Factors that affect the delivery of diabetes care

A thesis submitted for the Degree of
Doctor of Philosophy

by

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2000

Summary

Diabetes is emerging as a major threat to health, with global economic and social implications. Recent research has shown that the morbidity and mortality associated with diabetes can be reduced by timely and effective treatment. However, unless people with diabetes have access to this treatment, the impact of diabetes will continue to rise. This thesis therefore explores the current standards of care which people with diabetes receive. It also looks at factors likely to impact on delivery of diabetes care. Studies were conducted at two levels. In the studies described in Chapters 2 and 3, general data applicable to all or nearly all patients with diabetes were collected. This approach substantially eliminates selection bias but precludes the ability to examine clinical outcomes. In the other studies, detailed in Chapters 4, 5 and 6, specific aspects of diabetes care pertaining to more select groups of diabetic subjects were examined. This approach allows clinical parameters to be examined in more detail but is more subject to selection bias. It is hoped that the combination of these two approaches provides a more balanced view of the topic under examination.

In Australia, the Medicare Program, a single government controlled universal health insurance fund, provides access to medical services for all residents. Medicare occasions of service data therefore represent the most comprehensive source of information regarding health service utilisation

in Australia. The data does not account for people receiving diabetes care through public hospital based services. However, a survey of public hospitals within NSW (n=198), described in Chapter 2, showed that the number of individuals in this category is relatively small and represents only 5.2% of the diabetic population.

Using Medicare item codes, and with the permission and assistance of the Commonwealth Department of Health and Aged Care, data were extracted on attendance to medical practitioners and utilisation of diabetes related procedures for people living in New South Wales (NSW) for the individual years between 1993 to 1997. All data were stratified by the presence of diabetes, gender and age group. Individuals were deemed to have diabetes if an HbA_{1c}, which can only be ordered for a person with known diabetes, had been performed over the 5-year period and the sample size adjusted for the incidence of diabetes. Once adjusted, the number of people with diabetes in NSW for the individual years 1993 to 1997 were 143,920, 156,234, 168,216, 177,280 and 185,780. Comparison with 1996 census data confirmed a 91.7% capture of the total NSW population (5,495,900/5,995,545 individuals).

The data were retrieved for NSW as a whole and for individual postcodes. Postcodes were then classified by population density as either major urban, urban or rural. On average over the study period, persons with diabetes accounted for 3.1% of the population but they used 5.5% of general practitioner services. As seen in Chapter 2, a large proportion of

people with diabetes were also under the care of specialists and consultant physicians, up to 51.2% and 41.8% respectively, a 3 to 4 fold increase when compared with their non-diabetic counterparts. In regard to geographical location, once adjusted for age and gender, the odds ratio of attending a specialist was only slightly higher for people with diabetes living in areas of high population density when compared to people with diabetes living in rural areas. This ratio reached as high as 1.85 in regard to attendance to consultant physicians (Chapter 3). The odds ratio for the non-diabetic population was similar indicating that the difference in access to consultant physicians was not disease specific.

Analysis of results showed that despite the increase in service utilisation, large proportions of people with diabetes were not routinely monitored in regard to diabetes and its complications across the State. By 1997, HbA_{1c} was still not performed in over 40% of people with diabetes each year and only 11.6% of the diabetic population had undergone microalbuminuria estimation. Interestingly, the differences in levels of monitoring between rural and urban areas were surprisingly small. Monitoring of diabetes and its complications did improve in all parts of the State over the study period. However, the greatest improvement was seen in rural areas, despite rural patients having fewer attendances to general practitioners and fewer patients attending specialist care.

In the face of finite resources and the rising prevalence of diabetes, an increasing number of patients will need to rely on general practitioners to

provide diabetes care regardless of where they live. A 'shared care' approach which encourages and supports general practitioners to manage patients with diabetes, while giving them access to specialist services for those patients that require them, is increasingly being advocated as a way of maximising efficacy while minimising costs. Yet if health care professionals leave undone what they think is done by others, shared care can become neglected care. Chapter 4 reports a detailed audit of 200 randomly selected shared care patients who were assessed on two or more occasions. This study showed that the majority of specialist treatment recommendations are implemented by general practitioners. Doctors formally registered with the Diabetes Shared Care Programme and those who write longer referral letters were more likely to implement recommendations than their counterparts. Moreover, the average HbA_{1c} and the complication profile of these patients were similar to those found in various studies around the world. This suggests that diabetes can be well managed by a shared care approach that is adequately integrated.

To overcome the problem that data is lacking on those patients that did not return for specialist review, a further 200 shared care patients who were lost to follow up from the shared care system were traced. Information regarding whether treatment recommendations had been implemented was sought from both the referring doctor and the patient. Overall, information on 182 of the 200 patients could be obtained. As discussed in Chapter 5, comparison of the returned and non returned patients' demographic and clinical profiles at time of their initial specialist

review showed that general practitioners differentiated between the 'more complicated' patients, choosing to re-refer those with macrovascular disease, while maintaining the care of 'less complicated' patients. Re-referral for specialist review was also dependent on the patient remaining under the care of their original doctor. Encouragingly, general practitioners seemed to take a more active role in the non-returned group. They included more details regarding type and duration of diabetes in the referral letters of patients who were not re-referred for specialist review. They also implemented more treatment recommendations in the non-returned group, with the difference in implementation rate for metabolic recommendations reaching statistical significance. This study also showed that movement of patients between doctors raises concern regarding continuity of care.

The multi-factorial nature of diabetes means that best practice is not easily accommodated within a single appointment. Thus continuity of care becomes an important issue. To assess the current status, 479 consecutive patients referred to the Royal Prince Alfred Hospital Diabetes Centre in a 6-month period were recruited and underwent a detailed clinical assessment. They were also questioned regarding the number of general practitioners they attended and the length of time they had been under the care of the referring doctor. The results outlined in Chapter 6 showed that the majority of people with diabetes (87.7%) attended only one general practitioner and had been under the care of that doctor medium to long term. Younger patients, who were relatively healthy apart from the

presence of diabetes, were more likely to attend several general practitioners or have changed their general practitioner within the last year. This lack of continuity had little difference on acute outcomes such as glycaemic and blood pressure control. Appropriately, continuity of care increased with increasing age and the increasing prevalence of diabetes complications, mainly macrovascular disease.

These studies indicate that further efforts are required to improve the overall standard of diabetes care within Australia. At present there is a heavy dependency on specialist services. As the population ages and the number of people with diabetes increases, much of this burden will fall on general practitioners, as is already evident in rural areas. When provided with appropriate support and infrastructure, general practitioners are able to maintain standards of care through referral of patients with more complex medical problems and by maintaining the degree of continuity appropriate to the patient's needs. However, the collection of relevant information to monitor future trends in diabetes services provision is important. As shown in this thesis, Medicare data represents an easy and cost effective method with which to do so.

Publications arising from this research

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NSW	New South Wales
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Chapter 1

Literature Review

Introduction

Diabetes is a chronic disease, characterised by hyperglycaemia (high levels of blood glucose), and is caused by deficient insulin production, resistance to insulin's action or a combination of both. The chronic hyperglycaemia of diabetes is associated with long term damage, dysfunction or failure of several organs, especially the eyes, kidneys, nerves, heart and blood vessels. Symptoms of hyperglycaemia include polyuria, polydipsia, weight loss, polyphagia and blurred vision. Further symptoms of impaired growth in children and susceptibility to infection are associated with chronic hyperglycaemia.

In the past diabetes was considered to be a single disease. However, it is now clear that diabetes is a heterogeneous metabolic disease caused by many different mechanisms. The vast majority of cases fall into two broad categories, Type 1 and Type 2 diabetes. These categories are based on differences in the aetiology, natural history and clinical presentation of the disorder.

Type 1 diabetes

Type 1 diabetes is ranked as one of the most common childhood diseases in developed countries (American Diabetes Association, 1993[a]), although nearly half of all newly diagnosed cases are in adults (Scott and Brown,

1991). This form of diabetes most frequently results from a cell mediated autoimmune destruction of the islet beta cells that are responsible for the production of insulin (Atkinson and Maclaren, 1994). Islet cell-related auto-antibodies against molecules such as glutamic acid decarboxylase and tyrosine phosphatase-like molecule have been shown to be present in 85% to 90% of individuals at the clinical onset of Type 1 diabetes (Pozzilli et al, 1998).

The rate of beta cell destruction is variable, being rapid in some individuals, mainly infants and children, and slower in others, mainly adults (Zimmet et al, 1994). This means that some patients, particularly children, present with ketoacidosis, characterised by extreme hyperglycaemia and acidosis, while others retain enough residual beta cell function to prevent ketoacidosis for many years. At the latter stage of beta cell destruction there is little or no insulin secretion and insulin therapy is required for the patient to survive.

The autoimmune destruction of beta cells has multiple genetic predispositions. The risk of developing Type 1 diabetes is increased within families where a member is already effected. However, more than 80% of cases occur in persons with no family history of Type 1 diabetes and concordance among identical twins is less than 50% (Verge et al, 1995; Singh et al, 1998).

Autoimmune destruction of beta cells is also related to environmental factors. For example, children who are breastfed for a shorter time or are introduced to cow's milk early may be at increased risk of autoimmune mediated Type 1 diabetes (Dahl-Jorgensen et al, 1991; Gerstein, 1994). Rapid growth in infancy has also been linked with an increased risk of Type 1 Diabetes (Hypponen et al, 1999). There may also be certain viruses that act as a catalyst of beta cell destruction (Andreoletti et al, 1998) but this has not been substantiated in large-scale studies.

Type 2 diabetes

Type 2 diabetes accounts for 85% to 90% of all diabetes in developed countries and virtually all diabetes in developing countries. It results from a combination of abnormalities of insulin action and insulin secretion. In this type of diabetes, the cells on which insulin mainly acts, muscle, fat and liver cells are resistant to its action. This is known as insulin resistance. This is usually combined with a relative rather than absolute insulin deficiency. Although insulin therapy is often used to treat Type 2 diabetes, persons with this condition are not dependent on insulin therapy to survive. Treatment commonly involves management of risk factors, dietary modification and the use of oral hypoglycaemic agents.

There are probably many different causes of Type 2 diabetes. According to the new classification system, once a known cause of diabetes has been established, such as an insulin receptor mutation or defect in insulin action, it is no longer considered Type 2 diabetes. Instead, they are

grouped as ‘other specific types’ (Alberti and Zimmet, 1998). Autoimmune destruction of the beta cells was not considered to be a main aetiological factor. However, in more recent times it has been found that a proportion of adults who present with apparent Type 2 diabetes actually have a slowly evolving autoimmune insulitis, a condition that has been called latent autoimmune diabetes in adults (LADA) (Tuomi et al, 1993).

Table 1-1. Aetiological classification of disorders of glycaemia

Type 1
Autoimmune
Idiopathic
Type 2
Other specific types
Genetic defects of beta cell function
Genetic defects of insulin action
Diseases of the exocrine pancreas
Endocrinopathies
Drug or chemical induced
Infections
Uncommon forms of immune-mediated diabetes
Other genetic syndromes sometimes associated with diabetes
Gestational Diabetes

Adapted from Alberti KGMM, Zimmet PZ. Definition, diagnosis and classification of diabetes mellitus and its complications. Part 1: diagnosis and classification of diabetes mellitus. Provisional Report of a WHO Consultation. Diabetic Medicine 1998; 15:539-53.

Type 2 diabetes has a strong genetic component with almost 100% concordance of disease in monozygotic twins (Hitman and McCarthy, 1991). Although the genes for certain rare forms of diabetes have been identified, it is likely that multiple genes, in various combinations, acting on different metabolic functions, are involved in the pathogenesis of the usual cases of Type 2 diabetes.

The increasing patterns of Type 2 diabetes in developing countries and migrant populations suggest that factors inherent in Western lifestyles are also involved (Zimmet et al, 1978; Zimmet, 1992). The risk of developing diabetes has been shown to rise with both increasing obesity and physical inactivity (Perry et al, 1995). Studies have also linked low birth weight (Hales and Barker, 1992; Carlsson et al, 1999), maternal weight (Fall et al, 1998) and weight change (Wannamethee and Shaper, 1999) with an increased risk of developing disease later in life. Diet is an important determinant of both obesity and weight gain, therefore it is thought to play a crucial role in the development of Type 2 diabetes. High saturated fat intake has been found to be linked with progression to overt diabetes in persons with impaired glucose tolerance (Marshall et al, 1994). In a study in Da Qing, China, dietary modification was shown to reduce the risk of developing diabetes by almost a third in persons at risk (Pan et al, 1997).

Type 2 diabetes frequently goes undiagnosed for many years because the hyperglycaemia develops gradually and at early stages of the disease process it is often not severe enough for the patient to notice any of the

classic symptoms of diabetes (Harris et al, 1992). Nevertheless, these patients are at risk of developing the complications of diabetes.

The complications of diabetes

Over the course of diabetes a variety of complications can develop, often resulting in disability or premature death. These complications can be broadly classified as microvascular or macrovascular.

Microvascular complications

The microvascular complications of diabetes include retinopathy, nephropathy and neuropathy (although this complication is likely to have many other metabolic components in its aetiology). Microvascular complications appear to result from the interaction of metabolic, genetic and environmental factors, but most importantly they develop in the presence of long-standing hyperglycaemia (Pirart, 1978, Brownlee, 1992; Greene et al 1992; Klein, 1995). Persons with Type 1 diabetes are exposed to the disease for a longer duration than their Type 2 counterparts and consequently exposure to hyperglycaemia and subsequent microvascular disease is greater for this group (Pirart, 1978; Krolewski et al, 1985).

