-	-	-
Duration of diabetes			
10+ years	2 (4.44%)	4 (0.58%)	2 (0.32%)
<10 years	1 (3.13%)	1 (0.37%)	-
Gender			
Female	2 (4.76%)	3 (0.62%)	1 (0.24%)
Male	1 (2.86%)	2 (0.40%)	1 (0.23%)
Rate / 1000 person-years	0.79 (0.2,3.1)	13.2 (4.2,40.8)	1.7 (0.7,4.1)
Age-adjusted rate	0.61 (0.1, 2.9)	9.21 (2.4, 35.6)	-

Adjusted hazard ratios confirm this finding (Table 5-23), with 46 times the risk of dialysis or transplant for Maori Type 2 diabetes patients. Maori diabetes patients in general (Type 1 and Type 2) have increased risk of renal admission (7 times), dialysis/transplant (25 times) and renal death (4 times).

Table 5-23. Hazard ratios (95% C.I) for renal events from Cox's proportional hazard model

	Renal admission	Dialysis/Transplant	Death due to renal
All patients			
Age (in years)	1.0 (1.0 , 1.0)*	1.0 (1.0 , 1.0)	1.1 (1.0 , 1.1)*
Type 1 (vs. Type 2)	4.2 (2.5 , 7.1)*	6.7 (3.0 , 15.0)*	7.1 (2.4 , 21.2)*
Male (vs. Female)	1.6 (1.1 , 2.4)*	1.8 (0.9 , 3.4)	0.9 (0.4 , 2.3)
Maori (vs. European)	7.0 (4.6 , 10.6)*	25.2 (10.7 , 59.7)*	4.1 (1.5 , 11.4)*
Type 2 diabetes patients			
Age (in years)	1.01 (1.0, 1.04)*	1.01 (0.98, 1.04)	1.07 (1.01 ,1.12)*
Male (vs. Female)	1.5 (0.99, 2.35)	1.4 (0.7, 2.9)	1.03 (0.36, 2.9)
Maori (vs. European)	6.7 (4.2, 10.8)*	46.4 (10.7, 201)*	2.1 (0.6, 7.4)

Variables are mutually adjusted

Of the 21 patients who died due to renal disease, only one patient had a previous renal admission and two patients were on the ANZDATA register. 18 were neither in the ANZDATA register nor picked up through renal admissions. They included 12 (67%) Europeans, 5 (28%) Maori and 1 (6%) Pacific Islander. Nine of these deaths occurred at hospitals, four at rest homes and five at a private residence.

Maori diabetes patients progress much faster than Europeans in all renal events (Figure 5-9 to Figure 5-11). Among the 116 patients with renal admission, 42 (36%) progressed to dialysis/transplant during follow up. The progression from first renal admission to dialysis or transplant was significantly faster among Maori (Figure 5-12).

Figure 5-9. Age and gender adjusted survival curves for renal admission among European and Maori patients

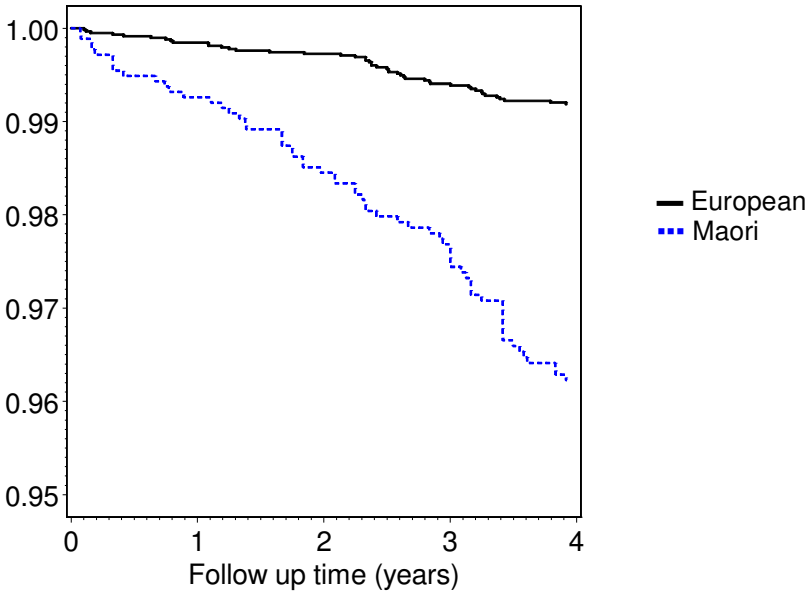


Figure 5-10. Age and gender adjusted survival curves for dialysis or transplantation among European and Maori patients

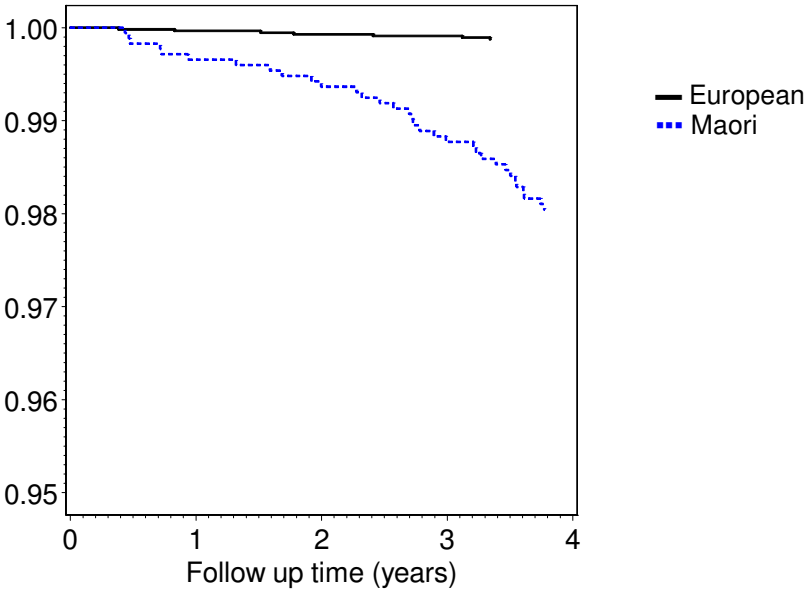


Figure 5-11. Age and gender adjusted survival curves for deaths from renal disease among European and Maori patients

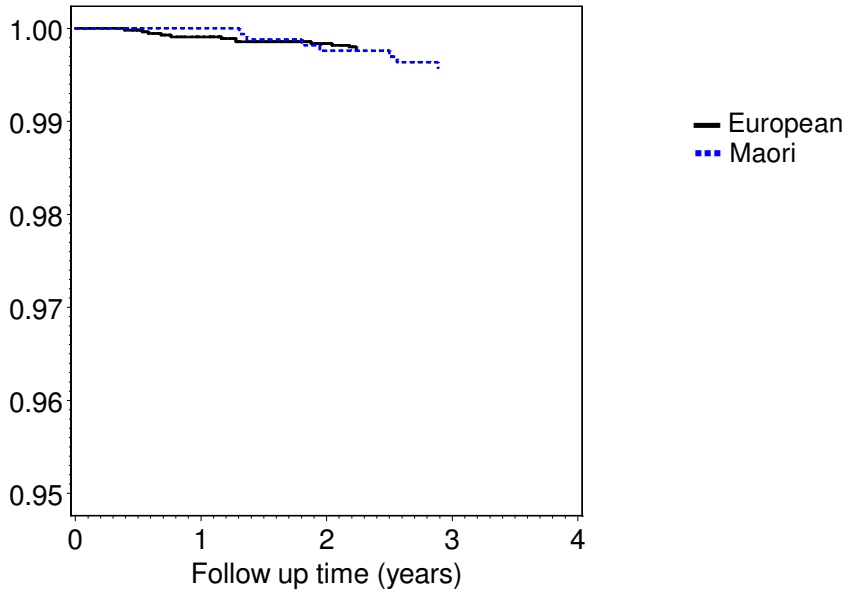
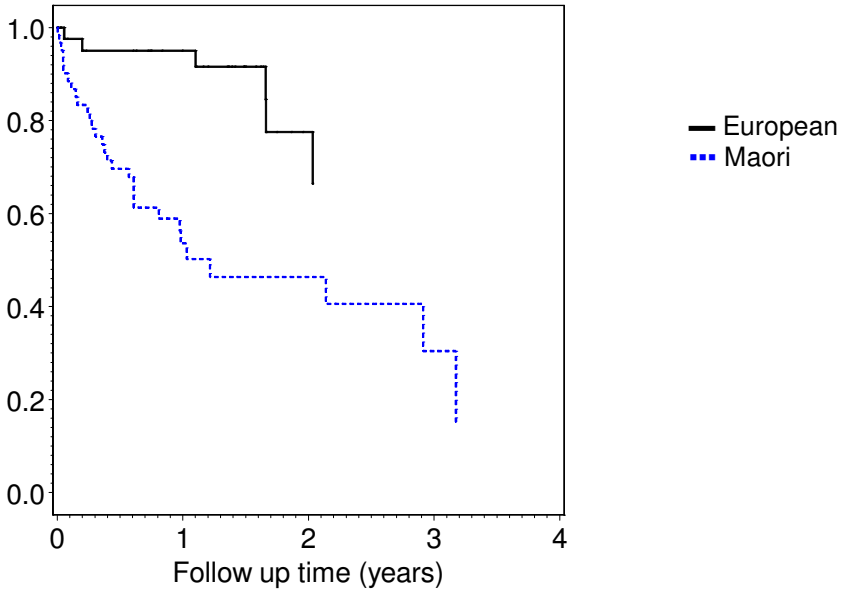


Figure 5-12. Age and gender adjusted survival curves for dialysis or transplantation from first renal admission among European and Maori patients



Discussion

The study of progression of renal disease shows that ESRD is a relatively rare disease in NZ Europeans but the risk is much greater in Maori. Findings are similar to those in other indigenous populations. Early-onset Type 2 diabetes mellitus is associated with substantially increased incidence of ESRD and mortality in middle age among Pima Indians.[367] Native Americans, Hispanics & African-Americans in the US [367] and Indian-Asians [369] have much higher risks of developing ESRD than Europid populations with Type 2 diabetes. Present results confirm that indigenous Maori in New Zealand share this profile.

While population incidence rates for ESRD among Maori exceed non-Maori rates by four-fold (200 vs. 50 per million)[210], the present study results indicate that incidence rates for Maori with diabetes exceed Europeans with diabetes by 15 times (5.14 vs. 0.33 per 1000 person years). Among people with diabetes, Maori are up to 46 times more likely to have renal failure, much higher than the current official estimate of three-and-a-half times.[306]

Maori have a familial predisposition to nephropathy[368] and high rates of hypertensive ESRD.[369] Thompson et al [368] found that a family history of ESRD among both diabetic and non-diabetic subjects was associated with an increased mean albumin-creatinine ratio compared with diabetic and non-diabetic subjects without a family history of ESRD. An increased albumin-creatinine ratio was independently associated with systolic blood pressure, hyperglycaemia, a family history of renal failure, female gender, and total cholesterol, but not with a family history of diabetes. Although undiagnosed diabetes may not be major problem among Maori, family history of renal disease and albuminuria at diagnosis of diabetes probably fuels the progression to renal failure.[148] Evidence suggests that progression to kidney failure in patients with diabetes can be delayed or prevented by controlling blood sugar levels & blood pressure and by treating proteinuria.[370-372] Poorer glycaemic control, higher obesity and smoking rates may also be responsible for the increased progression rate among Maori. Maori and Pacific people with Type 2 diabetes who

attended the diabetes annual review in 2004 received similar high rates of appropriate CVD and renal preventive drug therapy to Europeans, but their prevalence of smoking, obesity, raised HbA_{1c} and albuminuria were substantially higher.[39] But general practitioners have expressed concerns over Maori compliance with prescribed medications.[207] This could be just the tip of the iceberg, given the low diabetes annual review attendance rates for Maori.[172] It was not possible to estimate the impact of these risk factors in the present study since they are not collected as part of routine retinal screening data collection.

Studies of health service use suggest sub-optimal Maori access to health care in general, poorer adherence with medication and a range of other barriers to diabetes care. These may account for some of the observed disparities, but these are true in cardiovascular disease as well, where the disparities in outcome are much less. Indigenous people are less likely to receive a renal transplant prior to dialysis and there is anecdotal evidence of lower uptake of dialysis among Maori. The large disparity in recording of ESRD may actually be an under-representation of the need.

Since this is a retrospective study, the changes in kidney function and the contribution of potential aetiological factors could not be assessed due to missing data, particularly in those patients who did not develop renal disease. Maximum data capture was ensured by using a number of data sources including the ANZDATA registry, the NZHIS mortality data and the Waikato DHB hospital discharge data. The NZHIS mortality data captures all deaths that are registered within New Zealand including deaths outside of hospitals, except deaths overseas. Our methodology is relatively complete for those patients with ESRD as Waikato is the only provider of renal service in the region and patients are not funded to go out of the area. The NZHIS audits indicate a concordance between clinical notes and discharge codes of over 90%. Hospital admissions may have been underestimated since data were not available for private hospitals and hospitals outside of Waikato DHB region. So there may be some under-recording of earlier stages of renal disease. This analysis is limited to the cohort of diabetes

patients attending retinal screening. Although a small proportion (10-14%), those who are not part of the retinal screening register include newly diagnosed patients and patients with more advanced diabetes complications who may not benefit from retinal screening. The latter subgroup may result in some underestimation of ESRD and renal death. Although Waikato has a high proportion of Maori, it is reasonable to generalise the present findings to the nation's Maori population in general.

Although observed renal hospital admission rates among Type 1 and Type 2 European diabetes patients in this study (1.9% and 0.65% respectively for 2003-2006) are similar to previously reported rates (1.2% and 0.4% for 2000-2002) from the predominantly European Southlink Health diabetes register[190], we have demonstrated that there are huge disparities in renal admission for Maori diabetes patients (3.6% and 9.1% for Type 1 and Type 2 respectively for 2003-2006). The disparities for Maori in mortality due to renal disease observed in the South Auckland [77] study in the early nineties still hold true after a decade, although this difference was less than the difference in incidence of ESRD.