Retinopathy is a frequent complication of diabetes and is one of the leading causes of blindness and visual disability in adults. The prevalence of retinopathy increases with duration of Type 1 diabetes; between 50% and 100% of persons with Type 1 diabetes have evidence of retinopathy after 20 to 50 years (Klein, 1991). The prevalence of retinopathy and the association with duration is not as obvious in the Type 2 population as the time of onset of disease is not always known. In this type of diabetes,

diabetic status is often diagnosed through a routine medical examination or when they present with symptoms of disease related to diabetes. Nevertheless, studies have estimated the prevalence of proliferative retinopathy to be as high as 15% to 20% (Gill, 1986; Klein, 1991). After 15 years duration, approximately 10% of all persons with diabetes develop a severe handicap due to retinopathy, glaucoma and cataract while around 2% become blind (Klein, 1991).

Nephropathy is also a major threat to people with diabetes. The reported prevalence of nephropathy in persons with Type 1 diabetes is between 35% to 40% (Hanssen et al, 1986; Deckert et al, 1991). The prevalence in the Type 2 population is not as well defined, and rates vary between 3% and 16% for different ethnic populations (WHO Expert Committee on Diabetes Mellitus, 1980; Dekert et al, 1991). People with Type 1 diabetes have a 23 fold increased risk of developing end stage renal disease (ESRD), which accounts for 55% of overall mortality in this group of patients (Gill, 1991[a]). The risk of ESRD is also increased in persons with Type 2 diabetes (Leese, 1992), although most die from cardiovascular disease.

The last microvascular complication, diabetic neuropathy, has been shown to occur with similar frequency in both Type 1 and Type 2 populations (Pirart, 1978). It is one of the most common complications of diabetes with studies showing that around 7% to 8% of people have diabetic neuropathy at the time of diagnosis (Pirart, 1978; UK Prospective

Diabetes Study Group, 1994), rising to over 50% after 25 years duration (Pirart, 1978). Diabetic neuropathy can affect the peripheral or autonomic nervous system. Peripheral sensory neuropathy is the more common form of diabetic neuropathy and is a major contributing cause of non-traumatic lower limb amputation (US Department of Health and Human Services, 1991; Reiber et al, 1992). It can also cause distressing pain. Autonomic neuropathy is less common and may result in bladder and bowel dysfunction and impotence. It may also affect the heart (Cowie and Eberhardt, 1996).

Macrovascular complications

A major cause of morbidity and mortality in persons with diabetes is atherosclerosis, which manifests itself as coronary heart disease, cerebrovascular disease or peripheral vascular disease (Pyorala, 1989). Predisposing risk factors to macrovascular disease in diabetes are the same as those for the non-diabetic population: smoking, obesity, hyperlipideamia, hypertension, insulin resistance and platelet abnormalities, as well as the added risk factors of hyperglycaemia and hyperinsulinaemia (Reaven, 1988; Hsueh and Anderson, 1992).

In age and sex matches studies it has been shown that the Type 2 diabetes population has a mortality rate which is twice that of their non-diabetic counterparts (Panzram, 1987). Coronary heart disease is the greatest causes of death in persons with Type 2 diabetes in Caucasian and industrialised countries. The estimated mortality rates range between 50%

to 60% (Kessler, 1971; Panzram, 1987); conferring a 2 to 4 fold increase in mortality risk compared with the non-diabetic population (Jarrett, 1984). The mortality rate of coronary heart disease in Type 1 diabetes is lower and is estimated to be 15% (Gill, 1991[a]). While there is a higher prevalence of obesity, high blood pressure and cholesterol in persons with diabetes, this does not fully explain this excess of coronary heart disease (Tuomilehto et al, 1998).

Cerebrovascular disease, which presents as transient ischaemic attack or stroke, is less prevalent than coronary heart disease. In the United States, the risk of stroke is 2 to 4 times higher in persons with Type 2 diabetes when compared with the non-diabetic population (Cowie and Eberhardt, 1996). The presence of diabetes also doubles the risk of mortality following stroke (Bell, 1994). Cerebrovascular disease accounts for approximately 12% to 15% of deaths in persons with Type 2 diabetes and 3% in persons with Type 1 diabetes (Panzram, 1987; Gill, 1991[a,b]), and is associated with the risk factors hyperglycaemia, hypertension and smoking (Oppenheimer et al, 1985; Morrish et al, 1991).

Peripheral vascular disease is more common in persons with diabetes than health control subjects (Janka et al, 1980). People with Type 2 diabetes have been found to have 4 to 8 times the risk of peripheral vascular disease, which causes intermittent claudication or rest pain (Cowie and Eberhardt, 1996). The prevalence of peripheral vascular disease in persons with Type 2 diabetes is estimated at 12%, and rises with the

duration of diabetes (WHO Expert Committee on Diabetes Mellitus, 1980).

The importance of glycaemic control

The complications of diabetes described above result in increasing disability, reduced life expectancy and enormous health costs for virtually every society. However, with advances in diabetes medicine and clinical practice, there is the distinct prospect of improved prognosis for persons with diabetes.

Control of blood glucose has always been deemed an essential component of diabetes management. However, it wasn't until the early 1990's that the Diabetes Control and Complications Trial (DCCT), which studied the effect of intensified glycaemic control on 1,411 Type 1 subjects over a period of 10 years, showed unequivocally that maintenance of near normoglycaemia was associated with a 40% to 70% reduction in risk of microvascular complications. This landmark study concluded that, notwithstanding the 2 to 3 fold increase in hypoglycaemia, intensive therapy results in a delay in the onset and a major slowing of the progression of the microvascular and neurological complications of diabetes (Diabetes Control and Complications Trial Group, 1993).

The Ohkubo study and the United Kingdom Prospective Diabetes Study (UKPDS) showed that persons with Type 2 diabetes also benefited from tight management of glycaemic control (Ohkubo et al, 1995; UK Prospective Diabetes Study Group, 1998[a,b]). This latter study recruited 5,102 patients with newly diagnosed Type 2 diabetes in 23 centres within the United Kingdom between 1977 and 1991. Patients were followed for

an average of 10 years to determine whether intensive use of pharmacological therapy to lower blood glucose would result in clinical benefits, that is reduced macrovascular and microvascular complications, and whether the use of sulphonylureas, metformin or insulin, had specific therapeutic advantages or disadvantages. The results of this study established that microvascular disease can be reduced in persons with Type 2 diabetes by lowering blood glucose levels. In the UKPDS, the overall microvascular complication rate was decreased by 25% (UK Prospective Diabetes Study Group, 1998[a]). While there was no statistically significant effect of lowering blood glucose on macrovascular complications, a 16% reduction (P=0.052) in the risk of combined fatal or non-fatal myocardial infarction and sudden death was observed.

The DCCT and UKPDS are the longest and largest prospective studies confirming that lowering blood glucose concentrations slows or prevents the development of diabetic complications. As such, they have major implications for health care providers and their patients.

The importance of treating blood pressure and lipids in diabetes

Despite the health and social implications of microvascular disease, mortality is often recognised to be a key marker of the impact of a disease. Mortality rates for patients with diabetes are 2 to 3 times higher than in people without diabetes (Riley et al, 1995). While the microvascular complication, nephropathy, accounts for 55% of deaths in persons with Type 1 diabetes (Gill, 1991[a]), cardiovascular disease is the major cause of death in persons with Type 2 diabetes. Coronary heart disease alone confers a 2 to 4 fold increase in mortality risk compared with non-diabetic individuals (Jarrett, 1984). Thus the prevention and treatment of macrovascular complications is of prime importance in the Type 2 population.

Unlike the clear relationship of glycaemia with microvascular disease, where the reduction in microvascular disease is proportional to the reduction in hyperglycaemia (UK Prospective Diabetes Study Group, 1998[a]), a relationship with macrovascular disease and mortality is clouded by the many risk factors that cause cardiovascular disease. As previously discussed, the UKPDS showed that lowering of blood glucose resulted in a 16% reduction in the risk of combined fatal or non-fatal myocardial infarction and sudden death but this reduction was not statistically significant. While blood glucose has not been clearly identified as a strong risk factor, diabetes is a strong and established risk factor for macrovascular morbidity and mortality. Multiple mechanisms exist for the increased incidence of macrovascular disease and for increased

morbidity and mortality once macrovascular disease occurs (Jacoby and Nesto, 1992; Aronson et al, 1997). High triglyceride levels, low HDL cholesterol and predominance of small, dense LDL particles increase the risk of plaque formation. Higher rates of hypertension are also present among diabetic individuals. In addition to increased plaque formation, diabetes is associated with thrombogenesis due to higher levels of fibrinogen and reduced fibrinolytic activity (Ceriello, 1993).

In terms of reducing morbidity and mortality for persons with Type 2 diabetes, it is treatment of these risk factors that has potential for greatest effect. A post hoc subgroup analysis carried out on data from 202 diabetic patients and 4,242 non-diabetic patients who had participated in the Scandinavian Simvastatin Survival Study (4S) showed that lowering of cholesterol in diabetic patients with coronary heart disease reduced total mortality by 43% and major coronary heart disease event by 47% (Pyorala et al, 1997). A comparison of the 7 year incidence of myocardial infarction, both fatal and non-fatal, among 1,373 non-diabetic subjects with the incidence among 1,059 diabetic subjects suggested that even diabetic patients without a history of cardiovascular disease have an increased risk of a vascular event, equal to that of the non-diabetic population with known cardiovascular disease (Haffner et al, 1998). These findings support the rationale for aggressive lipid treatment for all persons with diabetes.

Despite advances in therapeutic agents, lowering blood pressure to fully normotensive levels is often unachievable, even with multiple agents. However, aggressive treatment of blood pressure, aiming for a diastolic blood pressure of below 85 mmHg, confers a risk reduction of 51% in major cardiovascular events (Hansson et al, 1998) as well as reducing the risk of heart failure by 56% and stroke by 44% (UK Prospective Diabetes Study Group, 1998[c]). A clear benefit of treating isolated systolic hypertension was found in an analysis of the diabetic subgroup in the Systolic Hypertension in the Elderly Program (Curb et al, 1996), with a lowering in major cardiovascular disease event rates by 34%. Based on these and similar findings more intensive treatment of dyslipidaemia and hypertension are now seen as cornerstones of treatment for patients with diabetes.

Smoking cessation is also seen as particularly important, since smoking increases both microvascular and macrovascular disease risk. The use of aspirin to decrease thrombogenesis has also been promoted and has been shown to reduce myocardial infarction by 36% (Hansson et al, 1998). The use of beta-blockers and ACE inhibitors in diabetes has also been shown to be useful in the treatment of hypertension in diabetic individuals (UK Prospective Diabetes Study Group, 1998[c,d]). Indeed, beta-blockers and ACE inhibitors appear to have much greater benefit to diabetic patients than to those without diabetes (Nesto and Zarich, 1998). In the Heart Outcomes Prevention Evaluation Study, treatment with the ACE Inhibitor Ramapril reduced rates of death, myocardial infarction, stroke, coronary

revascularization, cardiac arrest, and heart failure as well as the risk of developing diabetes and complications related to diabetes (The Heart Outcomes Prevention Evaluation Study Investigators, 2000[a]). In the subgroup analysis of persons with existing diabetes, Ramipril lowered the risk of these combined outcomes by 25% and overt nephropathy by 24% (The Heart Outcomes Prevention Evaluation Study Investigators, 2000[b]).

These effective and affordable therapies can reduce the chronic complications of diabetes. Diabetes is often clustered with dyslipidaemia and hypertension. Therefore, many patients will require multiple drugs and considerable efforts from both health care provider and diabetic patients will be needed to achieve the maximal therapeutic benefit. However, our efforts to date are obviously not enough. A recent report from the EURODIAB IDDM Complications Study found that less than half (42.2%) of those patients identified with hypertension were on treatment and only 11.3% were controlled (defined as a blood pressure <= 140/90 mmHg). Moreover, the majority (81%) of these patients were only receiving single drug treatment (Collado-Mesa et al, 1999). Another study by Colhurn and colleagues (1999) found that only 46% of patients with hypertension had their blood pressure controlled at below 160/95 mmHg and only 6% of patients who met guidelines for lipid lowering treatment were taking appropriate medication.

Treatment guidelines for diabetes

As outlined above, research is producing increasing amounts of important new evidence for diabetes care. Over the last decade, numerous sets of best practice and consensus guidelines for diabetes care have been developed (European IDDM Policy Group, 1993; Alberti et al, 1994; NSW Department of Health, 1996; NHMRC, 1997; American Diabetes Association, 2000;), based on expert interpretation of this evidence as well as clinical experience. These guidelines aim to ensure that all people with diabetes receive optimal standards of care, to promote consistency in clinical practice and to ultimately improve health outcomes.

Each of the guidelines recognises the importance of achieving normoglycaemia, or near normoglycaemia, within the parameters of patient safety. They recommend that glycosylated haemoglobin levels, the most useful measure of glycaemic control, are within two standard deviations of the mean for the non-diabetic range or within one percentage point of the upper limit of normal. In order to monitor progress towards treatment goals and to detect incipient signs of complications, they also recognise that persons with diabetes must receive regular medical care. While American, European and Australian groups differ on the frequency of the components of the physical examination, they all agree on the need to regularly monitor weight and blood pressure and perform thorough eye and foot examinations. They also emphasise the importance of regular laboratory evaluation, including glycosylated haemoglobin, lipid profile and microalbuminuria.