Faster progression from first hospital admission for chronic renal disease to dialysis/transplant among Maori may be due to faster progression of renal disease among Maori or renal complication diagnosed at a more advanced stage among Maori or due to possible differences in the treatment of chronic renal disease. The free annual "Get Checked" diabetes review programme in New Zealand serves as a screening tool measuring albumin:creatinine ratio, but serum creatinine or eGFR are not part of the minimum dataset requirement.[38] Over 69% of New Zealand laboratories report eGFR results with most requests for serum creatinine in adult patients [302], but ethnic specific validation studies are needed to fine tune its use as a screening tool. [373]

The burden of chronic renal disease has been demonstrated using a population based sample. The costs to the health system are considerable.[374] However the greater cost is to Maori with the substantially increased mortality and morbidity. The challenge lies in reducing

these disparities in outcomes through early identification and intensive management of patients at risk. Those with a family history of renal disease, a reduced estimated GFR, microalbuminuria, hypertension or those with poor glycaemic control are all at increased risk and need early intervention. The disparities in outcomes for Maori may be in part due to the increased prevalence of these risk factors, or due to differences in treatment uptake. More aggressive systematic screening for chronic kidney disease among Maori diabetes patients is urgently required. This will need to be backed by intensive management of risk factors and interventions to improve treatment uptake and compliance in order to improve the outcomes.

5.3.2 Prevalence of Chronic Kidney Disease and the Implications of Using eGFR for Screening

Of the 1819 (3.74%) diabetes patients identified, 1353 (74%) had a "Get Checked" review in the last two years. 342 (19%) patients did not attend a review. 124 (6.8%) were newly diagnosed (36 Maori, 74 NZ European, 14 Others). 1796 were aged 18 or above. All patients had ethnicity and gender recorded. High level of data completeness was observed except in the case of year of diagnosis of diabetes (Table 5-24). Glomerular filtration rate could be estimated using both MDRD and CG equations for 942 adult patients aged 18+, who had serum creatinine, body weight and height data available from "Get Checked" records. Clinical and demographic characteristics of these patients are summarised in Table 5-25. Compared with Europeans, Maori patients were on average 5.9 years younger ($p<0.0001$), had higher BMI (+3.1 kg/m^2, $p<0.0001$), significantly higher rates of microalbuminuria/proteinuria (51% versus 28% among Europeans, $p<0.0001$) and higher HbA_{1c} levels (42% with HbA_{1c} >8% versus 30% among Europeans, $p<0.0002$). The extent of Statin and ACE therapy among Maori patients was similar to that in Europeans, but their prevalence of smoking was substantially higher (26% versus 12% among Europeans, $p<0.0001$).

Table 5-24. Completeness of data in the subgroup of patients who had attended a "Get Checked" review in the Rotorua study

Measurement Variable	***Number of patients (%) with non-missing data***
Year of diagnosis of diabetes	707 (52%)
Type of diabetes	1241 (92%)
HBA_{1c}	1352 (99.9%)
Serum creatinine	1267 (94%)
Total cholesterol	1336 (99%)
HDL cholesterol	1317 (97%)
LDL cholesterol	1264 (93%)
Systolic blood pressure	1345 (99%)
Diastolic blood pressure	1345 (99%)
Height	1083 (80%)
Weight	1081 (80%)
Smoking status	1353 (100%)

Data extracted from "Get Checked" review of patient files.

Table 5-25. Demographic and clinical characteristics of diabetes patients by ethnicity and gender in the Rotorua study

	European Female	European Male	Maori Female	Maori Male
	244	331	172	195
Age (years)	66.1 ± 0.9	64.5 ± 0.7	58.5 ± 1.0	59.9 ± 0.8
Duration of Diabetes (years)	9.4 ± 0.6	8.3 ± 0.4	9.1 ± 0.7	9.1 ± 0.7
BMI (kg/m^2)	30.4 ± 0.5	30.0 ± 0.3	33.4 ± 0.6	33.2 ± 0.4
HbA_{1c} (%)	7.5 ± 0.1	7.5 ± 0.1	8.5 ± 0.2	8.0 ± 0.1
> 8 %	73 (29.9%)	98 (29.6%)	77 (44.8%)	76 (39.0%)
High Blood Pressure (sBP>130/dBP>85)	190 (77.9%)	227 (68.8%)	126 (73.7%)	143 (73.7%)
Current Smoking	31 (12.7%)	36 (10.9%)	51 (29.7%)	45 (23.1%)
Statin Treated	151 (61.9%)	226 (68.3%)	103 (59.9%)	124 (63.6%)
ACE Treated	139 (57.0%)	180 (54.4%)	119 (69.2%)	133 (68.2%)
Serum Creatinine (mmol/l)*	70 (62, 82.5)	90 (78, 103)	71 (62, 90)	88 (76, 101)
Albumin creatinine ratio (ACR)*	1.3 (0.5,3.4)	0.9 (0.4,3.7)	2.4 (0.9, 12)	4.2 (1.1, 21.1)
Microalbuminuria	44 (18.9%)	75 (24.1%)	44 (28.4%)	71 (39.0%)
Proteinuria	14 (6.0%)	18 (5.8%)	23 (14.8%)	35 (19.2%)

Data are n (%) or mean ± sd. * Serum Creatinine and ACR are reported as median (inter quartile range).

Overall prevalence of CKD (Stage 3, 4 and 5)[375] among diabetes patients as identified through eGFR<60 ml/min/1.73m^2 was 19.5% using the MDRD equation and 23.5% using the the CG equation. Prevalence of CKD among Europeans was 18.8% using the MDRD equation, 25.9% using CG equation and that among Maori was 20.4% using the MDRD equation, 19.1% using CG equation. The prevalence of eGFR <30 ml/min/1.73m^2 (CKD Stages 4 and 5) among European and Maori was 2% & 3% respectively using the MDRD equation, 3% using the CG equation.

There are significant differences in the agreement between the MDRD and the CG equations in identifying patients with eGFR <60 ml/min/1.73m^2 for Maori females, European females and European males (Table 5-26). While the CG equation identifies more European of both genders, more Maori females are identified by MDRD.

Table 5-26. Agreement between MDRD and CG equations in identifying patients with eGFR<60 ml/min/1.73m^2

	n	MDRD	CG	Diff (%)	Kappa	p-value
European Male	331	59 (17.8%)	85 (25.7%)	-7.9% (-11.5, -4.2)	0.65 (0.55, 0.75)	<0.0000
European Female	244	49 (20.1%)	64 (26.2%)	-6.1% (-10.6, -1.7)	0.64 (0.53, 0.76)	0.0107
Maori Male	195	30 (15.4%)	35 (17.9%)	-2.6% (-6.4, 1.3)	0.72 (0.59, 0.86)	0.3018
Maori female	172	45 (26.2%)	35 (20.3%)	+5.8% (1.1, 10.6)	0.71 (0.58, 0.83)	0.0309

Statin and ACE prescriptions among CKD patients were higher in the presence of microalbuminuria/proteinuria (71% vs. 57%, p=0.02 and 79% vs. 61%, p=0.001 respectively). CKD patients with normal ACR levels had better control of HbA_{1c} (80% with HbA_{1c}<8% vs. 66%, p=0.01) and blood pressure (34% with BP<130/80 vs. 20%, p=0.01) compared with CKD patients with microalbuminuria/proteinuria (Table 5-27).

Table 5-27. Differences in management of diabetes patients with evidence of CKD compared with diabetes patients with normal renal function

	Number (%)	% with HbA_{1c} < 8%	% with BP < 130/80	% Prescribed Statin	% Prescribed ACE
eGFR < 60 & Micoalb/Proteinuria	128 (13.7%)	66%	20%	71%	79%
eGFR < 60 & no Micoalb/Proteinuria	125 (13.8%)	80%	34%	57%	61%
eGFR ≥ 60 & Micoalb/Proteinuria	218 (23.3%)	50%	22%	68%	75%
Normal renal function	463 (49.6%)	70%	31%	62%	49%
Total	934	66%	28%	64%	61%

After adjustment for age, gender and BMI, Maori diabetes patients were significantly more likely to have clinically significant CKD compared with Europeans [odds ratio 1.8 (1.2, 2.8) using MDRD equation]. Similar results were yielded using the CG equation.

Discussion

Given the higher rates of renal complications among Maori, robust screening tools are needed to identify complications at an early stage. The Rotorua study has identified gaps in systematic screening for chronic kidney disease using eGFR. Automatic reporting of MDRD eGFR serves as a useful screening tool for kidney disease, although clinicians should recalculate it using the patient's actual body surface area for patients with extreme body size.[301] The MDRD equation has a correction factor for black ethnicity. Given the high obesity rates, a similar correction factor may be required for Maori and other high risk ethnic

minorities. Australasian Creatinine Consensus Working Group's recommends that laboratories continue to automatically report eGFR (MDRD) in Aboriginal and Torres Strait Islander peoples and other ethnic groups, pending publication of ethnic specific validation studies.[373]

The MDRD equations were derived from patients with varying degrees of renal impairment employing a stepwise regression technique, where GFR was measured from the renal clearance of [^{125}I] iothalamate.[300] On the other hand, Cockcroft-Gault formula was constructed from hospitalised patients to predict creatinine clearance from the serum creatinine in the absence of urine collection.[303] It has been shown that MDRD equation consistently underestimates GFR, whereas the CG equation consistently overestimates GFR in people without kidney disease.[376] In contrast, a New Zealand study with predominantly Europeans subjects found that the MDRD formula produced a statistically significant overestimation of GFR and the CG prediction equation gave a statistically significant underestimation of GFR.[377] But there was no significant difference in performance in estimating GFR between the two prediction equations. A validation study in patients with ESRD showed that the MDRD equation is more accurate than the Cockcroft-Gault formula in predicting the group mean.[378] However, the predicted GFR using either formula was related to the basal GFR and percentage body fat. MDRD is said to be preferable to the CG method in patients with diabetes.[379] However, our results indicate that while the CG equation will identify more European diabetes patients at risk of CKD, it seems to miss some Maori women with diabetes.

The National Kidney Foundation in the US[380] and the National Service Framework for Renal Services in the UK[381] have recommended routine eGFR reporting. It has been endorsed by several other counties including New Zealand, Australia, Canada.[373 382] A recent review has shown the increasing use of eGFR in America, Europe, Asia and Australia, in population based studies which look at the prevalence of CKD.[383] Automatic reporting of eGFR, which

constitutes *de facto* screening for chronic kidney disease is of concern[384], given that and the validity of eGFR for this purpose has not been appropriately tested.[385 386]

More research is needed to develop a modified equation with a correction factor for Maori and similar high risk ethnicities. It appears that a generic approach will be unsuccessful in considering the validity of the eGFR in ethnic subpopulations. Each such subpopulation may need to be validated separately, and by gender.

5.3.3 Hospital Admissions Among Diabetes Patients Registered with the WRDS Database

A total of 9936 patients (including 796 patients diagnosed in 2005) were registered with the WRDS database in 2005 (Table 5-28). The population mean age was 61years ± 15.9 and mean duration of diabetes 9.6 ± 8.5 years. 86% had Type 2 diabetes and 51% were male. Ethnic groups identified included European (67%), Maori (20%), Indian (2.6%), Pacific Islander (2.3%) and Other Asian (1.6%).

WRDS registered diabetes patients had a total of 6275 admissions in 2005 including 3287 day admissions. This resulted in 20,637 inpatient days in 2005 (Table 5-29).

Table 5-28. Profile of patients registered with the WRDS in 2005

All Patients	***European***	***Maori***	***Pacific***	***Indian***	***Asian***
N	6696	2006	228	255	162
Age	63.2 ± 16.6	56.0 ± 13.6	56.5 ± 12.7	57.0 ± 12.3	55.7 ± 13.5
Duration of Diabetes	10.0 ± 8.9	9.2 ± 8.0	7.1 ± 6.2	8.8 ± 7.7	7.6 ± 6.7
Age at diagnosis	53.1 ± 18.8	46.8 ± 14.0	49.4 ± 12.8	48.2 ± 12.3	48.2 ± 13.2
Type 1					
N	1143	111	5	15	18
Age	43.0 ± 19.4	39.1 ± 18.1	41.0 ± 24.0	52.1 ± 20.7	43.4 ± 17.6
Duration of Diabetes	18.5 ± 12.0	14.4 ± 10.1	14.2 ± 11.3	20.4 ± 13.5	12.3 ± 8.3
Age at diagnosis	24.5 ± 16.8	24.7 ± 14.2	26.8 ± 21.5	31.7 ± 15.7	31.2 ± 15.0
Type 2					
N	5553	1895	223	240	144
Age	67.3 ± 12.4	57.0 ± 12.6	56.8 ± 12.2	57.3 ± 11.6	57.3 ± 12.1
Duration of Diabetes	8.3 ± 6.9	8.9 ± 7.7	6.9 ± 6.0	8.1 ± 6.6	7.0 ± 6.3
Age at diagnosis	59.0 ± 12.9	48.1 ± 12.8	49.9 ± 12.1	49.3 ± 11.3	50.3 ± 11.3