Do guidelines work?

While these guidelines may provide a framework for 'quality' diabetes care, the overall standard of care is unlikely to change unless they are recognised and broadly implemented. A recent Australian study reporting on the impact of nationally developed guidelines on procedural and surgical management of coronary heart disease on cardiologists and cardio-thoracic surgeons within NSW found that only half the respondents were aware of the guidelines (Shah et al, 1999). It is obvious that guidelines can not have an impact on clinical practice when only half of the key audience is aware of their existence. The potential for their irrelevance is even greater when the target audience is wider than the sample used in this study, where 26% of the respondents had been consulted during the formulation of the guidelines.

Even if guidelines were widely disseminated and promoted, there remains a lingering doubt about how effective they can be in achieving the desired effect of improving the quality of health care. Unfortunately, previous studies have demonstrated considerable difficulty in bringing clinical practice in line with the guidelines. A study that examined the effect of a nationally endorsed consensus statement recommending decreases in the use of Caesarean sections found that the majority of obstetricians agreed with the recommendation and reported changing their behaviour. However, data on actual practice showed that the rates of Caesarean section were 15% to 49% higher than that reported, resulting in only a slight change from the previous upward trend (Lomas et al, 1989).

In terms of diabetes, Australian guidelines recommend that persons with diabetes undergo an ophthalmological review every 2 years, yet a study by McCarty et al (1998) found that 31.8% of people with diabetes had never visited an ophthalmologist. A survey of physician practice behaviours related to diabetes in the United States reported a wide variation in adherence to recommendations, with a relatively high adherence for eye exams and blood pressure examination (~ 80%), but poor adherence with examination of feet and urinary protein (~ 30 to 50%) (Kenny et al, 1993). The study also highlighted differences in behaviour between doctors. For example, older doctors often had lower adherence rates. Although this finding is supported by other studies (Marrero et al, 1991; Jacques et al, 1991; Overland, 1996), it must be interpreted with some caution, as the physicians were not asked about their adherence based on the age and the duration of diabetes of the patients under their care, important characteristics that may have differed between doctor age groups.

In many countries, the majority of persons with diabetes are managed at the community level. Many general practitioners feel that experts who don't understand general practice develop guidelines (Gupta et al, 1997). Moreover, general practitioners work in a large, 'contextual framework' and environmental factors such as patient load and time constraints, are likely to have a profound effect on their behaviour and adherence to guidelines (Starfield, 1994; Veale et al, 1999).

After a decade of experience with evidence-based guidelines, we now know that guidelines are not enough. Integrating clinical prevention into busy practices is a political and logistical process. Designed to update and disseminate new information to practitioners, continuing medical education has been proposed as a potential mechanism for closing the gap between evidence based practice and those practices actually taking place. However, a number of studies have demonstrated that continuing medical education courses and workshops are not enough to ensure clinicians incorporate clinical guidelines into their practice (el-Kebbi et al, 1997; Gerstein et al, 1999). While Gerstein et al (1999) showed in a large survey of family physicians that attitudes, knowledge and patterns of practice in regard to diabetes clinical practice guidelines can be improved short term, the long-term effect of continuing medical eduction was disappointing. It is therefore important to develop or identify systems of care that inherently provide quality diabetes management. This is especially important given the projected epidemic of chronic disease such as diabetes.

The evolving diabetes epidemic

Diabetes is certain to be one of the most challenging health problems facing all nations this century. It has been estimated to affect over 135 million people throughout the world (King et al, 1998). Without any proven methods available to prevent diabetes, the burden of this chronic disease will continue to rise. Using the best available epidemiological data, it is projected that as many as 300 million people will be affected by diabetes by the year 2025 (Table 1-2). The overall prevalence of diabetes will increase by 35%, rising from 4.0% to 5.4%, over this same period. While diabetes has been thought of as a disease of developed countries, the anticipated increase in prevalence is estimated to be greater in economically developing than developed countries, with a rise of 48% versus 27% (King et al, 1998).

Early work by Zimmet and colleagues documented substantial increases in the prevalence of Type 2 diabetes in areas where economic development was accompanied by life style changes and Westernisation (Zimmet et al, 1977; Zimmet et al, 1978). The progressive aging of the world's population, resulting from better control of communicable diseases and improved nutrition and hygiene, has also played an important role in the marked increase in non-communicable diseases such as Type 2 diabetes. Risk factors such as obesity, inappropriate nutrition and physical inactivity are also unmasking those at risk of this chronic disease. This transition in economic status and disease patterns, combined with the rise in diabetes related risk factors, has catapulted diabetes from a rare disease at the turn

of the 20th century to its current position as a major contributor to disability and death.

Table 1-2. Top 10 countries for estimated numbers of adults with diabetes, 1995 and 2025

Country	1995 (millions)	Country	2025 (millions)
India	19.4	India	57.2
China	16.0	China	37.6
United States	13.9	United States	21.9
Russian Federation	8.9	Pakistan	14.5
Japan	6.3	Indonesia	12.4
Brazil	4.9	Russian Federation	12.2
Indonesia	4.5	Mexico	11.7
Pakistan	4.3	Brazil	11.6
Mexico	3.8	Egypt	8.8
Ukraine	3.6	Japan	8.5
All other countries	49.7	All other countries	103.6
Total	135.3	Total	300

Adapted from King H, Aubert RE, Herman WH. Global burden of diabetes, 1995-2025: prevalence, numerical estimates, and projections. Diabetes Care. 1998; 21(9): 1414-31.

The personal impact of diabetes

There is no denying that the personal impact of diabetes is substantial. Diabetes reduces both quantity and quality of life. The life expectancy for people with diabetes is, even in developed countries, considerably lower

than for people without diabetes (US Department of Health and Human Services, 1991). In the United States, for example, the life expectancy for people with Type 1 diabetes is reduced by 15 years or more for those diagnosed with the disease under the age of 30 years (Cowie and Eberhardt, 1996). In terms of quality, it has been shown that people with diabetes experience increased morbidity and have a lower perception of self-worth (Jacobson, 1996; Jacobson et al 1997).

While overall absenteeism from work due to sickness is not significantly greater, absenteeism rises sharply once people with diabetes develop long-term complications. These complications can lead to permanent disability. Olivera et al (1991) showed that this disability, due mainly to macrovascular disease and retinopathy, can result in an average of 11 years of work production lost per patient. In the United States it has been estimated that diabetes accounts for one million lost workdays, 47,800 permanently disabled workers and 6.8% of the total mortality (Fox-Ray et al, 1993).

The economic impact of diabetes

The economic impact of diabetes is also substantial. The International Diabetes Federation (1994) calculates that persons with diabetes in developed countries have health costs 2 to 4 times higher than the general population. This figure may be exceeded in either direction in developing countries, depending on the intensity of care available to people with diabetes and on the size of the countries health care budget.

While individual figures vary, the cost of diabetes for countries such as England and the United States in the late 1980s and early 1990s hovered around the £500 million and $(US) 20.4 billion mark, and represented 5% of the gross national production (Gerard et al, 1989; Laing and Williams, 1989; American Diabetes Association, 1993[b]). While these estimates are staggering, they probably underestimate the true cost as many of the complications of diabetes, particularly those related to the cardiovascular system, are seldom considered in the cost calculations. In studies where cardiovascular disease was considered, it accounted for over 70% of the total cost of diabetes complications (Jacobs et al, 1991; American Diabetes Association, 1993[b]), thus its exclusion would have a major impact on the reliability of any cost estimate. Using a much wider approach to costing, Rubin and colleagues (1994) suggested that the total health care expenditure for people with diabetes in the United States to be $(US)105 billion or 1 in 7 health dollars spent.

An even more sobering thought is that the cost of diabetes has risen disproportionately. In the United States, the cost of diabetes health care escalated 380% from 1969 to 1980 while the medical health component of the consumer price index climbed only 134% over this same period (Songer, 1992). This rise is likely to continue as the population continues to age.

Who should look after people with diabetes

The rise in number of people with diabetes and increasing cost of diabetes care will necessitate the health care sector to examine who should look after patients with this chronic disease. Even at present, with increasing cost and scarcity of hospital beds, it is already a difficult task to have patients admitted to hospital for initiation of diabetic treatment or for re-stabilisation. Long-term follow up also poses a problem. Over the last few decades hospital clinics have found themselves facing increasing numbers of patients who are seen by a constantly changing array of doctors, many of whom are junior and unfamiliar with the nuances of caring for a person with a chronic disease (Bending and Keen, 1992).

Specialist care also has its problems. Despite relatively small numbers of patients followed at the specialist level, they constitute a large proportion of the cost. For example, a health maintenance organisation in America found that although patients with diabetes accounted for only 1.5% of their membership, they used 10% of the health budget. Most of this difference was attributed to a 4-fold difference in the use of medical specialists (Glauber and Brown, 1992). Without major increases in funding, specialist diabetes services will find it difficult to meet any growth in demand and either people with diabetes will receive fewer specialist services, or fewer people will be seen.

It therefore appears inevitable that general practitioners will play an increasingly significant role in diabetes care. The advantages of generalist care are essentially the person to person relationship that exists between patient and doctor and the fact that diabetes has implications on how patients live. General practitioners are the best placed of all health professionals to take an overall view of the person with diabetes health in its widest sense and to assist in their physical, psychological and social support.

Many areas of diabetes management, particularly those related to metabolic and blood pressure control and encouragement of life style change can be provided at the general practitioner level. Whitford et al (1995) conducted a review of diabetes care in North Tyneside in the United Kingdom from 1991 to 1994. They noted a significant shift in the proportion of patients attending primary care over this period. Of more importance, they found that attending a general practitioner contributed to a significantly lower glycosylated haemoglobin. A further study by McGill and colleagues (1993) found that the majority of general practitioners referring patients to a Diabetes Complications Assessment Service at a large teaching hospital in Sydney, Australia, were managing their patients' hypertension appropriately.

There is also evidence to suggest that many patients prefer to be managed by their own general practitioner rather than a hospital specialist (Tasker, 1984; Flemming, 1985; Whitford et al, 1995). A survey by Kamien et al

(1995) conducted in a metropolitan area of Perth, Australia, found that more than 90% of patients were highly satisfied with the diabetes care they received from their general practitioner. In another Australian study, Ward and colleagues (1997) assessed quality of life and patient satisfaction in a group practice in inner Sydney as well as auditing metabolic and process outcomes. This study also showed a high level of patient satisfaction, but at the cost of sub-optimal quality of care and significant inter-doctor variation.

While there are advantages in assigning management of diabetes to general practitioners alone, there are also difficulties. For example, there are certain patients that general practitioners may be reluctant to manage exclusively at the community level. A comparison of two populations of patients with diabetes demonstrated that the clinical picture of patients cared for exclusively by their general practitioner differed from that of those referred to specialist care, with significantly fewer patients requiring insulin therapy being managed at the general practice level (Overland et al, 1998). These findings were in line with results of an earlier survey of general practitioners which found that, in the majority of cases where patients were not referred to specialist care, the general practitioner felt the patient could be easily managed on diet alone or tablets (Wyndham, 1995). There also appears to be reluctance on the behalf of general practitioners to manage patients with complications of diabetes. When a group of primary care physicians in the United States were asked what care they routinely provided to people with diabetes and when they refer

patients, almost all managed hypertension and obesity, but ~ 70% referred patients for specialist care if diabetic complications such as neuropathy or nephropathy were present (National Institute of Diabetes and Digestive and Kidney Diseases, 1991).

In some instances, patients who receive their diabetes care exclusively at the community level fare less well in terms of blood glucose control and long term complications. In the early 1980s, Hayes and Harries (1984) reported on a 5 year follow up of 200 patients randomised to diabetes follow up through either hospital diabetic clinic or general practice. Their findings showed that general practitioner care was associated with a higher mean glycosylated haemoglobin concentration (10.4% versus 9.5%), an increase in hospital admissions due to medical reasons and a higher risk of death. Kemple and Hayter (1991) audited records of 223 patients with diabetes in Bristol around the same time and found that a considerable number had no diabetes review within the previous year. A larger audit by Benett et al (1994) showed similar findings. The latter study also found that glycosylated haemoglobin level, the most valuable test in assessing diabetic control, was documented in only 57% of patients. While measurement of blood pressure was relatively high (81%), assessment of feet, eyes and lipids were disappointingly low (37%, 48% and 34% respectively).

A recent study in the United States found similar rates of glycosylated haemoglobin estimation, with a glycosylated haemoglobin result

documented in only 56% of patients cared for by primary care physicians. Moreover, for those with a glycosylated haemoglobin level measured, 39% had a result greater than 10%, a level clearly indicative of inadequate metabolic control. This study also found that 60% of patients had a serum cholesterol greater than 5.2 mmol/L but were not on lipid lowering agents (Peters et al, 1996).

Diabetes care in Australia

In Australia, as in many parts of the world, it is thought that the care of the majority of patients with Type 2 diabetes is provided solely by their general practitioner, without the involvement of diabetes specialists. For patients requiring specialised care, access to specialist services, provided by either the public hospital system through traditional diabetes clinics or in private practice, is dependent on referral from the general practitioner. Despite the importance of information for future health care planning, there has only been limited work examining the extent to which people with diabetes use these services and the standards of care they receive. A survey of members of Diabetes Australia, the national organisation for people affected by diabetes, found that only 41% of Sydney residents with Type 2 diabetes and 70% of a rural sample nominated their general practitioner as the main provider of diabetes care (Baker, 1990). As membership to Diabetes Australia is voluntary these results may be biased. By contrast, the results of the 1989-90 National Health Survey suggested that general practitioners were seen as the main health care provider for as many as 90% of the diabetic population (Australian Bureau of Statistics, 1991). However, this does not distinguish care for diabetes or other health problems.

In regard to standards of care, a study conducted in inner Sydney found a significant proportion of patients cared for exclusively by their general practitioner had sub-optimal metabolic control and had developed the long

term complications of diabetes (Overland et al, 1998). However, the ability to generalise these results was limited due to the relatively small catchment area from which the patients were selected.

Two larger studies have been conducted in South Australia and Western Australia. In the mid 1990s, Beilby and colleagues (1994) presented findings of a questionnaire sent to 173 randomly selected general practitioners working in South Australia which was designed to assess self-reported diabetes management in the areas of detection, diagnosis, assessment, monitoring and knowledge. The research found that a substantial proportion of doctors did not include monitoring of glycosylated haemoglobin levels in their routine management of their diabetic patients. Only half of the general practitioners surveyed examined lower limb sensation and more than a third (37% for patients with Type 1 diabetes and 43% for patients with Type 2 diabetes) assessed tendon reflexes, tests considered important as part of periodic diabetic assessment. The second study by Kamien and colleagues (1994) audited the medical records of general practitioners working in metropolitan areas of Western Australia and provided a snap shot of diabetes care. Findings from this study showed that the most commonly recorded clinical parameters were diet, body weight, glycosylated haemoglobin and ophthalmoscopy however the medical records were highly variable. Other important parameters, such as foot examination, were rarely recorded.

While these studies have helped to shed some light on the possible inadequacies in regard to the level of care provided, they may not be representative of the diabetic population as a whole. For example, the South Australian study relied on provider self report, a methodology likely to produce results that exceed actual performance. There is also the issue of respondant bias with 24% of eligible doctors failing to return the questionnaire. Of more concern, only 42% of eligible doctors recruited patients for the Western Australian study. It is not unreasonable to assume that participating general practitioners were more comfortable with having their diabetes practices scrutinised than were the non-participating doctors. If this were true, it suggests that doctors in both studies provided better care than general practitioners as a whole. In regard to the latter study, the possible variable quality of medical records and variable adherence to medical record review protocol may also have resulted in either an over or underestimation of the true standard of care. It would therefore appear that existing research remains lacking.

Further studies to identify more representative data sources, which are population based or near population based, are required to assist with ongoing monitoring of diabetes management within the Australian health care setting. Obviously the method used to identify people with diabetes is of critical importance to ensure accurate assessment of resource utilisation and standards of care. While it has been suggested that lists from Diabetes Australia or The National Diabetes Supply Scheme, a government funded system to subsidise insulin syringes and blood glucose

strips, may be useful to identify people with diabetes, these lists are biased towards those requiring insulin therapy. A national register to include all persons with Type 2 diabetes would be exorbitantly expensive and unrealistic. On the other hand, smaller data sets using information collected on patients selected from hospital care or one district alone is unlikely to be representative of the diabetic population as a whole.

In Australia, the Medicare Program, a single government controlled universal health insurance fund, provides access to medical and hospital services for all residents. Under this system, patients are subsidised for the cost of attendances to medical officers and associated laboratory and other investigations. Information regarding occasions of service are maintained by the body responsible for the administration of the Medicare Program, the Health Insurance Commission. Data regarding patient characteristics such as age, gender and place of residence are also known. Data relating to services provided for public patients in hospitals is not included. There may also be groups such as the Australian Aboriginal population who may be more likely to be missed by the Medicare system for reasons such as non-diagnosis or use of traditional medicine. Nevertheless, the Medicare database is recognised as the most up-to-date and representative source of information regarding quantity and type of health service utilisation. As will be seen in this thesis, the proportion of diabetic patients treated by the public hospital system is quite small. Therefore, the use of Medicare data is able to provide valuable

information regarding the patterns and standards of diabetes care within Australia, on a near population based scale.

Supporting diabetes care – The shared care approach

In a study by Larme and Pugh (1998) primary care physicians in the United States rated diabetes as significantly harder to treat than diseases such as hypertension and angina. While they recognised that the complexity of diabetes treatment contributed to their frustration, many of the participants also cited lack of support from the health care system as an important cause. This would imply that diabetes care at the primary care level needs support.

As the burden of diabetes care is likely to fall progressively on general practitioners, it is essential to study the interaction between them and specialists. Improved health outcomes for a chronic disease such as diabetes may be heavily dependent on access to specialised services at the optimal time. Alternative models of care, aimed at facilitating improved integration of primary and secondary care to ensure efficient use of resources may be crucial to improving quality and outcomes of care. While the United Kingdom has systematised care by providing mini-clinics, other countries such as Australia have leaned towards systems of 'shared' care. Shared care is a collaborative approach to coordinating patient care between specialists and primary health care providers. Its purpose is to support general practitioners manage the majority of persons with diabetes at the primary care level, to improve the efficacy of secondary care and to transfer the coordination of care from the secondary care level back to the primary care level. Ideally, shared care combines

the strengths of both levels of care and contribute to better health outcomes for the individual and the community while reducing costs. The hypothesis that care will be improved as a result of better relationships between general practitioners and specialists is, most certainly, a reasonable one.

In terms of maximising the quality of diabetes care within the confines of available resources, it is important to consider how much benefit shared care programmes can achieve. In the early 1990s, Hoskins et al (1993) conducted a randomised-controlled trial comparing shared care with conventional care, comprising of specialist clinics or usual general practitioner care. The study recruited 206 patients referred by their general practitioner to the diabetic clinic of a major teaching hospital in the inner city area of Sydney, Australia. Patients were followed for 12 months and key end points of metabolic and blood pressure control, attendance rates and completeness of clinical notes were recorded. The results showed that metabolic control and blood pressure improved equally in all 3 groups. However, the shared care group had better attendance rates than either general practitioner alone or specialist care. Shared care was also better in terms of measurement and recording of random blood glucose, weight and blood pressure and resulted in a more appropriate balance of care. However, this study examined only an acute intervention in a local area over a relatively short period of time and excluded patients with diabetic complications or other serious medical conditions, accounting for nearly a quarter of ‘eligible’ patients. The

shared care arm was also supported by a liaison nurse who encouraged patients to return to their general practitioner at 3 monthly intervals for review of their diabetes. A longer follow up may have lessened the patients' enthusiasm for shared care and enabled assessment of whether long term shared care improves clinical outcomes rather than just the process of care.

Two British studies also featured regular prompting of patients and/or doctors. Hurwitz and colleagues (1993) conducted a randomised controlled trial in the Islington area of London comparing hospital clinic care with prompted care, consisting of 6 monthly reminders for patients to complete blood and urine tests, followed by a clinical review with their general practitioner. Five hundred and seventy patients, who had attended diabetes clinics in the Islington area over the preceding 2 years and attended 1 of the 38 general practices agreeing to participate in the study, were identified. The 209 patients who agreed to participate were followed for a median of 2 years, after which time their hospital and general practitioner notes were reviewed for process and outcome data. At the end of the study there were no significant differences in glycaemic control, number of patients admitted to hospital with a diabetes related condition or number of deaths between the groups. However, measurement and recording of albuminuria, plasma glucose concentrations and glycated haemoglobin estimations were more frequent and follow up for retinal screening better with prompted care.

The second study conducted by the Diabetes Integrated Care Evaluation Team (1994) used a pragmatic randomised trial. By design, the 274 patients agreeing to participate in the study were permitted to chose between conventional diabetes clinic care and integrated care. Patients choosing the later alternative were seen by 1 of 3 participating general practice groups every 3 or 4 months and in the hospital clinic annually. Patients choosing clinic care continued to be seen by the clinic at 4 monthly intervals. The hospital clinic's computer based record system coordinated patient recall for both arms of the trial. As with the previous studies, there were no differences in metabolic control between the groups at the completion of the study but higher frequencies of examinations and more visits with the doctor were noted for patients choosing integrated care.

While these studies reported glycaemic control that were at least as good in general practice as with specialist care, there are a number of problems in interpreting and generalising the results. For example, both studies enrolled self-selected local practices. The patients were also self-selecting, were stabilised, had no medical complications and were already attending specialist services. Moreover, the follow up of these trials was only 2 years. The reported success of shared care may therefore have been a reflection of the inclusion of enthusiastic doctors and patients. The relatively short follow-up period and the trial context may also have affected it.

The studies described above were all published before 1994. Developments in shared care models have continued since this time, with potential for both enhancement and reduction in the quality of care. Our knowledge of the effects of these developments is limited. Moreover, randomised controlled trials, which are arguably the gold standard for the evaluation of therapeutic interventions, are not necessarily the best design to study approaches to diabetes care. Health care delivery is often complex with a large variability in clinical practice. The potential to consider this variability or to include 'blinding' of either patient or health care provider within the study design is clearly not available. Thus there is a need to conduct new studies that examine the effectiveness of shared care in 'real life'.

Conclusions

It is evident by the above review that diabetes is emerging as a major threat to health, with global economic and social implications on an enormous scale. However, recent research has shown that the morbidity and mortality of diabetes can be reduced and has provided us with the tools to do so. However, unless people have access to quality care, the devastating personal and financial impact of diabetes will continue to rise. It is therefore important to develop accurate systems to monitor current standards of diabetes care and to identify models that inherently provide quality care. These are the major themes of the studies presented in this thesis.

Chapter 2

The pattern and standard of diabetes care in New South Wales

Introduction

It is estimated that 1.5 million Australians will be affected by diabetes by the year 2010 (McCarty et al, 1996). Despite this prediction, very little is known regarding the general pattern and standard of diabetes care in Australia, information that is vital for future health care planning. The most frequently used methods to monitor diabetes care have been provider self report and review of medical records. There are potential limitations in each of these methods. Provider self report usually exceeds the actual performance and is prone to respondant bias. On the other hand, medical record review usually results in under-estimation. Another problem is that a great deal of our current knowledge is based on patients selected from hospital care or from one district. The use of these selected data is unlikely to be representative of the diabetic population as a whole. Similarly, the use of overseas data would not be the optimal method of studying local health care delivery.

In Australia, the Medicare Program, a single government controlled universal health insurance fund, provides access to medical and hospital services for all residents. Medicare occasions of service data held by the

Health Insurance Commission therefore represents the most reliable and comprehensive source of health service utilisation data in Australia. The use of such data may provide valuable information while addressing some of the limitations of other monitoring methods. The Health Insurance Commission Act allows release of Medicare data through the Commonwealth Department of Health and Aged Care provided that such release does not enable the identification of individual patients or providers. To ensure there is no inadvertent disclosure of confidential information, access to data relating to less than 60 services is restricted. However, under section 130(3)(a) of the Act, full data may be released if it is viewed to be 'necessary in the public interest'. After liaising with the Commonwealth Department of Health and Aged Care certified release of data relating to diabetes care was granted using this section of the Act. The study described in this Chapter used this information to construct a profile of diabetes care for people living in NSW over a 5-year period.

Method

Identification of individuals with diabetes

Under the Medicare Program, reimbursement for HbA_{1c} is only awarded if the test is performed in a person with established diabetes. Therefore, individuals were deemed to have diabetes if this test had been performed anytime between 1993 and 1997. This 5 year capture period was chosen because some diabetic individuals may not have an HbA_{1c} performed every year. To overcome the problem of individuals not developing diabetes until the latter part of the study period, the data for the first 4 years was adjusted for the incidence of diabetes (Kenny et al, 1995). Once adjusted, the number of people with diabetes for the individual years 1993 to 1997 were 143,920, 156,234, 168,216, 177,280 and 185,780.

Quantification of medical service usage

Medicare item codes were used to extract data on attendance to medical practitioners (general practitioners, specialist, consultant physicians and ophthalmologists) as well as utilisation of diabetes related procedures (fluorescein angiography, laser photocoagulation, HbA_{1c}, lipid studies, HDL cholesterol and microalbuminuria) for people living in NSW for each of the individual years between 1993 to 1997.

The item codes used for the retrieval are shown in Table 2-1. Information on number of individuals and number of services for the selected Medicare item codes was retrieved and stratified by the presence of

diabetes, gender and age group (<40 years, 40 to 64 years and > 64 years). The age group of individuals was based on their age at January 1 of each year. Data on any individual without a Medicare service for a particular 12 months was omitted for the remainder of the study period to exclude people who may have died. The item codes used to retrieve data on lipids, HDL cholesterol and microalbuminuria were introduced during 1993. While information regarding these tests was retrieved for this year they were not included in this analysis due to possible inaccuracies in the data.