Table 5-29. Hospital admissions among the WRDS registered patients in 2005

	All Admissions	No: of Patients	% Patients	Inpatient days	Day Admissions
Overall	6275	2296	2296 (23%)	20637	3287
Duration of Diabetes					
<2	265	182	182 (23%)	1628	69
2-<5	985	524	524 (21%)	4121	376
5-<10	1393	615	615 (21%)	5110	598
10+	3632	975	975 (26%)	9778	2244
Gender					
Female	2957	1158	1158 (24%)	9824	1460
Male	3318	1138	1138 (22%)	10813	1827
Type of Diabetes					
Type 1	1049	286	286 (21%)	2610	661
Type 2	5226	2010	2010 (23%)	18027	2626
Age as in 2005					
0-15	78	33	33 (35%)	118	49
16-24	91	51	51 (25%)	542	17
25-44	532	188	188 (16%)	2272	309
45-64	2289	686	686 (18%)	4998	1416
>65	3285	1338	1338 (29%)	12707	1496
Ethnicity					
Asian	33	22	22 (14%)	100	12
European	3518	1610	1610 (24%)	14416	1499
Indian	67	42	42 (16%)	227	28
NZ Maori	2366	524	524 (26%)	4649	1567
Not	195	40	40 (11%)	833	150
Other	41	26	26 (11%)	114	14
P Islands	55	32	32 (14%)	298	17

Table 5-30. Hospital admissions in 2005 for diabetes related complications

	Renal Admissions	No: of Renal Patients	CAD Admissions	No: of CAD Patients	CVD Admissions	No: of CVD Patients
Overall	1704	74 (1%)	281	210 (2%)	101	89 (1%)
Duration of Diabetes						
<2	1	1 (0.1%)	11	10 (1%)	7	6 (1%)
2-<5	16	3 (0.1%)	55	41 (2%)	25	22 (1%)
5-<10	147	10 (0.3%)	78	58 (2%)	19	17 (1%)
10+	1540	60 (1.6%)	137	101 (3%)	50	44 (1%)
Gender						
F	668	34 (1%)	128	87 (2%)	48	44 (1%)
M	1036	40 (1%)	153	123 (2%)	53	45 (1%)
Type of Diabetes						
Type 1	421	20 (1%)	22	16 (1%)	5	5 (0%)
Type 2	1283	54 (1%)	259	194 (2%)	96	84 (1%)
Age as in 2005						
25-44	186	8 (1%)	7	5 (0%)	1	1 (0%)
45-64	974	38 (1%)	86	62 (2%)	24	21 (1%)
>65	544	28 (1%)	188	143 (3%)	76	67 (1%)
Ethnicity						
Asian	0	0 (0%)	1	1 (1%)	1	1 (1%)
European	295	25 (0%)	204	151 (2%)	80	71 (1%)
Indian	0	0 (0%)	5	3 (1%)	0	0 (0%)
NZ Maori	1284	47 (2%)	56	43 (2%)	19	16 (1%)
P Islands	0	0 (0%)	1	1 (0%)	0	0 (0%)

CAD: Coronary artery disease, CVD: Cerebrovascular disease

Renal admissions have a major role to play in the secondary service utilisation among diabetes patients (Table 5-29 to Table 5-31). Logistic regression analysis shows that Maori patients and those with Type 1 diabetes have significantly greater risk of admission whilst Asian and Pacific people are less likely to be admitted to hospital (Table 5-32). Maori patients have significantly high renal admission risk (odds ratio of 9) compared with Europeans. But they do not have an increased risk for coronary artery disease admissions or

cerebrovascular disease admissions. Type 1 diabetes patients are at high risk for renal admissions. Male patients are at higher risk of cardiovascular disease admissions. After co-variate adjustment, Maori, Pacific and Indian patients have significantly higher risk of vision threatening retinopathy compared with Europeans (Table 5-33). Type 1 patients and male patients are also at high risk for retinopathy.

Table 5-31. Non-day admissions and median length of stay (LOS)

	All admissions		Renal Admissions		CVD Admissions		CAD Admissions	
	No: of Pts (%)	Median LOS (Q3-Q1)	No: of Pts (%)	Median LOS (Q3-Q1)	No: of Pts (%)	Median LOS Q3-Q1)	No: of Pts (%)	Median LOS (Q3-Q1)
Total	1664 (16.7%)	6 (2 - 13)	56 (0.6%)	5 (3 - 11)	83 (0.8%)	5 (3 - 8)	194 (2.0%)	5 (3 - 10)
European	1141 (17.0%)	6 (3 - 13)	23 (0.3%)	4 (2 - 14)	66 (1.0%)	4 (2 - 8)	140 (2.1%)	5 (3 - 8)
Maori	409 (20.4%)	5 (2 - 13)	32 (1.6%)	6 (3 - 10)	15 (0.7%)	6 (3 - 8)	39 (1.9%)	6 (4 - 13)

CAD: Coronary artery disease, CVD: Cerebrovascular disease

Table 5-32. Odds ratios (95% C.I) for hospital admissions in 2005

	All Admissions	Renal[@]	CVD[@]	CAD[@]
Female vs. Male(=1)	1.06 (0.96 - 1.16)	0.76 (0.47 - 1.21)	0.92 (0.60 - 1.40)	0.73 (0.55 - 0.98)*
Type 1 vs. Type 2(=1)	1.23 (1.03 - 1.48)*	2.25 (1.08 - 4.70)*	0.71 (0.25 - 1.99)	0.76 (0.41 - 1.41)
Maori vs. European(=1)	1.34 (1.18 - 1.51)*	9.64 (5.55 - 16.76)*	1.11 (0.62 - 1.99)	1.29 (0.89 - 1.86)
Pacific vs. European(=1)	0.62 (0.42 - 0.91)*			
Asian vs. European(=1)	0.59 (0.38 - 0.93)*			
Indian vs. European(=1)	0.73 (0.52 - 1.03)			

CAD: Coronary artery disease, CVD: Cerebrovascular disease.
Adjusted for age, duration of diabetes, gender, ethnicity and type of diabetes.
[@]Analysis includes European and Maori patients only. * $p<0.05$

Table 5-33. Odds ratios (95% C.I) for retinopathy finding during retinal screening among the WRDS registered patients

	Retinopathy	Vision Threatening Retinopathy
Maori vs. European(=1)	1.52 (1.28 - 1.80)*	1.53 (1.13 - 2.07)*
Pacific vs. European(=1)	2.66 (1.82 - 3.88)*	2.18 (1.08 - 4.40)*
Asian vs. European(=1)	1.42 (0.85 - 2.39)	2.13 (0.97 - 4.70)
Indian vs. European(=1)	1.83 (1.23 - 2.74)*	2.86 (1.60 - 5.12)*
Female vs. Male(=1)	0.84 (0.73 - 0.96)*	0.69 (0.54 - 0.88)*
Type 1 vs. Type 2(=1)	1.32 (1.03 - 1.69)*	1.72 (1.14 - 2.59)*

Adjusted for age, duration of diabetes, gender, ethnicity and type of diabetes. * $p<0.05$

Discussion

Mention of diabetes on discharge codes depends on changes to coding procedures. From July 2000, an additional diagnosis of diabetes or its complication in hospital data indicates that the diabetes co-exists with the complication without inference of causality.[66] The non-concordance between discharge codes and physician diagnoses previously observed in New Zealand[67] is improving.[318] Diabetes patients in the Southlink Diabetes Register[190] were more likely to be admitted to hospital for any reason than matched patients without diabetes. A significant proportion of all admissions (46% of all admissions for Type 1 diabetes patients and 33% for Type 2 diabetes patients) were due to diabetes related complications. Figures from Waikato indicate that diabetes and related complications result in high hospital admission rates, especially for renal disease among Maori. Compared with Europeans, Maori in this study did not have increased risk of hospital admission for coronary artery disease or cerebrovascular disease. It may be reflective of the similar high rates of appropriate CVD and renal preventive drug therapy that Maori and Pacific people receive to Europeans.[39]

Maori with newly diagnosed diabetes have low prevalence of retinopathy[308], but they have disparities in access to retinal screening.[21 40] Increased risk of vision threatening retinopathy among Maori and Indian patients is consistent with the poorer access to retinal screening for Maori and Asian patients observed in the Hamilton study.

The growing number of patients and their hospital admission rates will increase the burden on health care resources. It is vital for diabetes service providers to keep track of service utilisation which can be directly translated into health costs. The exercise of linking Waikato DHB hospital admissions in 2005 with the WRDS database clearly demonstrates the gaps in current reports.

Routine utilisation reports using primary diabetes diagnosis coding on discharge data alone grossly underestimates service utilisation by diabetes patients, especially those related to diabetes complications. Although utilisation analyses using the WRDS registered cohorts can provide utilisation rates for diabetes complications as well, they are limited by the coverage of the retinal screening programme. There is a time lag of 1-2 years between initial diagnosis of diabetes and referral to retinal screening. This time difference could be greater among patients first diagnosed with diabetes in secondary care. Cohort analysis approach using the WRDS registered patients alone underestimates service utilisation among diabetes patients who do not access secondary diabetes services (older patients with existing eye disease, patients who are too frail to attend retinal screening and newly diagnosed diabetes patients), the bias increasing with age. A diabetes register linking patients from primary and secondary care can provide the ideal base cohort. In the absence of such a register, a combined approach using the WRDS database and analysis using discharge codes for diabetes is recommended.

5.3.4 Mortality Among Diabetes Patients: A Cohort Study

From the WRDS database, 9043 diabetes patients diagnosed with diabetes before 2003 were identified. Patients were of mean age 59 ± 16 years, 69% Europeans, 21% Maori, 8% Other and 2% Unknown (Table 5-34). 921 deaths were observed during the five year follow up period with 46,261 person-years of follow up (Table 5-35). Of them, 441 deaths until end of 2005 (26,581 person-years of follow up) had cause of death information available from the NZHIS. 268 (61%) had diabetes mentioned on the death certificate. Maori are more likely than Europeans to have diabetes reported on the NZHIS coding (p-value 0.0098), but cause specific differences were not statistically significant (p-value 0.0760 and 0.6414 for cardiovascular disease and cancer respectively). Due to small number of observed deaths among Pacific Islanders, Asians and Indians (18, 4 and 8 respectively), they are not analysed as separate ethnicity categories but are included in the total. Age-specific SMRs decreased with age among both European and Maori (Table 5-36, Table 5-37).

Table 5-34. Characteristics of the study cohort and their mortality rates by ethnicity

	European	Maori	Total
n	6236	1915	9043
Age at start of follow-up (mean ± sd)	61 ± 16	54 ± 13	59 ± 16
Male	3246 (52%)	924 (48%)	4649 (51%)
Type of diabetes			
Type 2	4948 (80%)	1749 (94%)	7501 (84%)
Type 1	1202 (20%)	115 (6%)	1391 (16%)
Missing	86	51	151
Age at diagnosis of diabetes (mean ± sd)			
Type 2 (non-missing cases = 7276)	57.7 ± 12.6	46.5 ± 12.4	54.3 ± 13.4
Type 1 (non-missing cases = 1361)	24.8 ± 16.9	27.1 ± 15.1	25.3 ± 16.8

Table 5-35. Crude and age-adjusted death rates for diabetes patients by gender and ethnicity

	European	Maori	Total
All diabetes patients			
Observed deaths (Male/Female)	656 (380/276)	206 (108/98)	921 (520/401)
Crude mortality per 1000 person years (Male / Female)	24.7 / 19.2	24.6 / 20.7	23.49 / 18.98
Age-standardised‡ to Segi world population (rate/100,000 person-years)			
Male	551 (496-606)	1,012 (821-1,203)	632 (578-686)
Female	491 (433-549)	808 (648-968)	569 (513-625)
Type 2 diabetes patients			
Observed deaths (Male/ Female)	570 (340/230)	180 (94/86)	803 (463/340)
Age-adjusted* mortality rate/1000 person-years (Male / Female)	24.84 / 16.58	33.48 / 34.63	26.95 / 19.35
Age-standardised‡ to Segi world population (rate/100,000 person-years)			
Male	458 (409-506)	960 (766-1,154)	570 (518-622)
Female	353 (308-399)	724 (571-877)	459 (411-508)
Type 1 diabetes patients			
Observed deaths (Male/ Female)	70 (41/29)	22 (12/10)	93 (41/52)
Age-adjusted† mortality rate/1000 person-years (Male / Female)	10.85 / 14.31	65.72 / 65.99	12.15 / 15.56

* Direct standardisation to Type 2 diabetes population in the study.
† Direct standardisation to Type 1 diabetes population in the study.
‡ Direct standardisation using Segi world population.

Table 5-36. Age-specific all cause standardised mortality ratios (SMRs) after 5 years of follow-up for European and Maori diabetes patients in relation to NZ general population

		All diabetes patients		Type 2 diabetes patients	
	Age group	Deaths	SMR (95% CI)	Deaths	SMR (95% CI)
European Female					
	40-49	10	4.32 (2.33, 8.03)	4	2.64 (0.99, 7.04)
	50-59	17	1.76 (1.09, 2.83)	16	2.02 (1.24, 3.30)
	60-69	50	1.44 (1.09, 1.90)	41	1.30 (0.96, 1.77)
	70-79	94	1.07 (0.88, 1.31)	78	0.97 (0.77, 1.21)
	80+	102	0.90 (0.74, 1.09)	91	0.87 (0.71, 1.07)
European Male					
	40-49	6	1.64 (0.74, 3.65)	2	0.82 (0.21, 3.28)
	50-59	25	1.55 (1.05, 2.29)	18	1.29 (0.81, 2.04)
	60-69	72	1.21 (0.96, 1.52)	66	1.20 (0.95, 1.53)
	70-79	189	1.29 (1.12, 1.49)	176	1.29 (1.11, 1.49)
	80+	86	0.85 (0.69, 1.05)	78	0.84 (0.67, 1.05)
Maori Female					
	40-49	16	9.32 (5.71, 15.2)	14	8.48 (5.02, 14.3)
	50-59	16	3.05 (1.87, 4.97)	14	2.82 (1.67, 4.75)
	60-69	36	3.64 (2.63, 5.05)	31	3.29 (2.31, 4.67)
	70-79	23	1.94 (1.29, 2.91)	21	1.86 (1.21, 2.85)
	80+	5	2.20 (0.91, 5.27)	5	2.20 (0.91, 5.27)
Maori Male					
	40-49	12	5.50 (3.12, 9.69)	10	4.96 (2.67, 9.21)
	50-59	29	4.10 (2.85, 5.90)	26	3.92 (2.67, 5.75)
	60-69	41	2.79 (2.05, 3.79)	33	2.39 (1.70, 3.36)
	70-79	21	1.51 (0.98, 2.31)	20	1.47 (0.95, 2.28)
	80+	4	0.82 (0.31, 2.18)	4	0.82 (0.31, 2.18)

SMR is the ratio of observed number of deaths in the diabetic population to the expected number of deaths. Expected deaths were calculated by applying the age (five-year group) and gender specific mortality rates of the general population applied to the number of person-years of follow-up in each group.