Table 2-1. Medicare item codes used for data retrieval

Service	**Item code**
Attendance to a general practitioner (surgery consultation)	3,23,36,44,52,53,54,57
Attendance to a specialist	104,105
Initial attendance to an ophthalmologist	106
Attendance to a consultant physician	110,116,119
Fluorescein angiogram	11215,11218
Retinal photocoagulation	42809
Lipid studies	66331,66335,66337,66339,66341
HDL cholesterol	66317
Microalbuminuria	66316
HbA_{1c}	66319

Estimation of State funded services

In NSW, medical services provided by the public hospital system are funded by the State health budget and are not captured by Medicare occasions of service data. Therefore, some adjustment needs to be made to include people receiving diabetes care through hospital based services. Although it is widely suspected that the number of individuals in this category is relatively small, to calculate the adjustment factor, a short questionnaire (Appendix 1) was sent to the General Manager and Director of Pathology Services of all State funded hospitals within NSW (n=198). The General Manager was asked to provide details regarding whether their hospital conducted a diabetes clinic, and if so, an estimation of the number of individual patients seen by the clinic for the previous calender year. Directors of Pathology of the same hospitals were independently asked to provide information regarding whether their laboratory performed HbA_{1c} assays and if so, the number of assays performed for the previous calendar year. Further information regarding the proportion of assays funded by the Federal (Medicare) versus State health system was also sought. A stamp-addressed envelope was provided to expedite return of the questionnaire. To maximise the response rate, the hospitals were contacted by telephone if a response had not been received within a month of the initial mailing.

Statistical methods

Statistical analysis was performed using SAS (SAS Institute Inc, 1991). The data is presented as the proportion of people with and without

diabetes using the services. The data was also analysed in terms of the average number of services per individual attending the various medical officers and the average number of tests for patients in whom tests were performed. The Mantel-Haenszel trend test (Armitage and Berry, 1990) was used to examine for changes in patterns of care over the study period. The effect of diabetes on the proportion of patients attending the various doctors and undergoing surveillance was examined using logistic regression, adjusting for age and gender and interaction between age, gender and year. Results are expressed as average, percentage or adjusted odds ratio (OR) and 95% confidence interval (95% CI).

Results

Patterns of attendance to medical practitioners

Comparison with 1996 census data confirmed that 91.7% of the NSW population (5,495,900 /5,995,545 individuals) use a Medicare service each year. On average over the study period, people with diabetes accounted for 3.1% of the population but used 5.5% of general practitioner services. As seen in Table 2-2, the mean number of their attendances to general practitioners over the years 1993 to 1997 remained relatively stable, ranging from 10.7 to 11.3 visits per year, a 1.8 fold increase when compared with the non-diabetic population.

A large proportion of people with diabetes also received care by specialists and consultant physicians. In Australia, specialist disciplines would include surgeons, some ophthalmologists and obstetricians. There was a slight fall in the proportion of people with diabetes seeing a specialist over the study period (52.3% to 51.2%) while the proportion of people seeing a physician slightly rose from 37.7% to 38.6%. While test for trend showed statistical significance (test for trend: $\chi^2_{(df-1)}$ =45.0; P<0.001 and $\chi^2_{(df-1)}$ = 37.0; P<0.001 respectively), these changes are unlikely to have any clinical effect. For the non-diabetic population, the proportion of people seeing specialists and consultant physicians was considerably lower, ranging from 25.7% to 26.9% and 11.0% to 12.2 % respectively. Attendance to specialists on a per patient basis remained

stable at 2.9 visits per year, a 1.3 fold increase when compared to the non-diabetic population. Attendance to consultant physicians varied between 3.7 and 3.9 visits per patient per year, representing a 1.4 fold increase.

Table 2-2. Average number of services per person for those people with and without diabetes who attended a general practitioner, specialist or consultant physician for the years 1993 to1997

	1993		1994		1995		1996		1997	
Service Provider	**Diabetes**	**No diabetes**	**Diabetes**	**No diabetes**	**Diabetes**	**No diabetes**	**Diabetes**	**No diabetes**	**Diabetes**	**No diabetes**
General practitioner	11.3	6.0	11.2	6.0	11.2	6.1	11.1	6.1	10.7	6.0
Specialist	2.9	2.3	2.9	2.3	2.9	2.3	2.9	2.3	2.9	2.3
Physician	3.9	2.9	3.8	2.8	3.7	2.7	3.8	2.7	3.8	2.7

Adherence with clinical and laboratory recommendations

In 1993, only 3.4% of patients with diabetes were billed for an initial examination by an ophthalmologist. This fell slightly to 2.3% by 1997 (test for trend: $\chi^2_{(df-1)}$ =562.1; P<0.001). Ophthalmologists frequently bill using specialist item codes 104 and 105, which are shared with specialists of other disciplines. As seen previously, a large proportion of people with diabetes were billed under these item codes, rising slightly from 51.2% to 52.3% over the study period. Thus the maximum possible proportion of patients seen by an ophthalmologist was 54.5%. The proportion of patients undergoing fluorescein angiography and laser photocoagulation remained stable, fluctuating by only 0.2% (2.2% to 2.4%; test for trend: $\chi^2_{(df-1)}$ =30.1; P<0.001 and 1.7% to 1.9%; test for trend: $\chi^2_{(df-1)}$ =32.8; P<0.001 respectively).

Table 2-3 lists the frequency of laboratory evaluations performed compared to the standards of care recommended in Principles of Care and Guidelines for the Clinical Management of Diabetes Mellitus produced by the NSW Department of Health (1996). Changes in adherence to clinical and laboratory guidelines were more notable in the monitoring of HbA_{1c} and microalbuminuria. In 1993, only 48.8% of people with diabetes had a HbA_{1c} estimation within the 12-month period. By 1997, this had risen to 56.8%, a rise of 8.0% (test for trend: $\chi^2_{(df-1)}$ =2085.9; P<0.001). A rise of similar magnitude was seen in the proportion of patients undergoing a microalbuminuria estimation (4.7% to 11.6%; test for trend: $\chi^2_{(df-1)}$

=5488.0; P<0.001). Improvement in monitoring of lipids was less marked, with a rise of only 2.6% (49.4% to 52.0%; test for trend: $\chi^2_{(df-1)}$ =295.6; P<0.001).

Table 2-3. Frequency of laboratory investigations in people with diabetes for the years 1993 to 1997

Test	1993	1994	1995	1996	1997
HbA_{1c} *					
% patients tested	48.9	51.3	50.8	52.8	56.8
tests per patient	1.5	1.5	1.5	1.6	1.5
Lipid studies † §					
% patients tested		49.4	50.1	51.7	52.0
tests per patient		1.5	1.6	1.6	1.6
HDL cholesterol † §					
% patients tested		18.3	19.0	17.7	18.8
tests per patient		1.3	1.3	1.3	1.3
Microalbuminuria ‡ §					
% patients tested		4.7	7.1	8.5	11.6
tests per patient		1.1	1.2	1.2	1.2

NSW Health Department (1996) guidelines for the management of diabetes
* 1-4 tests per year
† Every 1 to 2 years if normal, every 3 to 6 months if abnormal or on treatment
‡ Every year
§ Possible inaccuracy as the item codes used to retrieve data on lipids, HDL cholesterol and microalbuminuria were introduced during 1993 therefore information for this year is not listed

The effects of age and gender

The difference in the proportion of diabetic and non-diabetic patients undergoing clinical and laboratory investigations and attending the various medical practitioners, adjusted for age and gender, is shown in Table 2-4. For patients with diabetes, age and gender had different effects on attendance to specialist practitioners. As seen in Table 2-5, the proportion of patients attending a consultant physician increased with age, whereas, individuals aged 40 to 64 were significantly less likely to be under the care of a specialist than their younger counterparts (adjusted OR: 0.88; 95%CI: 0.84 to 0.92). Fewer men than women received care at the specialist level (adjusted OR: 0.51; 95% CI: 0.49 to 0.52). These findings are consistent with the obstetric requirements of the younger and female cohorts. The effect of gender on attendance to a consultant physician was less strong.

The effect of age and gender on the frequency of laboratory evaluations in persons with diabetes is shown in Table 2-6. While the proportion of patients with an HbA_{1c} estimation increased with age, there was a bias towards those aged 40 to 64 in regard to lipid and microalbuminuria testing.

Table 2-4. The difference (OR and 95% CI) in the proportion of patients using services over the years 1993 to 1997 for people with diabetes (people with no diabetes used as reference group), adjusted for age and gender

Service	**1993**	**1994**	**1995**	**1996**	**1997**
Attendance to specialist	2.97 (2.94 to 3.00)	2.99 (2.96 to 3.02)	3.05 (3.02 to 3.08)	3.05 (3.02 to 3.08)	3.03 (3.00 to 3.06)
Initial attendance to ophthalmologist	2.86 (2.78 to 2.95)	3.07 (2.97 to 3.16)	2.98 (2.90 to 3.07)	3.16 (3.06 to 3.25)	3.13 (3.04 to 3.24)
Attendance to physician	4.91 (4.86 to 4.97)	4.82 (4.77 to 4.87)	4.75 (4.70 to 4.80)	4.60 (4.56 to 4.65)	4.52 (4.48 to 4.57)
Fluorescein angiogram	18.28 (17.54 to 19.04)	16.38 (15.73 to 17.06)	15.65 (15.05 to 16.28)	13.85 (13.31 to 14.41)	16.19 (11.04 to 23.73)
Retinal photocoagulation	32.74 (31.0 to 34.6)	30.23 (28.70 to 31.84)	27.40 (26.05 to 28.83)	28.87 (27.50 to 30.30)	33.15 (31.60 to 34.77)
Lipid studies *		7.06 (6.99 to 7.13)	6.87 (6.80 to 6.94)	6.93 (6.86 to 6.99)	6.62 (6.56 to 6.68)
HDL cholesterol *		6.56 (6.47 to 6.65)	5.89 (5.82 to 5.97)	5.17 (5.10 to 5.24)	4.92 (4.86 to 4.98)
Microalbuminuria *		35.04 (33.91 to 36.21)	53.27 (51.74 to 54.85)	58.93 (57.35 to 60.55)	70.47 (68.78 to 72.19)

* Possible inaccuracy as the item codes used to retrieve data on lipids, HDL cholesterol and microalbuminuria were introduced during 1993 therefore information for this year is not listed

Table 2-5. The effect of age and gender on attendance to specialists and consultant physicians for people with diabetes

	Adjusted OR (95% CI)	
	Specialist	**Consultant physician**
Age		
< 40 years	1.0	1.0
40-64 years	0.88 (0.84 to 0.92)	1.41 (1.34 to 1.48)
>64 years	1.13 (1.08 to 1.19)	1.63 (1.55 to 1.71)
Gender		
Female	1.0	1.0
Male	0.51 (0.49 to 0.52)	1.03 (1.00 to 1.06)

Table 2-6. The effect of age and gender on the proportion of people with diabetes with laboratory investigations performed

	Adjusted OR (95% CI)			
	HbA_{1c}	**Lipid studies**	**HDL cholesterol**	**Microalbuminuria**
Age				
< 40 years	1.0	1.0	1.0	1.0
40-64 years	1.22 (1.16 to 1.27)	3.77 (3.53 to 4.02)	6.45 (5.79 to 7.19)	1.77 (1.55 to 2.01)
>64 years	2.29 (2.19 to 2.41)	3.00 (2.80 to 3.21)	6.44 (5.76 to 7.20)	1.19 (1.04 to 1.36)
Gender				
Female	1.0	1.0	1.0	1.0
Male	1.12 (1.09 to 1.15)	1.63 (1.57 to 1.70)	2.15 (2.03 to 2.28)	1.60 (1.52 to 1.68)

Adjustment for State funded services

The response rate to the questionnaires sent to the General Managers and Directors of Pathology of all state-funded hospitals within NSW was 85.4% and 79.8% respectively. Response rates for both teaching and major referral hospitals were 100% for both questionnaires. A total of 10,123 patients attended a hospital diabetes clinic, the majority of whom (71.6%) attended services based within a teaching or major referral hospital. More than 50,000 HbA_{1c} estimations had been performed by hospital pathology laboratories, 32,198 of which had been funded by the State health system.

As seen in Table 2-7, assuming no patients attending a diabetes clinic had been captured by the Medicare occasions of service data (ie. they had not undergone a Medicare funded HbA_{1c} throughout the 5-year study period), the total number of individuals with diabetes living in NSW in 1997 rose to 195,903. During this year, the combined number of Medicare and State funded HbA_{1c} estimations were 200,228.

Table 2-7. Comparison of 1997 findings using Medicare data alone versus data adjusted for State funded services

	No. of individuals with diabetes	**% patients attending a consultant physician**	**No. of HbA_{1c} estimations**	**% patients undergoing an HbA_{1c} ***
Medicare data	185,780	38.6%	168,030	56.8%
Adjusted for State funded services	195,903	41.8%	200,228	68.1%

* Calculated assuming an average of 1.5 tests per patient (Table 2-3)

Discussion

This study has provided an overview of the current pattern and standard of diabetes care in NSW. With over 90% of the population using Medicare services at least once within a 12 month period, Medicare occasions of service data held by the Health Insurance Commission represents the most comprehensive and reliable source of information regarding health utilisation in Australia. This data may play a significant role in ongoing monitoring of patterns and standards of care. Indeed since the initial release of data from the Health Insurance Commission, a Best Practice Implementation Support Project has commenced aimed at promoting best practice at the primary care level through the use and feedback of similar Health Insurance Commission data.

The method used to identify people with diabetes is of critical importance to ensure accurate assessment of resource utilisation and current standards. A previous study has shown that over 30% of people with diabetes are managed on diet alone (Overland et al, 1996), therefore the use of supplementary secondary data sources, such as Prescription Benefit Scheme files, would fail to capture a large proportion of the diabetic population. There are similar problems with using lists from organisations such as Diabetes Australia and The National Diabetes Supply Scheme as membership is voluntary and biased towards people requiring insulin therapy. A National Registry to include people with Type 2 diabetes would be exorbitantly expensive and unrealistic. Using HbA_{1c} to identify diabetic

individuals addresses these problems. As seen in this study, a large proportion of people with established diabetes do not have a HbA_{1c} performed every year, thus limiting its potential to recognise diabetic individuals if a 12-month capture period is used.

It is unlikely that the use of HbA_{1c} would capture non-diabetic individuals. As discussed previously, reimbursement for this test is only allowed if it is performed in a person with known diabetes. While theoretically some doctors may use this test to screen persons at risk, this is likely to be extremely rare. Moreover, unless a history of established diabetes has been provided as a clinical indication, the Health Insurance Commission would not hold details of these tests.

While Medicare data does not account for people receiving care entirely through hospital based services, over recent decades there has been a trend towards moving patients traditionally cared for by hospital clinics back to their general practitioner for ongoing diabetes care. As seen in this study, the number of people retained under the traditional hospital model is small and represents only 5.2% of the diabetic population. Therefore, at least for diabetes and for the type of information sought, Medicare occasions of service data provided a near complete snap shot of the total picture. The prevalence of diabetes calculated using Medicare data alone was 3.1%. This compares with the 1989-1990 prevalence figure of 2.0% reported by Welborn and colleagues (1995) using National Health Survey data, which relied on patient self-report.

This present study has confirmed the large disparity in service utilisation for people with diabetes. It has previously been estimated that 80% to 90% of people with Type 2 diabetes are managed by their general practitioner alone (Australian Bureau of Statistics, 1991). However, our findings show that up to 41.8% of people with diabetes are under the care of a physician, a 4 fold increase when compared with the non diabetic population. Management of chronic disease does not always fit into general practice where the patient volume is high and the time for consultations is limited. There will also be patients who, due to the severity of their disease, need specialist care. This is particularly so in diabetes where there is a high prevalence of vascular disease and other complications. However, specialist care places a higher burden on the health care dollar. A health maintenance organisation in America found that although patients with diabetes accounted for only 1.5% of their membership, they used 10% of the health budget (Glauber and Brown, 1992). Much of this difference was attributed to a 4-fold difference in the use of specialist services.

These data suggest that practice of diabetes care does not match what is recommended. In the past decade, organisations such as the Royal Australian College of General Practice and the NSW Health Department have tried to improve standards of care by formally adopting consensus guidelines for the management of diabetes. While these guidelines have been broadly publicised, the overall adherence rate is relatively unchanged. This has been clearly illustrated by this study. In early 1996 the Principles of Care and Guidelines for the Clinical Management of Diabetes Mellitus

(NSW Department of Health, 1996) were released recommending HbA_{1c}, the most useful objective measure of the success or failure of treatment of a diabetic patient, be measured between 2 and 4 times a year depending on the patient's treatment mode. While the proportion of patients undergoing this test rose throughout the study period, the rise after the guidelines were widely disseminated was disappointingly small at 4.0%. By 1997, HbA_{1c} was still not performed in over 40% of people with diabetes on a yearly basis.

The guidelines also suggest that microalbuminuria, one of the most useful screening tools to determine the renal and macrovascular status of patients with Type 2 diabetes, be assessed annually. The poor recognition of the importance of microalbuminuria is of concern. The UKPDS has clearly shown the benefit of treatment of even mild hypertension in terms of reducing morbidity and mortality (UK Prospective Diabetes Study Group, 1998[c]), regardless of microalbuminuria status. However, the argument for tight blood pressure control is even stronger in the presence of microalbuminuria. Without information regarding patients' microalbuminuria status the commencement of timely treatment of macrovascular risk factors may be delayed with obvious long term effects in regards to early morbidity.

Effective and affordable lipid agents are now readily available and can reduce major coronary heart disease events by up to 47% (Pyorala et al, 1997). Accordingly, the NSW guidelines recommend monitoring of lipids

every 1 to 2 years if normal, or every 3 to 6 months once the patient is identified as having a lipid abnormality (NSW Department of Health, 1996). Despite this recommendation, and a lowering of the lipid drug-prescribing threshold in the middle of the 1990s, the frequency of lipid monitoring remained inadequate over the 5-year study period.

In regard to diabetic eye disease, the guidelines recommend a comprehensive ophthalmological examination be carried out at diagnosis and then every 1 to 2 years for patients whose diabetes onset was at age 30 years or more. For those diagnosed at age 30 years or less, the recommendations suggest review within 5 years of diagnosis and then every 1 to 2 years (NSW Department of Health, 1996). The findings from this study suggest actual behaviour falls short of this recommendation. Even if the assumption is made that all specialist services were provided by an ophthalmologist, each year nearly half the diabetic population is not screened for diabetic retinopathy. This may underestimate the proportion of diabetic individuals screened for eye disease as attendance to optometrists was not assessed in this study. However, our finding is supported by earlier work by Kamien et al (1994) that found annual eye examination had been performed in only 50.1% of diabetic patients attending general practitioners in metropolitan areas of Western Australia.

The findings presented in this Chapter relate to people with diabetes living in NSW alone. Whether they can be applied to the rest of Australia is unknown. It is not unreasonable to assume that diabetes practice varies

between States, thus a large proportion of Australians diabetes may be receiving a different standard of care than that found by this study. It is also possible that various groups within NSW, such as the Aboriginal population or people living in remote areas, experience even less adequate care due to issues of access.

While the limitations regarding the use of Medicare occasions of service data have been described above, it remains one of the most reliable sources of data from a nationally representative sample. It therefore provides unique information on health service utilisation and standards of care that can be used by policy makers, economists and service providers. If minor modifications are made to Medicare item code numbers, considerable epidemiological and public health data can be collected for a wide range of diseases at virtually no cost. The use of existing data has already served to highlight the heavy burden imposed by a chronic disease such as diabetes.

Chapter 3

The impact of geographic isolation on the use of Medicare services related to diabetes

Introduction

In Australia there is a significant maldistribution of medical practitioners with many rural areas being under-serviced. In the mid-1990s, 32% of the Australian population lived in rural areas yet they were cared for by only 23% of the general practice workforce (Commonwealth Department of Health and Family Services, 1996). The inequity is even greater in terms of specialist services. Of concern in this regard is the issue of access to appropriate health care for individuals with diabetes. Current research shows that the devastating complications of diabetes can be avoided by timely and effective treatment (Diabetes Control and Complications Trial Research Group, 1993; Ohkubo et al; 1995; UK Prospective Diabetes Study Group, 1998[a,b]). Accordingly, the NSW Health Department (1996) has issued management guidelines that define basic medical care for people with this chronic disease. These guidelines emphasise preventive practices, close monitoring and routine visits to medical practitioners. The implication is if medical services are limited, this high-risk population may experience inadequate levels of care. This may, in turn, have a long-term affect on health and economic outcomes.

Information regarding the use of health and medical services for persons with diabetes living in Australia is relatively scarce. Over 90% of the Australian population see a general practitioner each year. Thus Medicare occasions of service data held by the Health Insurance Commission represents the most reliable and comprehensive source of health service utilisation data in Australia. The study described in the previous Chapter used this data to construct a general profile of diabetes care for people living in NSW. In this Chapter, the data has been used to describe the impact of geographic location on the use of diabetes health care services.

Methods

Identification of individuals with diabetes

The sample in this study was drawn from all persons living in NSW with a Medicare service between 1993 and 1997. Under the Medicare Program, reimbursement for HbA_{1c} is only awarded if the test is performed in a person with established diabetes. Individuals were deemed to have diabetes if this test had been performed anytime during the study period and the sample size adjusted for the incidence of diabetes as described in Chapter 2.

Quantification of medical service usage

Medicare item codes were used to extract data on attendance to medical practitioners (general practitioners, specialist, consultant physicians and ophthalmologists) as well as utilisation of diabetes related laboratory evaluations (HbA_{1c}, lipid studies, HDL cholesterol and microalbuminuria) for the individuals identified to have diabetes for each of the individual years between 1993 to 1997.

Information on number of individuals and number of services for the selected Medicare item codes was retrieved by NSW postcode and stratified by the presence of diabetes, gender and age group (<40 years, 40 to 64 years and > 64 years). The age group of individuals was based on their age at January 1 of each year. Data on any individual without a Medicare service for a particular 12 months was omitted to exclude people who may have died. The item codes used to retrieve data on lipids, HDL cholesterol and

microalbuminuria were only introduced during 1993. While information regarding these tests was retrieved for this year they were not included in this analysis due to possible inaccuracies in the data.

Determination of geographic location

Using the population distribution based on the Australian Bureau of Statistics 1996 Census and the regional classifications outlined by The Department of Health Services and Health, each postcode was classified by geographic location. The locations were major urban centre (population of 100,000 or more), urban centre (population between 1,000 and 99,999), rural locality (population up to 999).

Statistical methods

Statistical analysis was performed using SAS (SAS Institute Inc, 1991). The data is presented as the average number of services per individual attending the various medical officers and the average number of tests for patients in whom tests were performed, stratified by geographic location. The data was also analysed in terms of the proportion of people living in major urban, urban and rural localities using these services. The effect of location on the proportion of patients attending the various doctors and undergoing surveillance was examined using logistic regression, adjusting for age and gender. Results are expressed as average, percentage or adjusted odds ratio (OR) and 95% confidence interval (95% CI).

Results

Slightly more than half (50.3%) of the diabetic population identified were male. On average over the study period, 139,594 (70.8%) persons with diabetes lived in major urban, 48,544 (24.6%) in urban and 9,140 (4.6%) in rural areas of NSW. This represented a prevalence of diabetes across the 5-year study period of 3.7%, 3.5% and 3.2% for the major urban, urban and rural populations respectively.

Attendance to medical practitioners for patients with diabetes

The mean number of attendances to general practitioners remained relatively stable in all localities, averaging 10.9 visits a year for patients living in major urban areas, 8.6 visits a year for patients in urban areas and 8.0 visits a year for patients residing in rural areas. This represented a 1.3 fold greater use of services between major urban and urban areas and a 1.4 fold greater use between major urban and rural areas.

A large proportion of diabetic individuals also received care at the specialists level with up to 51.3% of patients living in major urban areas, 50.9% of patients in urban areas and 46.8% of patients in rural localities seeing a specialist each year (Table 3-1). As seen in Table 3-2, once adjusted for age and gender, the OR of attending a specialist was slightly higher for patients living in areas of high population density. The overall

number of attendances to specialists was also higher for these patients, averaging 2.9 visits per patient per year compared to 2.6 and 2.5 visits per patient per year for the urban and rural groups, a 1.1 to 1.2 fold increase.

Table 3-1. The proportion of patients with diabetes living in major urban, urban and rural localities attending a specialist, consultant physician and ophthalmologist during the years 1993 to 1997

Service	Region		1993	1994	1995	1996	1997
Attendance to specialist	Major urban	% patients	46.6	48.0	49.2	50.5	51.3
		visits per patient	2.9	2.9	2.9	2.9	2.9
	Urban	% patients	44.3	46.6	48.6	49.9	50.9
		visits per patient	2.6	2.6	2.6	2.7	2.6
	Rural	% patients	41.0	43.5	47.2	46.4	46.8
		visits per patient	2.5	2.5	2.5	2.4	2.5
Attendance to physician	Major urban	% patients	34.4	36.6	38.1	40.2	41.8
		visits per patient	3.8	3.7	3.7	3.8	3.9
	Urban	% patients	22.3	23.0	26.1	27.4	28.8
		visits per patient	3.5	3.1	3.1	3.5	3.2
	Rural	% patients	21.6	26.0	28.5	26.7	29.4
		visits per patient	3.5	2.8	3.1	3.3	3.8
Initial attendance to ophthalmologist	Major urban	% patients	3.0	3.1	2.9	2.5	2.3
		visits per patient	1.0	1.0	1.0	1.0	1.0
	Urban	% patients	2.3	2.6	2.2	2.4	1.7
		visits per patient	1.0	1.0	1.0	1.0	1.0
	Rural	% patients	1.8	1.3	2.2	1.4	2.0
		visits per patient	1.0	1.0	1.0	1.0	1.0

Table 3-2. The difference (OR and 95% CI) in the proportion of patients with diabetes living in major urban, urban and rural localities attending medical practitioners and undergoing diabetes related investigations for the individual years 1993 to 1997, adjusted for age and gender