Table 5-37. Age-specific all cause standardised mortality ratios (SMRs) after 5 years of follow-up for Maori diabetes patients in relation to prioritised Maori general population of New Zealand

Maori Female					
	40-49	16	3.99 (2.44, 6.51)	14	3.63 (2.15, 6.12)
	50-59	16	1.27 (0.78, 2.08)	14	1.18 (0.70, 1.99)
	60-69	36	1.55 (1.12, 2.15)	31	1.40 (0.99, 1.99)
	70-79	23	0.96 (0.64, 1.44)	21	0.92 (0.60, 1.41)
	80+	5	1.74 (0.72, 4.18)	5	1.74 (0.72, 4.18)
Maori Male					
	40-49	12	2.30 (1.31, 4.05)	10	2.07 (1.12, 3.86)
	50-59	29	1.60 (1.11, 2.31)	26	1.53 (1.04, 2.25)
	60-69	41	1.32 (0.97, 1.79)	33	1.13 (0.80, 1.59)
	70-79	21	0.87 (0.57, 1.34)	20	0.85 (0.55, 1.31)
	80+	4	0.62 (0.23, 1.66)	4	0.62 (0.23, 1.66)

SMR is the ratio of observed number of deaths in the diabetic population to the expected number of deaths. Expected deaths were calculated by applying the age (five-year group) and gender specific mortality rates of the prioritised Maori general population applied to the number of person-years of follow-up in each group.

Table 5-38. Primary causes of death and the extent of recognition of diabetes on the NZHIS coding

	Causes of Deaths			Mention of diabetes		
	European	Maori	Total	European	Maori	Total
Cancer	71 (22.7%)	25 (24.5%)	103 (23.4%)	48%	40%	44%
Renal	9 (2.9%)	14 (13.7%)	25 (5.6%)	100%	100%	100%
CVD	141 (45.1%)	46 (45.1%)	197 (44.7%)	61%	76%	64%
Diabetes/complications	25 (8.0%)	5 (4.9%)	31 (7.0%)	96%	-	97%
Cerebrovascular	21 (6.7%)	1 (1.0%)	23 (5.2%)	43%	-	39%
Gastro intestinal	9 (2.9%)	3 (2.9%)	14 (3.1%)	22%	-	29%
Respiratory	17 (5.4%)	5 (4.9%)	23 (5.2%)	59%	-	70%
Other	20 (6.4%)	3 (2.9%)	25 (5.7%)	35%	-	48%
All Cause	313	102	441	58%	73%	61%

Among both Europeans and Maori, nearly half the deaths were due to cardiovascular disease and a quarter of deaths due to cancer (Table 5-38). Compared with European

diabetes patients, Maori diabetes patients are more likely to die from cardiovascular disease, cancer and renal disease. Maori and Type 1 diabetes patients have significantly higher risk of death due to renal disease (Table 5-39).

Table 5-39. Cox's proportional hazards ratios (95% C.I) for all cause, cardiovascular, cancer related and renal mortality among European and Maori diabetes patients

	All cause mortality by diabetes type		Cause Specific Mortality†		
	Type 2	Type 1	CVD	Cancer	Renal
No: of deaths	750	92	185	96	23
Age (years)	1.08 (1.07-1.09)*	1.08 (1.06-1.09)*	1.09 (1.07-1.1)*	1.06 (1.04-1.1)*	1.06 (1.03-1.1)*
Maori (vs. European)	1.92 (1.61-2.30)*	5.43 (3.31-8.92)*	2.31 (1.6-3.3)*	1.83 (1.1-3)*	11.74 (4.8-29)*
Male (vs. Female)	1.44 (1.25-1.68)*	0.83 (0.56-1.25)	1.99 (1.47-2.7)*	1.25 (0.8-1.9)	0.93 (0.4-2.1)
Type 1 (vs. Type 2)	-	-	2.96 (1.94-4.5)*	0.91 (0.3-2.2)	13.16 (5.3-33)*

European and Maori patients only. Variables are mutually adjusted.
* Significant at 5% level.
† Only those events with cause of death information available.

Discussion

Results of the present study indicate that Maori continue to have nearly double the age adjusted mortality rates than Europeans.

Age-specific SMRs decreased with age among all subgroups of ethnicity and gender. Convergence of SMRs with age is expected with the mortality rates in the general population rising exponentially with age. SMRs were higher among females (both European and Maori) compared with males. Gender differences in SMRs were higher in the younger age groups (40s and 50s), especially among Type 2 diabetes patients, but the differences diminished with age.

The observed all cause SMRs, especially in the older age groups, were lower than that found in previous New Zealand studies in the 1990s looking at mortality among people with diabetes.[387] [77] [185] This could be due to a range of factors including increased screening[388] resulting in earlier detection of diabetes before the onset of complications[389], the introduction of evidence based guidelines in 2003[49], improvements in the management of risk factors for diabetes complications (example: blood pressure and lipids)[173] and increased rates of cardiovascular and renal preventive drug therapy.[39] Mortality rates have been estimated based on a cohort of diabetes patients registered with the WRDS database. The WRDS database is estimated to cover almost 90% of the diabetes patients in the Waikato[111], with the exemption of newly diagnosed diabetes patients who are yet to attend their first retinal screening, those with established eye disease and those who are too frail to attend retinal screening.[91] Observed mortality rates may be underestimated since deaths among older diabetes patients not needing retinal screening would not be captured. As opposed to the prioritised ethnicity used commonly in New Zealand, a single ethnicity in collected and stored in the WRDS database. But results of the hospital system audit indicate that multiple ethnicities are not commonly recorded and the use of prioritised ethnicity is unlikely to make a huge difference.

Reductions in all-cause mortality among women and men with diabetes mellitus have occurred over time in the US[390] [391], but mortality rates among individuals with diabetes mellitus remain two-fold higher compared with individuals without diabetes. Although overall mortality rates in the New Zealand general population decreased over time[392], such trends are not available separately for people with and without diabetes.

National estimates of mortality burden due to diabetes (compared with people without diabetes) in New Zealand, derived from multi-state life tables[393], are constrained by data uncertainties in the estimates of prevalence of diabetes and in the estimates of

relative risk of all-cause mortality conditional on diabetes. Previous studies in New Zealand have looked at mortality among diabetes patients in relation to that in the national general population. Maori Type 2 diabetes patients in aged 40-59 in South Auckland[77] experienced seven times excess mortality, in relation to the national total population rates. A record linkage study using hospital discharges, comparing the mortality patterns of patients with diabetes to the general population of the same ethnic group, found that Maori with diabetes have nearly four times excess mortality, while Pacific have slightly over two times and non-Maori/non-Pacific have nearly three times excess mortality in the 25+ age-group.[387] Studies based on patients with diabetes identified through hospital records report higher SMRs[394], probably due to the selective inclusion of more patients in more advanced stages of diabetes and its complications. With high prevalence of diabetes among middle aged Maori in the general population[134], SMRs may not be indicative of the true burden due to diabetes. Mortality attributable to diabetes would be better estimated using studies involving people with and without diabetes. Such studies may be feasible using general practice information systems, as in the UK.[219 220]

The results suggest that the under-coding of diabetes on death certificates has not improved and continues to be a major limitation for routine mortality analysis solely based on these codes. Maori are more likely to have diabetes reported on death certificates. This would introduce significant bias to mortality analysis using diabetes coding on national mortality data.

Current findings are in agreement with the higher risk of death from nephropathy for Maori with Type 2 diabetes compared with Europeans with Type 2 diabetes observed in South Auckland (adjusted hazard ratio of 15).[77] Present results indicate that Maori diabetes patients experienced significantly higher mortality due to cardiovascular

disease and cancer as well. Excess mortality risk among Type 1 patients may be partly due to the longer duration of diabetes.

Maori in general have high prevalence of cardiovascular disease independent of social deprivation.[395] They are also at increased risk of first cardiovascular event in the presence of Type 2 diabetes.[177] Maori with diabetes experience significant excess mortality compared to the Maori general population.[77 387] Disparities in cancer survival are reported to be partly attributed to late presentation among Maori[396], as well as differences in exposure to risk factors and access to screening and treatment.[307] Ethnic mortality gradients are influenced by socio-economic factors[397-399] and smoking.[400] Maori with diabetes face a range of barriers to self-care.[204]

In conclusion, Maori diabetes patients experience significantly higher mortality than Europeans. The data yet again demonstrate the shortcomings of diabetes coding on death certificates. Studies on diabetes related mortality using national mortality database needs to take the increased recognition of diabetes on the NZHIS coding for Maori into account. Mortality among diabetes patients in New Zealand would need to be compared with that among people without known diabetes, to estimate the true burden due to diabetes.

5.4 Discussion

Population health and epidemiology: A critical problem in diabetes research has been the lack of population based data.[401] As demonstrated in this thesis, a key use of a diabetes registry is its contribution to population health and epidemiology, which can aid policy development, planning and service development.[348] Information from a diabetes registry can help to: (1) improve the quality and availability of population level information about diabetes (for example incidence, prevalence and service utilisation)

and (2) access the quality of service delivery and (3) monitor disparities in prevalence and complications. The most critical impact of a registry on a population is that it can allow timely identification of high-risk subpopulations, permitting the healthcare team to better target their care and to meet treatment guidelines.[402] The DARTS diabetes system has been extensively used to identify treatment gaps[403] and study diabetes complications[404-408] and mortality.[409]

Support for clinical care: Maintaining the diabetes registry as a web-based integrated information system with dynamic links between primary care and secondary care has potential for huge additional benefits.[326] It would then be possible to use the system for decision support at the point of clinical care providing near real-time clinical information, generation of patient letters and feedback to clinicians.[277] Completeness and quality of input data are also likely to improve as a result of regular feedback. It is vital that such a system be searchable[326] (to identify high risk patients), compliant with privacy/security requirements and support automated data capture.[275]

Improving outcomes for patients: The ultimate goal of diabetes care is improvement in patient outcomes. Simply providing information more clearly is not enough to motivate patients or providers.[84] [348] Implementation of interventions based on the Chronic Care Model[410] proposed by Wagner (which includes self-management support for patients, clinical information systems, redesigning the delivery of care, decision support, mobilising community resources and creating a health organisation that promotes high quality care) has been shown to improve diabetes outcome measures for diabetes patients.[411] [276] A key aspect of the chronic care model is the information system which has three important roles: (1) as reminder systems that help primary care teams comply with practice guidelines; (2) as feedback to physicians, showing how each is performing on chronic illness measures such as HbA_{1c} and lipid levels; and (3) as registries for planning individual patient care and conducting population-based care.

Integration of primary and secondary care information systems is needed in the case of diabetes which requires a multidisciplinary team to provide optimal care.[412] [413] Integrated diabetes care has been shown to be cost effective in Australia.[414] Growing evidence shows that chronic care management becomes more effective when it is established within a wider system of integrated care.[285] [418] Multidisciplinary teams armed with population based information system integrating primary care and secondary care are needed to improve process measures and clinical outcomes.[415-419] Another important driver for the improvement in outcomes is fee-for-performance based funding system as in the Quality Outcomes Frame work in the UK.[222]

Research and policy development: A diabetes information system provides a platform for translational research regarding effective approaches for prevention and management of diabetes and its complications.

CHAPTER 6 CONCLUSION

New Zealand's population is projected to reach five million in the late 2020s.[22] The age structure of the population will continue to undergo gradual but significant changes, resulting in a higher proportion of older people and further ageing of the population. Between 2001 and 2021, the broad Asian, Pacific and Maori ethnic populations are all projected to grow faster than the New Zealand population overall. The aging population structure and increasing numbers of non-European ethnic populations point to an increasing Type 2 diabetes burden for New Zealand.

This thesis has looked at the linking existing datasets to create a regional diabetes register. The potential benefit of such a system for monitoring disparities in prevalence of diabetes, access to diabetes care, complications (renal disease) and mortality have also been demonstrated using linked data. Major findings are summarised below.

6.1 Key findings from this thesis

Finding regarding the linking of existing datasets to create a regional register:

- The existing database systems fall short in their ability to access the true number of people diagnosed with diabetes, the coverage of diabetes care programmes (Get Checked programme, retinal screening), health service utilisation, and mortality among diabetes patients (especially due to complications).
- It has been demonstrated that the existing primary and secondary care data systems can be successfully linked using NHI numbers, to establish a local diabetes register which can monitor diabetes care and outcomes.

- Although case identification using primary care could be very high, it is dependent on practice IT systems and PHO data handling procedures. The WRDS database provides an excellent base for monitoring service utilisation and outcomes among diabetes patients in Waikato, but the lag time between diagnosis of diabetes and referral to the service is an issue. Case ascertainment improves with data linkage.
- Audit results indicate that better monitoring of outcomes may be achieved by linking the WRDS database with the other primary care and secondary care systems.
- Local diabetes registers established using NHI linkage would need continuous and dedicated administrative support for validation and data cleaning in order to handle data disagreement and missing data.