Service	Region	1993		1994		1995		1996		1997	
Attendance to specialist	Major urban	1.22	(1.17 to 1.28)	1.17	(1.12 to 1.23)	1.04	(0.99 to 1.08)	1.13	(1.08 to 1.18)	1.15	(1.11 to 1.21)
	Urban	1.08	(1.04 to 1.14)	1.09	(1.04 to 1.14)	1	(0.96 to 1.05)	1.09	(1.04 to 1.14)	1.12	(1.07 to 1.18)
	Rural	1		1		1		1		1	
Attendance to physician	Major urban	1.85	(1.76 to 1.95)	1.6	(1.52 to 1.68)	1.51	(1.44 to 1.58)	1.82	(1.73 to 1.90)	1.68	(1.61 to 1.76)
	Urban	1.16	(1.10 to 1.22)	0.98	(0.93 to 1.03)	1.01	(0.96 to 1.06)	1.2	(1.14 to 1.27)	1.12	(1.07 to 1.18)
	Rural	1		1		1		1		1	
Initial attendance to	Major urban	1.6	(1.37 to 1.87)	2.31	(1.93 to 2.77)	1.28	(1.10 to 1.47)	1.73	(1.45 to 2.07)	1.14	(0.98 to 1.33)
Ophthalmologist	Urban	1.2	(1.02 to 1.41)	1.95	(1.62 to 2.36)	0.94	(0.80 to 1.09)	1.6	(1.33 to 1.92)	0.85	(0.72 to 1.00)
	Rural	1		1		1		1		1	
Lipids *	Major urban			2.11	(2.01 to 2.21)	1.83	(1.75 to 1.92)	1.49	(1.43 to 1.56)	1.29	(1.24 to 1.35)
	Urban			1.1	(1.05 to 1.16)	1.11	(1.06 to 1.17)	1.01	(0.96 to 1.05)	0.91	(0.87 to 0.96)
	Rural			1		1		1		1	
HDL cholesterol *	Major urban			1.35	(1.26 to 1.43)	1.3	(1.22 to 1.38)	1.19	(1.12 to 1.27)	1.21	(1.14 to 1.29)
	Urban			0.92	(0.86 to 0.99)	0.95	(0.90 to 1.02)	1.07	(1.01 to 1.14)	1.12	(1.05 to 1.19)
	Rural			1		1		1		1	
HbA_{1c}	Major urban	1.12	(1.07 to 1.18)	1.09	(1.05 to 1.14)	1.17	(1.12 to 1.22)	1.05	(1.00 to 1.09)	0.89	(0.85 to 0.93)
	Urban	0.92	(0.88 to 0.96)	0.93	(0.89 to 0.98)	1.12	(1.07 to 1.17)	1.09	(1.04 to 1.14)	0.93	(0.89 to 0.97)
	Rural	1		1		1		1		1	
Microalbuminuria *	Major urban			2.27	(1.94 to 2.66)	1.29	(1.17 to 1.42)	1	(0.92 to 1.08)	0.9	(0.85 to 0.97)
	Urban			1.87	(1.59 to 2.20)	1.05	(0.94 to 1.16)	0.87	(0.80 to 0.94)	0.91	(0.85 to 0.97)
	Rural			1		1		1		1	

* Possible inaccuracy as the item codes used to retrieve data on lipids, HDL cholesterol and microalbuminuria were introduced during 1993 therefore this information is not listed

The difference in the proportion of patients attending consultant physicians was greater. During 1997, 41.8% of individuals with diabetes living in major urban areas attended a consultant physician compared to 28.8% and 29.4% of those in urban and rural areas. As seen in Table 3-2, the adjusted OR of the major urban group attending a physician reached as high as 1.85 (95% CI: 1.76 to 1.95) when compared with their rural counterparts. Examination of service utilisation for the non-diabetic population showed a similar pattern (OR: 1.88; 95% CI: 1.85 to 1.90). The mean number of attendances to consultant physicians was also higher, averaging 3.8 visits per patient per year in major urban areas and 3.3 visits per patient per year for both urban and rural areas, a 1.2 fold increase.

The proportion of patients billed by an ophthalmologist for an initial examination was extremely small for each locality. In 1997, only 2.3% of diabetic patients living in a major urban area were billed using the initial examination item code 106, falling to 1.7% of diabetic individuals in urban areas and 2.0% of individuals in rural areas. Ophthalmologists frequently bill using specialist item codes 104 and 105, which are shared with specialists of other disciplines. As seen previously, a large proportion of people with diabetes were billed under these item codes. Thus the proportion of patients in each locality under the care of ophthalmologists may be significantly higher than indicated.

Laboratory investigations

As seen in Table 3-3, the proportion of patients living in major urban areas with an HbA_{1c} estimation during 1993 was significantly greater than the proportion in rural areas (36.1% versus 32.9%; adjusted OR: 1.12; 95% CI: 1.07 to 1.18). By 1997, this had reversed with significantly fewer patients in major urban areas undergoing this investigation (55.2% versus 57.4%; adjusted OR: 0.89; 95% CI: 0.85 to 0.93). Although the absolute number was much smaller, a similar pattern was seen for monitoring of microalbuminuria with 3.9% versus 1.8% of patients in major urban and rural areas undergoing this test in 1994 (adjusted OR: 2.27; 95% CI: 1.94 to 2.66) compared to 11.3% versus 12.3% in 1997 (adjusted OR: 0.90; 95% CI: 0.85 to 0.93). The proportion of patients undergoing cholesterol and HDL cholesterol estimation remained higher in the major urban population throughout the study period. Overall, the mean numbers of tests per individual were relatively similar between localities (Table 3-3). The monitoring of diabetes and its complications using laboratory evaluations for both urban and rural areas improved between 1993 and 1997, although it continued to fall short of the standards of care recommended by the NSW Department of Health.

Table 3-3. Frequency of laboratory investigations in persons with diabetes living in major urban, urban and rural localities over the years 1993 to 1997

Service	Region		1993	1994	1995	1996	1997
HbA_{1c} *	Major urban	% patients tested	36.1	41.5	43.7	47.7	55.2
		tests per patient	1.5	1.5	1.6	1.6	1.6
	Urban	% patients tested	31.8	37.5	42.7	48.6	56.1
		tests per patient	1.5	1.5	1.5	1.5	1.5
	Rural	% patients tested	32.9	38.9	39.4	45.8	57.4
		tests per patient	1.4	1.4	1.5	1.5	1.6
Lipids †§	Major urban	% patients tested		45.3	47.6	50.4	52.7
		tests per patient		1.5	1.6	1.6	1.6
	Urban	% patients tested		30.2	35.6	40.6	44.2
		tests per patient		1.4	1.4	1.4	1.4
	Rural	% patients tested		28.0	32.7	39.8	45.8
		tests per patient		1.4	1.4	1.5	1.4
HDL cholesterol †§	Major urban	% patients tested		16.2	17.7	16.8	18.6
		tests per patient		1.3	1.3	1.3	1.3
	Urban	% patients tested		11.7	13.6	15.3	17.4
		tests per patient		1.2	1.3	1.3	1.3
	Rural	% patients tested		12.4	14.0	14.2	15.7
		tests per patient		1.3	1.3	1.3	1.2
Microalbuminuria ‡§	Major urban	% patients tested		3.9	6.3	8.0	11.3
		tests per patient		1.1	1.2	1.2	1.2
	Urban	% patients tested		3.2	5.0	7.0	11.3
		tests per patient		1.1	1.1	1.1	1.2
	Rural	% patients tested		1.8	4.9	8.0	12.3
		tests per patient		1.2	1.2	1.1	1.1

NSW Health Department (1996) guidelines for the management of diabetes
* 1-4 tests per year
† Every 1 to 2 years if normal, every 3 to 6 months if abnormal or on treatment
‡ Every year
§ Possible inaccuracy as the item codes used to retrieve data on lipids, HDL Cholesterol and microalbuminuria were introduced during 1993 therefore information for this year is not listed

Discussion

Routine monitoring of clinical status to promote optimal diabetes control, regular screening to facilitate the early detection and appropriate management of complications and access to specialist care for those patients that require it have all been identified as key components of effective diabetes care (Colagiuri et al, 1995). While many people with diabetes have access to this level of care, many do not. As reported in Chapter 2, large proportions of the diabetic population living in NSW are not routinely monitored in regard to diabetes and its complications. The present study has shown that monitoring of patients in rural areas is also less than adequate but the differences between rural patients and their city counterparts were surprisingly small. Standards of care did improve in all parts of the State over the study period. It is noteworthy, however, that the improvement in the proportion of patients with an HbA_{1c} or microalbuminuria estimation each year was greatest in rural areas, despite rural areas being serviced by less general practitioner per head of population (Commonwealth Department of Health and Family Services, 1996). Moreover, this improvement was achieved with fewer attendances to the general practitioner and fewer patients attending secondary care.

In 1996, the NSW Department of Health widely disseminated clinical guidelines for the management of diabetes. As part of their dissemination programme, diabetes specialists from major teaching hospitals were employed to visit rural locations to provide background training in diabetes care to the general practitioners working in these areas. Around

the same time the General Practice Branch of the Commonwealth Department of Health and Family Services established the Integration Support and Evaluation Unit (Integration SERU). As one of its first initiatives, Integration SERU set up a network to change the focus of diabetes programmes within Divisions of General Practice from providing patient education to monitoring clinical outcomes. Prior to these initiatives the proportion of patients undergoing investigations for HbA_{1c} and microalbuminuria had been higher in the major urban population. The education of general practitioners regarding the nuances of diabetes care, together with the network system aimed at changing general practitioners diabetes focus, may account, at least in part, for the notable improvement in monitoring practice in rural areas. Of interest is the finding that monitoring of lipids remained higher in the major urban population throughout the study period. This may reflect an emphasis placed on diabetes specific rather than diabetes related complications in the aforementioned training and support programs.

It is theoretically possible that geographical differences in the use of diabetes related services are greater than has been demonstrated by this study. Medicare occasions of service data does not capture persons with diabetes either receiving care through hospital based services or receiving no care at all. However, over recent decades there has been a trend towards moving patients traditionally cared for by diabetic clinics back to their general practitioner for ongoing care. As seen in the previous Chapter, a survey of all hospitals in NSW (n=198) showed that only about

10,000 patients are retained under the traditional hospital model, with the services spread across all localities. This would not impact greatly on the current findings. It is also possible that a number of persons with diabetes living in rural areas receive no medical care at all and are therefore not identified by the Medicare data. As seen in this study, the prevalence of diabetes in rural areas, calculated using the number of individuals using any Medicare service over the 5-year study period, was 0.5% lower than that found in areas of higher population density. While this is an interesting phenomenon to be studied further, it should not cause a great degree of distortion to the data.

Whether the differences in monitoring practice between areas of higher and lower population density are reflected by improved health outcomes cannot be addressed by this study as Medicare data is linked to service utilisation only. Over recent years several initiatives within NSW have tried to monitor outcomes such as HbA_{1c} and lipid levels but there remains a paucity of representative data on patients cared for by general practitioners, particularly those living in rural areas. The issue of accessibility and patient convenience has also not been fully addressed. While the differentials in service utilisation for patients in rural areas were surprisingly small, many of these patients would be required to travel long distances to seek medical care.

Despite these caveats, this study has provided unique information on both health service utilisation and standards of care for people with diabetes

living in different localities in NSW. It has served to highlight the differentials in the access of specialist services for patients living in the less densely populated areas. The development of innovative models of care that emphasise the coordination and cooperation among general practitioners and specialists and provide outreach services may help address these differentials (American College of Physicians, 1995). However, as suggested by this study, ensuring other mechanisms such as ongoing medical education are available to support general practitioners manage their patients with chronic diseases may be an equally important goal.

Chapter 4

Diabetes management: shared care or shared neglect

Introduction

The number of people with diabetes continues to escalate (Zimmet and McCarty, 1995). Simple calculations based on this number would dictate that no hospital or specialist system could provide care to all patients with diabetes without a significant increase in funds. It is therefore important to examine the different approaches to managing patients with this chronic disease. A system of 'shared' care between primary and secondary health services is increasingly being advocated as a way of maximising efficacy while minimising costs (Powel, 1991; Hoskins et al, 1993; Dunning et al, 1993). The shared care approach encourages and supports general practitioners to continue to manage their patients in the community while facilitating access to specialised services for those patients who require them.

The philosophy of diabetes shared care was first adopted by the Division of General Practice and the Diabetes Centre of Royal Prince Alfred Hospital, the Central Sydney Area Health Service (CSAHS), Sydney, Australia, in the mid 1980s. Under this model, it is the role of the general practitioner to mediate movement of patients between the community and specialist care when diabetes control deteriorates, when advice or

treatment of diabetic complications is required or when sufficient time has elapsed to warrant a complete diabetes review. The role of the Diabetes Centre is to provide specialised services that cover a spectrum of activities ranging from patient education to clinical care to which general practitioners can choose to refer. To emphasise the complementarity of primary and secondary care, the Diabetes Centre does not provide regular follow-up. It is an agreed tenet that patients are returned to their referring doctor for ongoing care within 3 months of the initial referral. Correspondence is sent to the general practitioner outlining treatment recommendations that require implementation. While they are invited to consider referring patients back to the Diabetes Centre in 12 to 24 months for a complication assessment, re-referral is left to their discretion. If this approach is to be effective, it is important to ensure that areas of diabetes management are not neglected due to confusion of roles (Williams, 1995). Therefore, the study reported in this Chapter aimed to evaluate shared care in terms of whether specialist treatment recommendations are implemented and if this affects diabetes outcomes.

Method

A total of 1669 patients were referred to the Royal Prince Alfred Hospital Diabetes Centre for assessment and clinical care between October 1993 and October 1995. Using the Diabetes Centre's computerised database, patients who were re-referred for a further assessment were identified. A total of 742 patients (44.5%) met this criterion. From this group, a random sample of 200 patients was selected and their records retrieved. The paper and computer records for the 2 referrals, hereafter referred to as Visit 1 and Visit 2, were audited for each patient. Subsets of data were collected regarding the patient, the referring general practitioner and the correspondence to and from the referring doctor.