Findings from hypotheses tested using linked data:

- Prevalence of diabetes varies widely across subgroups of age and ethnicity. Highest rates were observed among Indians (Hamilton study). High rates were noted among Asians as well (Hamilton & Rotorua studies).
- Unlike Europeans, the adjusted risk of diabetes for most deprived Maori is not significantly different from least deprived Maori. Interventions targeting Maori should be tailor-made to include the least deprived groups as well.
- Involvement of patients from ethnic minorities in the “Get Checked” programme was not a problem, if practices had good IT systems in place to handle “Get Checked” data entry and reporting. Non-attendees of the “Get Checked” programme generally have lesser cardiovascular co-morbidities, are younger, newly diagnosed patients or Type 1 patients. Patients of Maori or Asian origin, younger patients and those with Type 1 diabetes took a significantly longer time to return for a second “Get Checked” review. There are disparities for Maori and Asian patients in access to retinal screening programme. Psychological barriers

to diabetes care rank highly for all subgroups of ethnicity, age, gender, duration of diabetes and insulin treatment.

- Diabetes and related complications result in high hospital admission rates. A combined approach, using hospital discharges coded with diabetes and discharges among retinal screening patients may provide better estimates of service utilisation.
- Incidence rates of ESRD for Maori with diabetes exceed Europeans with diabetes by 15 times (5.14 vs. 0.33 per 1000 person years). Among people with diabetes, Maori are up to 46 times more likely to have renal failure.
- There are significant differences in the agreement between the MDRD and the CG equations in identifying patients with eGFR <60 ml/min/1.73m^2 for Maori females, European females and European males. While the CG equation identifies more European of both genders, more Maori females are identified by MDRD.
- Compared to European diabetes patients, Maori diabetes patients are more likely to die from cardiovascular disease, cancer and renal disease. They are also more likely to have diabetes mentioned on the NZHIS coding of causes of death.

Table 6.1. Summary of key findings by study

Study	Key Findings
Taumarunui	91% were registered with the WRDS database. 62% were registered with the "Get Checked" programme. There were significant differences between the "Get Checked" attendees and non-attendees in demographic profile and treatment received. Psychological barriers to diabetes care were the most frequently reported barriers in all subgroups of ethnicity, duration of diabetes, gender, insulin treatment and age.
Hamilton	86% were registered with the WRDS database. Older patients were less likely to be in the WRDS database. Maori or Asian ethnicity or female gender were more likely to have problems with access to retinal screening. 80% had a "Get Checked" annual review in the last 12 months. Older patients and those with Type 1 diabetes were less likely to have attended a "Get Checked" review. Maori ethnicity, male gender and longer duration of diabetes were at increased risk of unsatisfactory glycaemic control. General practice Read Codes for diabetes had a sensitivity of 98.0% and a specificity of 99.9% in identifying diabetes patients. Prevalence of diabetes varied widely across subgroups of age and ethnicity. Asians (a group which included Indians) had the highest age-standardised rate.
Rotorua	74% had a "Get Checked" review in the last two years. "Get Checked" review rates were significantly higher among older patients (age 60+), those with longer duration of diagnosed diabetes and those with better metabolic control. Prevalence of diabetes was higher among Maori, Pacific and Asian people. Diabetes prevalence rises with increasing deprivation among Europeans. The trend among Maori seems to be different where the least deprived are equally at risk of diabetes. There are significant differences in the agreement between the MDRD and the CG equations in identifying patients with eGFR <60 ml/min/1.73m^2. While the CG equation identifies more European of both genders, more Maori females are identified by MDRD.
Audits	There were 9936 WRDS registered diabetes patients in 2005. Another 1372 patients who were not registered with the WRDS in the 2005 were admitted to hospital with a primary diagnosis code of diabetes. A high proportion of the extra diabetes patients identified were aged over 60 years.
Hospital Admissions	Compared with Europeans, Maori patients were more likely to have a hospital admission for renal disease (odds ratio of 9). But they did not have an increased risk of hospital admission for coronary artery disease or cerebrovascular disease.
Renal progression	Maori diabetes patients had a significantly higher risk of end-stage renal disease (ESRD), renal admission and renal death (46-fold, seven-fold and four-fold increases, respectively). Maori patients progressed at a significantly faster rate from first hospital admission for chronic renal disease to ESRD.
Mortality	Maori were more likely than Europeans to have diabetes reported on mortality coding. They were also were more likely to die from cardiovascular disease, cancer and renal disease [Hazard-ratios 2.31(1.6-3.3), 1.83(1.1-3), and 11.74(4.8-29) respectively].
"Get Checked" Retention	Patients of Maori or Asian origin, younger patients and those with Type 1 diabetes took a significantly longer time to return for a second review. "Get Checked" data is underestimating the number of diabetes patients in the region.

6.2 Regional Vs National Register

Many countries have started establishing national diabetes registers.[92] So, why settle for a regional register in New Zealand, where we have the advantage of the unique NHI number?

The primary uses of a diabetes register are:

- Trend data for public health surveillance[402]
- Quality improvement[402] [(a) identify high-risk patients for treatment intensification, (b) provider feedback on performance, (c) provider reminders for overdue screening tests],
- Retrospective analysis for health services research[420]

A national register could be an excellent tool for surveillance, planning of services, assessing coverage of programmes/interventions and predicting future diabetes burden. Anonymous data would serve as an excellent platform for research. It would be possible to monitor measurements against standards and monitor equity by region. Regional registers would have some limitations in epidemiologic capability due to the geographic restriction. Regional registers would be helpful in looking at inequalities within the region, but may suffer from patient numbers being too small to make meaningful comparisons, especially in subgroup analyses. Aggregation of regional registers is a possible solution, if resource needs for co-ordination, IT interoperability and privacy limitations could be addressed.

Agreement among stakeholders would be crucial factor in the success of a national register. The MoH hosted a national diabetes epidemiology workshop in 2007 to seek a collective view about the best methodology for estimating the prevalence of diagnosed diabetes.[85] Diabetes experts from all over the country attended the workshop, but failed to reach consensus on the best methodology to create a national register. The

possibility of aggregating existing regional prevalence data was identified as a useful alternative.

Feedback to providers has been shown to improve diabetes care processes and outcomes[421], but electronic feedback alone may be of limited use.[275 422] Evidence suggests that physician feedback works better if it is timely and presented personally[423] or in peer groups. With 21 DHBs and numerous PHOs within the country, feedback to services and translating findings to patient level care using a national register in New Zealand would be extremely challenging. A key feature of a regional register would be the ability to provide patient level feedback to primary and secondary care. Canada uses a network of regionally distributed diabetes surveillance systems that compile administrative health care data relating to diabetes, to populate its National Diabetes Surveillance System.[227] Tracking and feedback are possible because data are captured routinely in the provision of publicly funded services and are stored provincial/territorial administrative databases. The DIABCARE Q-NET system in Europe, which was developed in 1996, performs an analysis of the local data and compares data with peer teams using telecommunication of anonymous data, with the goal of improvement in the local, regional, and national diabetes care.[223] There is no targeting of high-risk patients or any specific method to communicate decision support information to providers that may need additional help meeting target goals.[84]

Concerns regarding privacy, confidentiality and security of data cannot be understated. In the context of real of perceived obligation to the Health Information Code of Practice[345], clinicians may have ethical concerns about a lack of informed consent, leading them to veto the use of their patients' information in shared repositories, even where such use might be legally permissible.[346] Without clearer guidance from the government, setting up a national register would be much more challenging than implementing regional registers.

6.3 Limitations of research

General practices not covered by Waikato Primary Health: Only one study presented in this thesis has looked at general practices in the Waikato, managed by PHOs other than Waikato Primary Health. Although only around 14% of the Waikato DHB population is missed out this way, their profile and needs could be very different. For example, the Waikato DHB Health Needs Assessment Report 2008 indicates that there are significant differences between PHOs in the uptake and reporting of the "Get Checked" programme.[76] Six percent of the Waikato DHB population was not enrolled with any PHO in 2008.

Tracking internal migration: The studies using regional datasets are unable to track internal patient migration (patients moving to other DHB regions in the country).

Low uptake of Get Checked: Low uptake of "Get Checked" programme remains a problem when the database is component of the regional register.

Generalisation: The WRDS database is a regional diabetes service database, primary used for retinal screening. Although retinal screening is offered by all DHBs, there is no national directive on the corresponding data collection. Some of the methods using the regional WRDS database may not be easily reproducible elsewhere is New Zealand.

6.4 What Next

In summary, the implementation of a regional register would need:

- Substantial policy and direction support from government agencies regarding governance and confidentiality issues.
- IT support to align PHO and general practice system capabilities with integration needs.
- Financial backing for implementation and ongoing maintenance.
- Co-operation among stakeholders and a common vision.
- Clear understanding about the importance of accuracy and completeness of data among all providers who handle data collection.

A local diabetes register linking primary care and secondary care systems would bring together all the key research parameters: (1) reliable and timely demographic details, (2) clinical variables from the primary care and (3) outcomes and utilisation from secondary care. It would then be possible to closely follow up the quality of diabetes care and provide the much needed estimates of prevalence, utilisation and outcomes. Annual reports with these estimates based on local data would be of immense value for service planning, provision and stocktaking.

The true success of a diabetes information system lies in its ability to rise above routine surveillance and improve outcomes for diabetes patients. It would be necessary to further develop the regional register to support decision support and feedback and place the system within the wider concept of integrated care, linking the whole spectrum of multidisciplinary diabetes care providers.

Outcomes analyses using a regional diabetes register would be further enhanced by the availability of domicile codes, by the resulting GIS analysis capability. It may be

possible to better identify most geographical areas which would most benefit from interventions. Service provision may also be aligned depending on geographical needs.

More research is needed into the role of obesity in the observed differences in diabetes prevalence across deprivation quintiles among Maori. Given the high rates of renal outcomes among Maori, more aggressive systematic screening for chronic kidney disease among Maori diabetes patients is urgently required. This will need to be backed by intensive management of risk factors and interventions to improve treatment uptake and compliance in order to improve the outcomes.

Every long journey begins with a single step. A regional diabetes register would be the first step towards active diabetes surveillance and integrated diabetes care to improve outcomes.

APPENDIX 1. MINIMUM DIABETES DATASET FOR THE "GET CHECKED" PROGRAMME

Field	***Comments and explanatory notes***	***Field Structure and type: A=alpha N=numeric***	***Units***	***Field name***
NHI	National Health Index number (may be encrypted)	A3/N4	-	Nhi
Sex	Male =m, Female = f, not known=u not entered = k	A1	-	Sex
Date of birth	Date of birth	Ddmmyyyy	-	Dob
Ethnic origin	Numerically coded: Use NZHIS coding for ethnicity	N2	-	Ethn
Date of annual review	Date	Ddmmyyyy	-	rec_date
Type of diabetes	Type 1 = 1; Type 2 = 2; Gestational = 4; Other known = 6; Unknown=u; not recorded = k	A1	-	dm_type
Year of diagnosis	Date as year, unknown=9999	Yyyy	-	dm_year
Smoker	Currently smoking any tobacco material No = 1; Yes = 2; Past = 3	N1	-	Smoker
Height	No shoes	N3	cm	Height
Weight	Dressed without shoes	N3	Kg	Weight
Date last retinal examination or opthalmologist review	Date of last retinal examination or ophthalmologist review, if only year known, yyyy Use 9999 if not applicable (i.e. blind with no indications for ophthalmologist review)	Ddmmyyyy	-	Retdate
Systolic Blood Pressure:	Sitting	N3	mm Hg	bp_sys
Diastolic Blood pressure	Sitting	N3	mm Hg	bp_dia
HbA_{1c}	Expressed to one decimal place (mmol/l)	N2.1	%	hba1c

Urine albumin:creatinine ratio (micro-albuminurea)	If clinically indicated (see guidelines)	N3.1	mg/mmol creatinine	Uacr
Dip-stick test for micro-albuminurea	If clinically indicated (see guidelines) and laboratory urine albumin:creatinine ratio not practicable.	N1		Uacr_d
Total cholesterol	Expressed to one decimal place (mmol/l)	N4.1	mmol/l	Chol
HDL-cholesterol	Expressed to 2 decimal places (mmol/l)	N1.2	mmol/l	Chol_hdl
Triglyceride	Fasting preferably. Expressed to one decimal place (mmol/l)	N2.1	Mmol/l	Tg
Diabetes Therapy: Insulin Oral medication for glycaemic control Diet only	The options need to be presented as yes /no for each modality since they may be used in a variety of combinations. The options can be presented as a pick list on a pop-up screen with a tick box. The data format should be as : No = 1; Yes = 2; Unknown =9 Note: “Insulin” and “oral medication” should only be selected for people on regular treatment with these medications.	3 x N1		Insulin Oral Diet_only
Other relevant therapies	Options presented as for diabetes therapy. Options include: ACE – inhibitor; Anti-hypertensive medication other than ACE inhibitor HMGCo-A reductase inhibitor (“statin”) Other medication specifically for controlling hyperlipidaemia (not HMGCo-A reductase inhibitor) The data format should be as : No = 1; Yes = 2; Unknown =9 Other fields from the Diabetes Health Information Report are included in the event that Primary Care Organisations wish to record more treatment information.	4 x N1		Acei Other_ah Statin Other_ll Beta_b ca_ant alpha_bl diuretic nitrate resin fibrate aspirin HRT Steroid

APPENDIX 2. THE WRDS DATABASE DICTIONARY

Table Name	Variable No	Variable Name	Label	Format	Length
PROFILE	1	MRN	MRN	$	7
PROFILE	2	TYPE	TYPE	$	50
PROFILE	3	YR_DIAG	YR DIAG		0
PROFILE	4	DURATION	DURATION		0
PROFILE	5	CURRENT	CURRENT	$	255
PROFILE	6	INITIAL	INITIAL	$	255
PROFILE	7	MARITAL_STATUS	MARITAL STATUS	$	255
PROFILE	8	EMPLOYMENT	EMPLOYMENT	$	255
PROFILE	9	NICOTINE	NICOTINE	$	255
PROFILE	10	ALCOHOL	ALCOHOL	$	255
PROFILE	11	ALLERGIES	ALLERGIES	$	1024
PROFILE	12	GLIADIN_IgA	GLIADIN IgA	$	50
PROFILE	13	GLIADIN_IgG	GLIADIN IgG	$	50
PROFILE	14	Parietal_Cell_AB	Parietal Cell AB	$	50
PROFILE	15	Adrenal_AB	Adrenal AB	$	50
PROFILE	16	ENDOMYSIAL_ABS	ENDOMYSIAL ABS	$	50
PROFILE	17	TTGLUTAMINASE	TTGLUTAMINASE	$	50
PROFILE	18	THYROID_ABS	THYROID ABS	$	50
PROFILE	19	IA2_ABS	IA2 ABS	$	50
PROFILE	20	ANTI_GAD_ABS	ANTI GAD ABS	$	50
PROFILE	21	Eyereview	Eyereview	$	255
PROFILE	22	Onset_Yr	Onset Yr		6
PROFILE	23	Exercise	Exercise	$	50
PROFILE	24	Key_Support	Key Support	$	50
PROFILE	25	Living_Group	Living Group	$	1024
PROFILE	26	Exercise_memo	Exercise memo	$	1024
PROFILE	27	Food_memo	Food memo	$	1024
PROFILE	28	General_notes	General notes	$	1024
PROFILE	29	Gen_Exercise_memo	Gen_Exercise memo		11
PROFILE	30	Gen_Food_memo	Gen_Food memo		11
PROFILE	31	Gen_Living_Group	Gen_Living Group		11
PROFILE	32	Notes	Notes	$	1024
PROFILE	33	Gen_TempField_0	Gen_TempField*0		11
PROFILE	34	s_GUID	s_GUID	$	36
PROFILE	35	Aen_Exercise_memo	Aen_Exercise memo		11
PROFILE	36	Aen_Food_memo	Aen_Food memo		11
PROFILE	37	Aen_Living_Group	Aen_Living Group		11
PROFILE	38	Gen_ALLERGIES	Gen_ALLERGIES		11
PROFILE	39	Gen_General_notes	Gen_General notes		11
PROFILE	40	Gen_Notes	Gen_Notes		11
PROFILE	41	s_ColLineage	s_ColLineage	$HEX	2048
PROFILE	42	s_Generation	s_Generation		11
PROFILE	43	s_Lineage	s_Lineage	$HEX	2048

Table Name	Variable No	Variable Name	Label	Format	Length
REGISTER	1	MRN	MRN	$	8
REGISTER	2	Surname	Surname	$	50
REGISTER	3	Other	Other	$	50
REGISTER	4	Title	Title	$	11
REGISTER	5	Gender	Gender	$	4
REGISTER	6	Race	Race	$	11
REGISTER	7	DOB	DOB	DATETIME	20
REGISTER	8	Age	Age		11
REGISTER	9	Street	Street	$	50
REGISTER	10	Town	Town	$	50
REGISTER	11	Town2	Town2	$	50
REGISTER	12	Tel_Home	Tel Home		0
REGISTER	13	Tel_Work	Tel Work	$	12
REGISTER	14	Tel_other	Tel other	$	13
REGISTER	15	GP	GP		11
REGISTER	16	Educator	Educator	$	60
REGISTER	17	Photostatus	Photostatus	$	5
REGISTER	18	Comment	Comment	$	200
REGISTER	19	Ed_Annual	Ed Annual		1
REGISTER	20	Dr_Annual	Dr Annual		1
REGISTER	21	AUTOID1	AUTOID1		11
REGISTER	22	AUTOID2	AUTOID2		11
REGISTER	23	Date	Date	DATETIME	20
REGISTER	24	Select	Select		1
REGISTER	25	Adult_Height	Adult Height		0
REGISTER	26	Midwife	Midwife		11
REGISTER	27	HCP	HCP	$	50
REGISTER	28	Status	Status	$	50
REGISTER	29	Patient_Type	Patient Type	$	50
REGISTER	30	s_GUID	s_GUID	$	36
REGISTER	31	s_ColLineage	s_ColLineage	$HEX	2048
REGISTER	32	s_Generation	s_Generation		11
REGISTER	33	s_Lineage	s_Lineage	$HEX	2048

APPENDIX 3. DRAFT OF RDIS PRINCIPLES FOR GAURDIANSHIP AND MANAGEMENT

Establishing the Regional Diabetes Information Service: Principles for Guardianship and Management

14 March 2006
David Simmons, Brett Anderson, Peter Dunn and Alan Grainer for the Regional Diabetes Information Service Steering Committee

Background

Diabetes remains a major health problem in New Zealand. Optimal management of diabetes requires high quality information at the clinical, organisational and population level. The Waikato has had high quality diabetes databases in primary and secondary care for several years based upon "Get Checked" and the retinal screening programmes respectively.
In February 2003, the Waikato District Health Board provided set up funds for a Professor of Medicine and a diabetes translational research team. On 23 July 2003, following discussions with Pinnacle, the Health Waikato diabetes services, the Waikato District Health Board Information Services, the Health Waikato audit office, and two Maori Health Providers, Professor David Simmons (University of Auckland) created a proposal for a Regional Diabetes Information Service as a way of addressing district, and potentially, regional diabetes information needs. This proposal was further developed with the support of Dr Brett Anderson, Dr Peter Dunn and the Waikato District Health Board Information Services and a joint proposal for funding was generated on 24th November 2003. This was placed before the Waikato District Health Board for funding in 2004. Pinnacle subsequently employed a Project Manager, a diabetes epidemiologist joined the diabetes translational research team and a steering committee was established. Partial Waikato District Health Board funding was approved early in 2005.
This document has been created to describe the background and principles for governance and management. Technical issues relating to the architecture of the data repository/repositories, data exchange, data handling, the data items, reporting and evaluation will be covered elsewhere.

Goals (the ultimate aims):

- To facilitate normal life expectancy, health and quality of life for those with and at risk of diabetes through working at 3 levels:
  - Clinical care – improving the quality, completeness and timeliness of clinical information
  - Population Health – improving the quality and availability of population level information about diabetes for policy development, planning and service development
  - Research – providing a platform for translational research regarding effective approaches to preventing and managing diabetes
- To support the development of wider integrated approaches to health care

Objectives

The initial objectives are:

1. Provide a reliable estimate of the number with known diabetes across the Waikato
2. Establish a robust system for monitoring changes in diabetes care and outcomes across the District:
    - to guide and evaluate health service development and purchasing
    - to provide patient specific clinical data and decision support to clinicians
    - to create a platform for continuous quality improvement
    - assist with the development and piloting of an integrated approach to diabetes care in rural Waikato (Taumaranui) for roll out across the District Health Board
3. Develop and test the governance principles for integrating health data between
    - Primary care (Waikato PHO, Maori Health Providers, Pacific Health Providers) and secondary/tertiary care (Health Waikato Diabetes Services)
    - Different secondary/tertiary care services within Waikato District Health Board (diabetes and at least one other)
    - Secondary/tertiary care services (Diabetes) in Waikato District Health Board and Lakes District Health Board (possible)
4. Develop and test a process for integrated information sharing (ie integrated clinical information from primary, secondary and tertiary care) for diabetic patients in the acute care setting (on the acute wards, Emergency Department and other sites), in primary care (including within a general practice consultations) and specialist clinical services (diabetes initially)

The above are expected to create new knowledge, which will be reported where appropriate in scientific forums including publications and scientific meetings.
Future objectives are to include (a) systems to support patient access to their own clinical material and information (b) systems to support the management of those at high risk of diabetes and related conditions. Data linkage is based upon the NHI number with additional identifiers where necessary.

Target Population Group

Those with known diabetes. Future target groups are those at risk of diabetes and related conditions.

Guardianship Principles

1. Ownership

The data are held in trust for the good of all of those individuals and groups who contribute to the RDIS process and for "society" (ie for all people) It is clear that the data are not owned by the Regional Diabetes Information Service and the data for any given individual are owned, at

least in part by that patient. Ownership of the data by the clinician who has collected that data also exists through the added value of their clinical skills.

2. Privacy and Confidentiality Principles

There are standard protocols for patient privacy, confidentiality and safeguard measures in data collection. The following have been derived from the New Zealand Health Information Privacy Code (1994) and other similar documents.

- Data collection must be for a lawful purpose
- Data must be collected directly from the individual concerned or their authorised representative
- Patients must be fully informed about why and how their information will be used and their rights of access.
- Data must be collected lawfully, fairly and without unreasonable intrusion
- Data must be protected by security safeguards against loss, inadvertent access, destruction, use modification or disclosure
- The policies and practices relating to the management of the database must be readily available
- Patients are entitled to confirmation that their data are on the database and to obtain access to the data unless a valid reason can be provided to deny such access (ie is prohibitively costly to provide, relates to investigations or potential court action, or could endanger the physical or mental health of the person making the request or any other person)
- Data must be correct and accurate
- Data must be kept for no longer that is required for the purposes for which they have been collected or any directly related purpose. Data must be disposed of in a secure manner
- Data must only be used for the purposes for which it was intended or a directly related purpose. Data can be used for improving the health, wealth or safety of the community where its use has been authorised by an appropriate ethics committee.
- A unique identifier should only be assigned to an individual if this is necessary to carry out one or more activities. A unique identifier should only be assigned where the identity has been established through the collection of other pieces of relevant information
- An independent compliance audit programme should be undertaken annually and the outcomes made available to the public

While the above ensure privacy and protection for patients, for the audit process to work and to maximise participation, clinicians need to feel safe with the process and that it will not be used against them (Haynes B. Legal safeguards for the audit process. Br Med J 1999;319:654-655).

The principles are therefore that the data held in repository by RDIS are not made subject to reports which identify individuals and are not to be used in an adverse manner (e.g. reinforcing negative stereotypes) toward:

- Any individual patient
- Any individual clinician
- Any individual participating organisation or group

3. Proposed role of the Local Diabetes Team

It is proposed that the Local Diabetes Team, as an advisory group to the Waikato District Health Board and the Ministry of Health and representing the interests of all of those with a stake in optimising diabetes outcomes in the Waikato, provide overarching Guardianship of Patient Information . This will involve:

- Receiving, and where appropriate, approving reports for the Waikato District Health Board and Ministry of Health in relation to Patient Information
- Reviewing proposed activities outside of this initial document and providing comment to future policy on such matters in relation to Patient Information
- Receive and comment on research applications relating to the Regional Diabetes Information Service
- Ensure that any publications arising from the Regional Diabetes Information Service follow the above principles
- Review applications from new users and/or contributors to the Regional Diabetes Information Service and approve access protocols.
- Review any complaints arising from the Regional Diabetes Information Service in relation to Patient Information
- Refer matters relating to Maori to the Kaitiaki Roopu where relevant

4. Proposed role for the Kaitiaki Roopu

The Diabetes Translational Research team has worked with Iwi Maori Council and the Tumuaki of the University of Auckland to establish a Kaitiaki Roopu. This Roopu meets quarterly and provides guidance on issues relating to Maori outside agreed parameters. It is proposed that this Roopu is asked by the Management Committee or, where deemed appropriate, the Local Diabetes Team, to comment on issues and reports relating to Maori which are not within the above agreed framework. This may require a special meeting to be held for this purpose in a timely way.

The RDIS Management Committee

The current steering group includes representatives from the Waikato PHO, Health Waikato Diabetes Services, WDHB Information services and the University of Auckland diabetes

translational research team. The Chair of the Local Diabetes Team has also been invited to attend.

The proposal is that this group becomes a Management Committee with an invitation to the other PHOs in the Waikato to identify a representative. This Committee would meet monthly to oversee the work underway including :

- the ongoing development of RDIS, including its architecture, systems and reporting
- reviewing and developing policies to manage protection and security of data
- developing policies to manage access to RDIS
- developing policies to manage use of RDIS data having regard to the needs of individuals and groups in the community especially Maori, as well as data contributors and RDIS users.

Contributors to the RDIS

It would be expected that clinicians who are contributing data to the RDIS will have full access to clinical data for their patients on an identifiable basis. Audit work will initially use de-identified data, but may require follow up of identifiable data for access to non-electronic data to complete the audit-action loop.

The founding data contributors to the RDIS (the Waikato PHO and Health Waikato including the diabetes services), will actively seek to include other potential diabetes data contributors, including, but not limited to, the other PHOs in the Waikato, laboratories, private hospitals, pharmacies. Other sources will also be pursued such as data from other District Health Boards for Waikato residents and from the Ministry of Health (eg NZHIS for mortality data).

For organisations in the Waikato agreeing to contribute to the RDIS, a memorandum of understanding will be developed clearly defining responsibilities (contribution of data, following up items requiring clarification) and benefits (access to the data at an agreed level, tools to allow them to analyse their data and that from agreed data items from the RDIS, District wide reports including those based upon different demographic characteristics such as geography and ethnicity) and opportunities for reports relating to specific analyses relevant to an individual organisations or clinician.

The role of the University of Auckland Diabetes Translational Research Team

The University of Auckland diabetes translational research team will work with the Management Committee and other partners to develop and validate the use of RDIS data for improving care including:

- The description of the development of the RDIS to serve as a diabetes surveillance tool including the validity and optimal use of the different data items, different data entry tools and decision support developments.
- The use of the RDIS to evaluate the impact of service developments in different geographically defined areas on metabolic control and outcomes through audit loops and including feedback mechanisms.

- Identification of the socio-economic and geographic risk factors for diabetic complications & metabolic control
- Interpretation of reports

The University of Auckland diabetes translational research team are also in a position to provide the benchmarking service. In due course, a range of specific research questions will be tackled.

APPENDIX 4. FORMS AND QUESTIONNAIRES USED IN THE TAUMARUNUI STUDY

Invitation Letter

Dear _____

Re: Integrated Diabetes Care Initiative

In 2003/4, many people with diabetes, doctors and nurses across the Waikato completed a survey of barriers to diabetes care. The response rate and interest was so high that the analyses of the information are still underway and a report will be sent to participants in 2005. Early findings reveal that several of the barriers to diabetes care relate to the way health services work together and share information. A range of other barriers to diabetes care have also been found to be important, and how to address these is starting to be considered.

In order to start addressing these barriers to diabetes care, the Regional Diabetes Services and your local general practice team have agreed to work together to develop ways to share diabetes related information. This information will be used to guide and evaluate the development of services for people with diabetes. An important aspect is the inclusion of patients' perspectives on diabetes care to which you may have contributed through the barriers to diabetes care survey.

This letter is to serve as advice to you that information sharing between Regional Diabetes Services and general practice relating to diabetes is about to commence.

In Taumarunui, a number of new initiatives will be commencing. These include:

- Diabetes Specialist clinic for those with very poor blood sugar and/or blood pressure control and some other conditions
- Joint diabetes specialist-general practice care planning.
- Group diabetes education sessions
- Further development of the local diabetes support group
- Targeted strategies for those with key barriers to care

As part of this development, we enclose a "barriers to care tick list", which we would be grateful if you would complete to help guide your individual care. We enclose a freepost envelope. Further information regarding other developments will be sent to you.

At the end of 2 years, the aspects of this initiative which are successful will be continued and extended to other parts of the Waikato. In order to justify this extension, research will be undertaken around this initiative, including interviews. This will be undertaken by a research team working with us and we include an information sheet and consent form for your consideration. If you would like to discuss this with someone, please ring Joy Blance (Tel: 896 0020 extension 4180). We would like to pass on your phone number to the research team, if you do not wish this to occur, please either state

this in the freepost envelope, or ring Joy Blance (Tel: 896 0020 extension 4180) within the next fortnight.

We look forward to working with you.

Yours sincerely

Professor David Simmons
Diabetes Specialist

Dr Peter Dunn
Head, Regional Diabetes Services

Please include in the freepost reply:

- The Barriers to Care Ticklist.
- Current Medications List.
- Consent Form.

Patient Information Sheet

Information Sheet for Diabetes Integrated Care Initiative

New approaches to diabetes care are being developed around the world to reduce the chance of damage and improve the quality of life among people with diabetes. The Barriers to Diabetes Care research project in which you may have participated, has revealed that there are a number of ways by which such new approaches could be introduced in the Waikato. The Waikato District Health Board is supporting a Diabetes Integrated Care Initiative which introduces a number of different ways to help those with diabetes to maintain or improve their current health. This Initiative is being commenced in Taumarunui, and if successful after 2 years, is likely to be extended across the Waikato (and perhaps other areas). Monitoring will continue for at least one further year.

In order to show "success" we need to undertake research, to find out whether the new services have improved health, which services have been helpful (and which ones not), how these new services have helped health to improve and the overall costs of these new services.

This research will include:

- Face to face interviews with staff members and some people with diabetes and their families using structured approaches.
- Accessing health records from GPs, clinics, pharmacies, hospitals and any other sources, to obtain existing clinical information such as which tests have been undertaken and their results (eg measures of glucose control), use of different health services

- Invitation to attend for an annual standardised blood pressure measurement at a local venue to add to the blood pressure measurements usually taken by your doctor or others (research measures are often much more precise than those taken in clinical practice)
- Completion of a questionnaire covering things not always collected in a standard way in clinical practice

What are we asking of you?

We now ask you to provide your consent to participate, complete the enclosed questionnaire, attend for the additional blood pressure each year for 3 years (ie 4 times), provide permission for accessing your health records as described above and assist with face to face interviews if approached.

Do I have to take part in this programme?

Your participation is **entirely voluntary**. If you agree to take part in the study, you are free to withdraw at any time and this will not disadvantage you in any way or affect your future health care. You do not have to answer all the questions and you may stop the interview at any time. It will not cost you anything to take part in this study.

What will happen to the results?

The information collected is completely confidential. No information which could identify you will be used in any reports on this study. The results will be stored by a code number in a computer at the Waikato Hospital site. The questionnaires will be stored in a locked room for 10 years and then destroyed. Blood pressure results will be passed onto your named GP.

Advocacy Services:
If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate on 0800 42 36 38 (0800 ADNET)

If you have any questions?
If you have any questions about this project, either now or in the future, please feel free to call us at 07 839 8750 and ask for Prof David Simmons. If you need an interpreter, one can be provided.

This study has received ethical approval from the Waikato Ethics Committee (Reference No: WAI/04/11/106).

Consent Form

Consent form for Diabetes Integrated Care Initiative

- I have read and I understand the information sheet dated <DATE> for those taking part in a three year study designed to look at ways of helping the further development of care for those with diabetes
- I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw myself from the study at any time without any reasons having to be given and this will in no way affect my future health care
- I understand that my participation in this study is confidential and that my identity will not be disclosed in any way, shape or form in any reports resulting from the study.
- I know whom to contact if I have any questions about the study.
- I agree for my health information to be accessed by the study team for the purposes of assessing the impact of the Diabetes Integrated Care Initiative

I_____ (Full name) hereby consent to take part in this study.

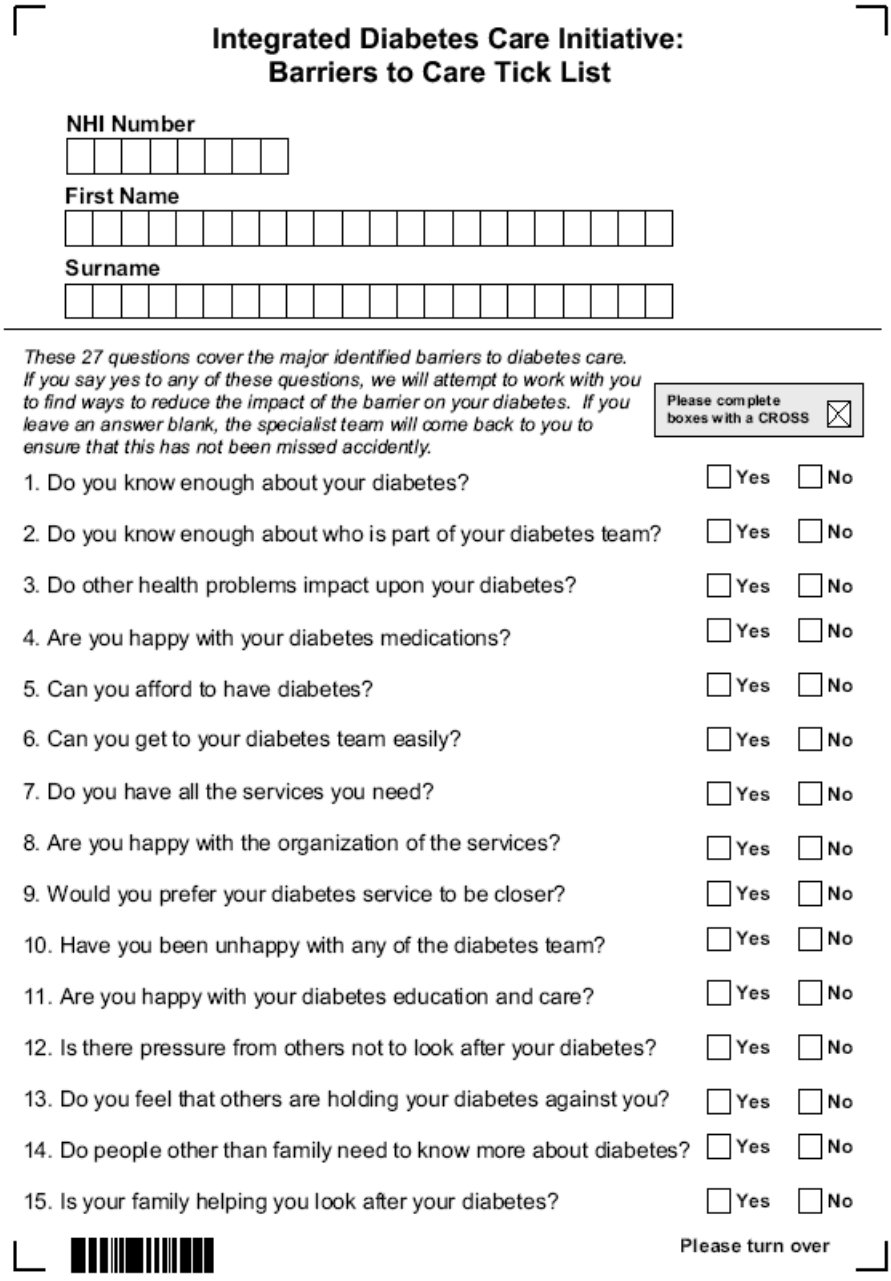
Date: _____

Signature: _____

This study was approved by the Waikato Ethics committee (Reference No: WAI/04/11/106 dated 22.Nov.2004). If you have any questions please contact the Chief Investigator, Professor David Simmons, on 839 8750, your GP or the health advocacy Service for Mid and Lower North island on 0800 42 36 38 (0800 ADNET)

Please complete and return by freepost envelope. ✉

Barriers to Care Tick List



Integrated Diabetes Care Initiative:
Barriers to Care Tick List

NHI Number

First Name

Surname

These 27 questions cover the major identified barriers to diabetes care. If you say yes to any of these questions, we will attempt to work with you to find ways to reduce the impact of the barrier on your diabetes. If you leave an answer blank, the specialist team will come back to you to ensure that this has not been missed accidently.

Please complete boxes with a CROSS ☒

1. Do you know enough about your diabetes?	☐ Yes	☐ No
2. Do you know enough about who is part of your diabetes team?	☐ Yes	☐ No
3. Do other health problems impact upon your diabetes?	☐ Yes	☐ No
4. Are you happy with your diabetes medications?	☐ Yes	☐ No
5. Can you afford to have diabetes?	☐ Yes	☐ No
6. Can you get to your diabetes team easily?	☐ Yes	☐ No
7. Do you have all the services you need?	☐ Yes	☐ No
8. Are you happy with the organization of the services?	☐ Yes	☐ No
9. Would you prefer your diabetes service to be closer?	☐ Yes	☐ No
10. Have you been unhappy with any of the diabetes team?	☐ Yes	☐ No
11. Are you happy with your diabetes education and care?	☐ Yes	☐ No
12. Is there pressure from others not to look after your diabetes?	☐ Yes	☐ No
13. Do you feel that others are holding your diabetes against you?	☐ Yes	☐ No
14. Do people other than family need to know more about diabetes?	☐ Yes	☐ No
15. Is your family helping you look after your diabetes?	☐ Yes	☐ No

Please turn over

Integrated Diabetes Care Initiative:
Barriers to Care Tick List

16. Do family demands stop you from looking after your diabetes? ☐ Yes ☐ No

17. Is there enough support for you in the community or at work? ☐ Yes ☐ No

18. Are you always able to speak with / understand your diabetes team? ☐ Yes ☐ No

19. Do you feel 'comfortable' talking with your diabetes team? ☐ Yes ☐ No

20. Should the public bear more financial responsibility for your care? ☐ Yes ☐ No

21. Are you willing to look after your diabetes? ☐ Yes ☐ No

22. Do you feel you are able to look after your own diabetes? ☐ Yes ☐ No

23. Would you look after your diabetes more if you felt worse? ☐ Yes ☐ No

24. Do you or your diabetes team have enough time for your diabetes? ☐ Yes ☐ No

25. Are you worried, afraid or ashamed of your diabetes? ☐ Yes ☐ No

26. Are you willing to look after your diabetes fully from today? ☐ Yes ☐ No

27. What is more important than looking after your diabetes?

☐ Family ☐ Having Fun

☐ Nothing else ☐ Other Health Conditions

☐ Work

Thank you for your contribution towards Diabetes Control

Medications Form

Integrated Diabetes Care Initiative:
Current Medications

NHI ☐☐☐☐☐☐☐

First Name ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Last Name ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Please include all current medications including non-prescription drugs, herbal medicines & traditional medicines that you use everyday. See example for Paracetamol 500mg, 2 tablets 3 times a day. For alternate day medications, please put half into the frequency column. For weekly, please put "weekly" and for monthly put in "monthly".

Aspirin is an important medication for many people and is often bought over the counter:

Do you use aspirin every day? Yes ☐ No ☐

If Yes, which dose? 100mg ☐ 150mg ☐ 300mg ☐

	Name of Medication	Dose (mg or ml)	Quantity (tablets/ spoons)	Daily Frequency
	EXAMPLE : PARACETAMOL	500mg	2	3
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Please complete and return by freepost envelope. ✉

APPENDIX 5. ADMISSION AND PROCEDURE CODES USED IN THE RENAL PROGRESSION STUDY

Code	Diagnosis Description
1310000	Haemodialysis
1310001	Intermittent haemofiltration
1310002	Continuous haemofiltration
1310003	Intermittent haemodiafiltration
1310004	Continuous haemodiafiltration
1310005	Haemoperfusion
1310006	Peritoneal dialysis, short term
1310007	Intermittent peritoneal dialysis, long term
1310008	Continuous peritoneal dialysis long term
1310008	Continuous peritoneal dialysis, long term
1310600	Thrombectomy of an external arteriovenous shunt
1310900	Insertion and fixation of indwelling peritoneal catheter for chronic peritoneal dialysis
1310900	Insertion and fixation of indwelling peritoneal catheter for long term peritoneal dialysis
1310901	Replacement of indwelling peritoneal catheter for peritoneal dialysis
1311000	Removal of indwelling peritoneal catheter for peritoneal dialysis
1311200	Establishment of peritoneal dialysis by abdominal puncture and insertion of temporary catheter
3450000	Insertion of external arteriovenous shunt
3450001	Replacement of external arteriovenous shunt
3450600	Removal of external arteriovenous shunt
3450900	Arteriovenous anastomosis of lower limb
3450901	Arteriovenous anastomosis of upper limb
3451200	Construction of arteriovenous fistula with graft of vein
3451201	Construction of arteriovenous fistula with prosthesis
3451500	Thrombectomy of arteriovenous fistula
3451800	Correction of stenosis of arteriovenous fistula
3650300	Renal transplantation
3650301	Autotransplantation of kidney
3651600	Laparoscopic complete nephrectomy unilateral
3651601	Complete nephrectomy unilateral
3652801	Radical nephrectomy
9035100	Removal of temporary catheter for peritoneal dialysis
9035200	Education and training for home dialysis
9035300	Test for haemodialysis adequacy
9035301	Test for peritoneal dialysis adequacy
E1020	Insulin-dependent diabetes mellitus with renal complications, not stated as uncontrolled
E1020	Type 1 diabetes mellitus with renal complication unspecified
E1021	Insulin-dependent diabetes mellitus with renal complications, stated as uncontrolled
E1023	Type 1 diabetes mellitus with end-stage renal disease [ESRD]
E1029	Type 1 diabetes mellitus with other specified renal complication
E1120	Non-insulin-dependent diabetes mellitus with renal complications, not stated as uncontrolled
E1120	Type 2 diabetes mellitus with renal complication unspecified
E1121	Non-insulin-dependent diabetes mellitus with renal complications, stated as uncontrolled
E1123	Type 2 diabetes mellitus with end-stage renal disease [ESRD]
E1129	Type 2 diabetes mellitus with other specified renal complication
E1320	Other specified diabetes mellitus with renal complications, not stated as uncontrolled
E1321	Other specified diabetes mellitus with renal complications, stated as uncontrolled
E1420	Unspecified diabetes mellitus with renal complications, not stated as uncontrolled
E1421	Unspecified diabetes mellitus with renal complications, stated as uncontrolled
I120	Hypertensive renal disease with renal failure
I129	Hypertensive renal disease without renal failure
I130	Hypertensive heart and renal disease with (congestive) heart failure
I151	Hypertension secondary to other renal disorders
N040	Nephrotic syndrome, minor glomerular abnormality
N041	Nephrotic syndrome, focal and segmental glomerular lesions
N042	Nephrotic syndrome, diffuse membranous glomerulonephritis
N043	Nephrotic syndrome, diffuse mesangial proliferative glomerulonephritis
N044	Nephrotic syndrome, diffuse endocapillary proliferative glomerulonephritis
N045	Nephrotic syndrome, diffuse mesangiocapillary glomerulonephritis

Code	Diagnosis Description
N046	Nephrotic syndrome, dense deposit disease
N047	Nephrotic syndrome, diffuse crescentic glomerulonephritis
N048	Nephrotic syndrome, other
N049	Nephrotic syndrome, unspecified
N060	Isolated proteinuria with minor glomerular abnormality
N061	Isolated proteinuria with focal and segmental glomerular lesions
N062	Isolated proteinuria with diffuse membranous glomerulonephritis
N063	Isolated proteinuria with diffuse mesangial proliferative glomerulonephritis
N064	Isolated proteinuria with diffuse endocapillary proliferative glomerulonephritis
N065	Isolated proteinuria with diffuse mesangiocapillary glomerulonephritis
N066	Isolated proteinuria with dense deposit disease
N067	Isolated proteinuria with diffuse crescentic glomerulonephritis
N068	Isolated proteinuria with specified morphological lesion, other
N069	Isolated proteinuria with specified morphological lesion, unspecified
N170	Acute renal failure with tubular necrosis
N172	Acute renal failure with medullary necrosis
N178	Other acute renal failure
N179	Acute renal failure unspecified
N180	End-stage renal disease
N188	Other chronic renal failure
N1890	Unspecified chronic renal failure
N1891	Chronic renal impairment
N19	Unspecified renal failure
T824	Mechanical complication of vascular dialysis catheter
T8571	Infection and inflammatory reaction due to peritoneal dialysis catheter
Y841	Kidney dialysis as the cause of abnormal reaction of the patient or of later complication without mention of misadventure
Z452	adjustment and management of vascular access device
Z490	Preparatory care for dialysis
Z490	prepartatory care for dialysis
Z491	Extracorporeal dialysis
Z492	Other dialysis
Z992	Dependence on renal dialysis

APPENDIX 6. CLASSIFICATION OF ADMISSION CODES IN THE HOSPITAL ADMISSIONS STUDY

Code	Group	Diagnosis
1310000	Renal	Haemodialysis
1310002	Renal	Continuous haemofiltration
1310004	Renal	Continuous haemodiafiltration
1310008	Renal	Continuous peritoneal dialysis long term
1310900	Renal	Insertion and fixation of indwelling peritoneal catheter for long term peritoneal dialysis
1310901	Renal	Replacement of indwelling peritoneal catheter for peritoneal dialysis
1311000	Renal	Removal of indwelling peritoneal catheter for peritoneal dialysis
3650300	Renal	Renal transplantation
3651600	Renal	Laparoscopic complete nephrectomy unilateral
3651601	Renal	Complete nephrectomy unilateral
3652801	Renal	Radical nephrectomy
E1020	Renal	Type 1 diabetes mellitus with renal complication unspecified
E1023	Renal	Type 1 diabetes mellitus with end-stage renal disease [ESRD]
E1029	Renal	Type 1 diabetes mellitus with other specified renal complication
E1120	Renal	Type 2 diabetes mellitus with renal complication unspecified
E1123	Renal	Type 2 diabetes mellitus with end-stage renal disease [ESRD]
E1129	Renal	Type 2 diabetes mellitus with other specified renal complication
I120	Renal	Hypertensive renal disease with renal failure
I129	Renal	Hypertensive renal disease without renal failure
I130	Renal	Hypertensive heart and renal disease with (congestive) heart failure
I151	Renal	Hypertension secondary to other renal disorders
N170	Renal	Acute renal failure with tubular necrosis
N172	Renal	Acute renal failure with medullary necrosis
N178	Renal	Other acute renal failure
N179	Renal	Acute renal failure unspecified
N180	Renal	End-stage renal disease
N188	Renal	Other chronic renal failure
N1890	Renal	Unspecified chronic renal failure
N1891	Renal	Chronic renal impairment
N19	Renal	Unspecified renal failure
T824	Renal	Mechanical complication of vascular dialysis catheter
T8571	Renal	Infection and inflammatory reaction due to peritoneal dialysis catheter
Y841	Renal	Kidney dialysis as the cause of abnormal reaction of the patient or of later complication without mention of misadventure
Z490	Renal	Preparatory care for dialysis
Z491	Renal	Extracorporeal dialysis
Z492	Renal	Other dialysis
Z992	Renal	Dependence on renal dialysis

Code	Group	Diagnosis
G458	Cerebro vascular	Other transient cerebral ischaemic attacks and related syndromes
G459	Cerebro vascular	Transient cerebral ischaemic attack unspecified
G463	Cerebro vascular	Brain stem stroke syndrome (I60-I67+)
G464	Cerebro vascular	Cerebellar stroke syndrome (I60-I67+)
I601	Cerebro vascular	Subarachnoid haemorrhage from middle cerebral artery
I610	Cerebro vascular	Intracerebral haemorrhage in hemisphere subcortical
I611	Cerebro vascular	Intracerebral haemorrhage in hemisphere cortical
I612	Cerebro vascular	Intracerebral haemorrhage in hemisphere unspecified
I613	Cerebro vascular	Intracerebral haemorrhage in brain stem
I614	Cerebro vascular	Intracerebral haemorrhage in cerebellum
I616	Cerebro vascular	Intracerebral haemorrhage multiple localised
I618	Cerebro vascular	Other intracerebral haemorrhage
I619	Cerebro vascular	Intracerebral haemorrhage unspecified
I630	Cerebro vascular	Cerebral infarction due to thrombosis of precerebral arteries
I631	Cerebro vascular	Cerebral infarction due to embolism of precerebral arteries
I632	Cerebro vascular	Cerebral infarction due to unspecified occlusion or stenosis of precerebral arteries
I633	Cerebro vascular	Cerebral infarction due to thrombosis of cerebral arteries
I634	Cerebro vascular	Cerebral infarction due to embolism of cerebral arteries
I635	Cerebro vascular	Cerebral infarction due to unspecified occlusion or stenosis of cerebral arteries
I638	Cerebro vascular	Other cerebral infarction
I639	Cerebro vascular	Cerebral infarction unspecified
I64	Cerebro vascular	Stroke not specified as haemorrhage or infarction
I650	Cerebro vascular	Occlusion and stenosis of vertebral artery
I652	Cerebro vascular	Occlusion and stenosis of carotid artery
I653	Cerebro vascular	Occlusion and stenosis of multiple and bilateral precerebral arteries
I660	Cerebro vascular	Occlusion and stenosis of middle cerebral artery
I663	Cerebro vascular	Occlusion and stenosis of cerebellar arteries
I669	Cerebro vascular	Occlusion and stenosis of unspecified cerebral artery
I671	Cerebro vascular	Cerebral aneurysm nonruptured
I672	Cerebro vascular	Cerebral atherosclerosis
I691	Cerebro vascular	Sequelae of intracerebral haemorrhage
I692	Cerebro vascular	Sequelae of other nontraumatic intracranial haemorrhage
I693	Cerebro vascular	Sequelae of cerebral infarction
I694	Cerebro vascular	Sequelae of stroke not specified as haemorrhage or infarction
I698	Cerebro vascular	Sequelae of other and unspecified cerebrovascular diseases

Code	Group	Diagnosis
1340000	Coronory artery disease	Cardioversion
3530400	Coronory artery disease	Percutaneous transluminal balloon angioplasty of 1 coronary artery
3530500	Coronory artery disease	Percutaneous transluminal balloon angioplasty of >= 2 coronary arteries
3530907	Coronory artery disease	Percutaneous transluminal balloon angioplasty with stenting multiple stents
3531000	Coronory artery disease	Percutaneous insertion of 1 transluminal stent into single coronary artery
3531001	Coronory artery disease	Percutaneous insertion of >= 2 transluminal stents into single coronary artery
3531002	Coronory artery disease	Percutaneous insertion of >= 2 transluminal stents into multiple coronary arteries
3531700	Coronory artery disease	Percutaneous peripheral arterial or venous catheterisation with administration of thrombolytic or chemotherapeutic agents b
3532000	Coronory artery disease	Open peripheral arterial or venous catheterisation with administration of thrombolytic or chemotherapeutic agents
3820300	Coronory artery disease	Left heart catheterisation
3820600	Coronory artery disease	Right and left heart catheterisation
3821500	Coronory artery disease	Coronary angiography
3821800	Coronory artery disease	Coronary angiography with left heart catheterisation
3821801	Coronory artery disease	Coronary angiography with right heart catheterisation
3821802	Coronory artery disease	Coronary angiography with left and right heart catheterisation
3849700	Coronory artery disease	Coronary artery bypass using 1 saphenous vein graft
3849701	Coronory artery disease	Coronary artery bypass using 2 saphenous vein grafts
3849702	Coronory artery disease	Coronary artery bypass using 3 saphenous vein grafts
3849703	Coronory artery disease	Coronary artery bypass using >= 4 saphenous vein grafts
3849705	Coronory artery disease	Coronary artery bypass using 2 other venous grafts
3849706	Coronory artery disease	Coronary artery bypass using 3 other venous grafts
3849707	Coronory artery disease	Coronary artery bypass using >= 4 other venous grafts
3850000	Coronory artery disease	Coronary artery bypass using 1 LIMA graft
3850001	Coronory artery disease	Coronary artery bypass using 1 RIMA graft
3850002	Coronory artery disease	Coronary artery bypass using 1 radial artery graft
3850300	Coronory artery disease	Coronary artery bypass using >= 2 LIMA grafts
3850302	Coronory artery disease	Coronary artery bypass using >= 2 radial artery grafts
3850304	Coronory artery disease	Coronary artery bypass using >= 2 other arterial grafts
I200	Coronory artery disease	Unstable angina
I201	Coronory artery disease	Angina pectoris with documented spasm
I208	Coronory artery disease	Other forms of angina pectoris
I209	Coronory artery disease	Angina pectoris unspecified

Code	Group	Diagnosis
I210	Coronory artery disease	Acute transmural myocardial infarction of anterior wall
I211	Coronory artery disease	Acute transmural myocardial infarction of inferior wall
I212	Coronory artery disease	Acute transmural myocardial infarction of other sites
I213	Coronory artery disease	Acute transmural myocardial infarction of unspecified site
I214	Coronory artery disease	Acute subendocardial myocardial infarction
I219	Coronory artery disease	Acute myocardial infarction unspecified
I220	Coronory artery disease	Subsequent myocardial infarction of anterior wall
I228	Coronory artery disease	Subsequent myocardial infarction of other sites
I229	Coronory artery disease	Subsequent myocardial infarction of unspecified site
I236	Coronory artery disease	Thrombosis of atrium auricular appendage and ventricle as current complications following acute myocardial infarction
I238	Coronory artery disease	Other current complications following acute myocardial infarction
I240	Coronory artery disease	Coronary thrombosis not resulting in myocardial infarction
I241	Coronory artery disease	Dressler's syndrome
I248	Coronory artery disease	Other forms of acute ischaemic heart disease
I249	Coronory artery disease	Acute ischaemic heart disease unspecified
I250	Coronory artery disease	Atherosclerotic cardiovascular disease so described
I2510	Coronory artery disease	Atherosclerotic heart disease of unspecified vessel
I2511	Coronory artery disease	Atherosclerotic heart disease of native coronary artery
I2512	Coronory artery disease	Atherosclerotic heart disease of autologous bypass graft
I252	Coronory artery disease	Old myocardial infarction
I253	Coronory artery disease	Aneurysm of heart
I254	Coronory artery disease	Coronary artery aneurysm
I255	Coronory artery disease	Ischaemic cardiomyopathy
I256	Coronory artery disease	Silent myocardial ischaemia
I258	Coronory artery disease	Other forms of chronic ischaemic heart disease
I259	Coronory artery disease	Chronic ischaemic heart disease unspecified

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