General practitioner data included the number of patients they had referred to the Diabetes Centre within the last 2 years, whether the doctor was enrolled with the CSAHS Diabetes Shared Care Programme and the type of practice in which they worked (solo practice, group practice or medical centre). The initial referral letter was audited for length and content. Correspondence from the Medical Director of the Centre was reviewed to ascertain whether treatment recommendations had been given to the referring general practitioner after Visit 1. Explicit directives to commence or adjust treatment were taken as a recommendation being given. For example, an instruction to ‘please commence this patient on an HMG CoA reductase inhibitor’ or ‘please continue to increase the Metformin to the maximal dose of 1 Gm tds’ was recorded as a treatment

recommendation. Information recorded at Visit 2 was used to assess whether these recommendations had been implemented. For example, the recommendation was taken as implemented if the patient had commenced an HMG CoA reductase inhibitor or the Metformin had been increased to the maximal dose.

For the purpose of the audit, values obtained for glycosylated haemoglobin levels (HbA_{1c}), blood pressure determinations, lipid levels and retinopathy status at Visit 1 and Visit 2 were collected as outcome data. HbA_{1c} had been measured by HPLC (Biorad, CA, USA; CV < 2%). Total cholesterol, HDL cholesterol and triglycerides had been measured using the CHOD-PAP method of enzymatic testing (Boehringer Mannheim. Mannheim, Germany; CV < 1%). Two blood pressure readings had been taken in a sitting position and the mean result reported. Examination of the optic fundus had been performed with pupils dilated using a direct ophthalmoscope by a single observer.

Statistical methods

The data was analysed using the Number Cruncher Statistical System software package (Hintze, 1999). Statistical methods for analysing paired data were adopted when comparing Visit 1 and Visit 2 outcome data. Unpaired statistical methods were adopted when analysing the data in terms of whether patients had or had not had treatment recommendations implemented. Continuous data were analysed by t-tests and Mann Whitney tests. Categorical data was analysed by χ^2 test. Logistic

regression was performed to determine independent predictors of a recommendation being implemented, eliminating non-significant variables from a base model which included all variables with a significance of 0.1 on initial analysis. Results were regarded as significant at the $P<0.05$ (two-tailed) level. Results are expressed as mean and standard deviation (SD) for parametric data and frequency and percent, median and inter-quartile range (IQR) for non-parametric data.

Results

The median time between referrals for the 200 patients was 15 months (IQR 13-18). Most patients (87.5%) attended one general practitioner at the time of referral and had been under the doctor's care for a median of 6 years (IQR 3-10 years); however, 27 patients (13.5%) changed doctors between referrals. Nearly half (43%) attended a doctor formally registered with the CSAHS Diabetes Shared Care Programme.

Overall, a total of 158 treatment recommendations were given for 110 patients (55%). Recommendations were given regarding metabolic control, blood pressure treatment and lipid treatment to 76 (38%), 29 (15%) and 38 (19%) patients respectively and referral to an ophthalmologist was suggested in 15 (8%) patients. As seen in Table 4-1, general practitioners were less likely to implement lipid treatment recommendations, although this did not reach significance. There were no significant differences in the mean age or duration of diabetes, gender or ethnicity between patients who did and did not have treatment recommendations implemented (Table 4-2).

Table 4-1. Number of patients with treatment recommendations implemented at Visit 2

Type of recommendation	Recommendation implemented (n=86)	Recommendation not implemented (n=24)
Metabolic control	58 (76%)	18 (24%)
Blood pressure	22 (76%)	7 (24%)
Lipids	21 (55%)	17 (45%)
Eyes	11 (73%)	4 (27%)
Any recommendation	86 (78%)	24 (22%)

Table 4-2. Demographic profile of patients who did and did not have treatment recommendations implemented

Patient characteristic	Recommendation implemented (n=86)	Recommendation not implemented (n=24)
Age (yrs)	59.9 (SD 10.0)	57.3 (SD 9.4)
Duration of diabetes (yrs)*	6 (3-10)	5 (1-9)
Male	44 (52%)	12 (50%)
Anglo-Celtic	55 (65%)	18 (75%)
Interpreter required	16 (19%)	4 (17%)
Duration of contact with the referring doctor (yrs)*	5 (3-10)	8 (3-20)
No. of general practitioners	1.1 (SD 0.3)	1.1 (SD 0.4)

Results expressed as mean (SD) except where indicated
* Median (IQR)

While change of doctor between referrals did not adversely affect implementation of treatment recommendations (84.6% versus 77.3%, NS), several other doctor-related factors emerged as having a significant effect. Doctors involved with the Diabetes Shared Care programme were more likely to implement treatment recommendations than their non-shared care counterparts (87.2% versus 70.9%; $\chi^2_{(df-1)} = 4.12$; P=0.04). Doctors who wrote longer referral letters were also more likely to implement recommendations (median number of words: 56 [IQR: 36-71] versus 45 [IQR: 23-59]; P=0.02). After adjusting for the content of the referral

letter, whether the referring general practitioner was a shared care doctor and the number of patients the doctor had referred in the last 2 years, the length of the referral letter emerged as the only independent factor associated with treatment implementation ($\chi^2_{(df-1)} = 5.40$; P=0.02); however, this only accounted for 7% of the variance.

As seen in Table 4-3, patients who had recommendations regarding metabolic and lipid treatment implemented had significantly lower HbA_{1c} (P=0.04), cholesterol (P=0.0005) and triglyceride (P=0.05) levels at Visit 2 as compared to Visit 1. The Visit 2 cholesterol of this group was also significantly lower than that of patients in whom recommendations had not been implemented (P=0.008).

Table 4-3. Clinical profile of patients who did and did not have treatment recommendations implemented

Outcome	Recommendation implemented (n=86)		Recommendation not implemented (n=24)	
	Visit 1	Visit 2	Visit 1	Visit 2
HbA_{1c} (%)	8.4 (7.6-9.4)	7.6 (7.0-9.1) †	8.0 (7.7-9.5)	8.1 (7.8-9.4)
Systolic BP (mmHg)	150 (137-160)	147 (137-159)	164 (150-175)	158 (150-182)
Diastolic BP (mmHg)	90 (80-100)	85 (80-90)	94 (90-100)	89 (80-92)
Cholesterol (mmol/L)	6.8 (6.2-7.3)	5.6 (4.9-6.3)§ ¶	6.5 (5.8-7.4)	6.5 (6.3-7.1)
Triglyceride (mmol/L)	2.8 (2.2-4.0)	2.0 (1.5-3.9) **	3.6 (2.9-4.6)	3.4 (2.3-5.4)
HDL cholesterol	1.1 (0.9-1.4)	1.1 (1.0-1.3)	1.1 (0.9-1.3)	1.0 (0.8-1.6)††

Results are expressed as median (IQR)
Different from Visit 1
† P=0.04 § P=0.0005 ** P=0.05 †† P=0.02
Different from recommendation not implemented
¶ P=0.008

Discussion

The hypothesis that the standard of care will be maintained by the shared care approach is a reasonable one and is supported by results of a clinical trial conducted in the Central Sydney area in the late 1980s (Hoskins et al, 1993). However, the success of shared care in 'real life' is not well established. If health care professionals within a shared care partnership leave undone what they think is taken care of by others, shared care may become 'shared neglect' (Williams, 1995). At least in the model described in this Chapter this does not appear to be the case; the majority of treatment recommendations made at the specialist level were implemented by the general practitioner. Unfortunately, due to the Australian health system, patients can move from one area to another to seek medical care. Moreover, under the CSAHS shared care model, patients do not routinely return for specialist care and re-referral is left to the discretion of the general practitioner. Thus, whether recommendations have also been implemented for patients who have not returned to the Diabetes Centre since their initial assessment has not been addressed by this study.

For those patients returning for specialist review, the only area where implementation rates were low was in regards to treatment of dyslipidaemia. Prior to 1995, regulations set down by the Australian Government meant that cholesterol and triglyceride levels could not be treated with pharmaceutical agents until the levels exceeded 6.5 mmol/L and 4.0 mmol/L respectively, yet diabetes best practice guidelines suggested treatment should be commenced at lower levels of abnormality.

As some of the treatment recommendations were made prior to 1995, this result may be a reflection of the prescribing threshold rather than a reluctance to implement lipid treatment. However, the finding that lipid treatment is under-utilised in general practice is not a new one (Leitha et al, 1994; McGill et al, 1993).

While the notion of 'diabetes shared care' has been widely adopted, it is inevitable that different health services will have adopted their own system of implementation. Thus each system of shared care needs to be independently tested and continually monitored. What components of shared care make each system 'work' or 'not work' also need to be identified. As seen in this study, doctors formally registered in the CSAHS Diabetes Shared Care Programme implemented recommendations more often than their non-shared care counterparts. Ongoing education, ranging from detailed correspondence through to practically based training days or after hour seminars, is an integral component of this programme. However, in the CSAHS system, doctors not registered with the programme can participate in all educational and clinical activities, thus it is not possible to be certain that ongoing education accounts for this finding.

Despite some recommendations not being implemented, the average HbA_{1c} of patients when returned to specialist care was 7.7%. As previously discussed, under the CSAHS shared care philosophy, it is the role of the general practitioner to refer patients to specialist care when they

deem it appropriate. The NSW Department of Health recommends that intervention is required when the HbA_{1c} exceeds 2.0% from the upper limit of normal. Therefore, a rise in HbA_{1c} to a level approaching 8.0% is an appropriate trigger for referral and a reasonable use of specialist health care resources. Moreover, the HbA_{1c} and complication profiles at time of re-referral of the study cohort were similar to those found in a recent Australian survey of 4,080 people receiving diabetes care under a variety of diabetes care models (Flack and Colaguri, 1998). Other studies elsewhere in the world have reported average HbA_{1c} values of 8.5% (Hayward et al, 1997) and 9.0% (Dunn and Bough, 1996). Therefore, it would seem that diabetes care provided under the shared care philosophy compares favourably to that provided by many other approaches.

Failure of shared care to achieve a higher rate at which recommendations are implemented may be the result of a number of reasons. While some countries such as the United Kingdom conduct diabetes clinics at the general practice level, in Australia, patients rarely present to their general practitioner for treatment of diabetes alone. This means that the opportunity to commence or adjust treatment may be missed. Moreover, the majority of general practitioners in the Central Sydney Area work in solo practice (Overland, 1996) and their patient load and time constraints may affect their ability to implement treatment guidelines (Starfield, 1994). Competition between doctors and the lack of government control has also led to patients shopping around for general practitioners. A previous study conducted in the Central Sydney Area in the late 1980s

found that 31% of patients with diabetes consulted more than one general practitioner (Constantino et al, 1991). The implication of this is that communication outlining treatment recommendations may not be forwarded to all the patients' medical advisers; therefore, areas of treatment may remain neglected. Over recent years the Diabetes Centre has tried to address this by emphasising to the patients the importance of not changing doctors unnecessarily. Hopefully, this is why the majority of patients in this study (87.5%) only attended one general practitioner and had been under the care of their referring doctor for several years.

The diverse characteristics of general practitioners make it difficult to formulate treatment and follow up policies that suit all clinical situations (Constantino et al, 1991). While some are reluctant to implement treatment changes, others are keen to take on this responsibility. Ideally, there should be a system of 'differential shared care'. For patients of doctors with extensive interest and experience in diabetes, the majority of care is left in the hands of the general practitioner. For patients of doctors with less interest or experience in diabetes, the Diabetes Centre assumes a more active role. To date, the Diabetes Centre has relied heavily on knowledge of the individual general practitioners (and vice versa) to select the degree of shared care that is appropriate. However, this approach is highly subjective. The results of this study would suggest that the length of the referral letter might be an indicator of the referring doctors' acceptance to implement treatment changes. However, this only explains a small degree of variation between referring doctors. Therefore further

study is needed to identify doctor characteristics that are associated with a desire to be more active within the shared care partnership.

Chapter 5

Shared care: does it promote the optimal use of specialist care

Introduction

Shared care models have evolved to encourage and support general practitioners to continue to manage their patients in the community while facilitating access to specialised services for those patients who require them. In many systems, a yearly review by the specialist is standard. However, with the increasing number of people with diabetes, it is unlikely that specialist services will be able to sustain these models. Ideally, there should be a system of differential shared care, where patients of doctors with extensive interest and experience in diabetes are primarily managed by the general practitioner whereas the specialist plays a more active role for patients of doctors with less interest or experience.

The model of shared care established by the CSAHS is based on the principles of differential care. As described in Chapter 4, under the CSAHS model the general practitioner is the primary provider of diabetes management and referral to specialist services is left to their discretion. To emphasise the complementary nature of primary and secondary care, the Diabetes Centre does not provide regular follow-up and patients are returned to their referring doctor for ongoing care within 3 months of the initial referral, although many are seen on several occasions during this

period. Detailed correspondence in a standardised format is sent to the referring doctor outlining treatment recommendations that require implementation.

To further prioritise the need of patients to see specialists, it is an agreed tenet that patients are not recalled at regular intervals for review. Instead, general practitioners are invited to consider re-referral of their patients back to the Diabetes Centre when metabolic control deteriorates, when advice or treatment of complications is required or when sufficient time has elapsed to warrant a complete diabetes review. If this approach to shared care is to be effective it is important to ensure that patients receive the level of care they require and that standards of care are maintained for all patients. As shown in the previous Chapter, at least for patients referred back for review, general practitioners are active within the shared care partnership and implement the majority of treatment recommendations made at the specialist level, resulting in favourable glycaemic, lipid and blood pressure profiles. However, data is obviously lacking for those patients whose care is kept at the primary care level. This current study therefore sought to trace patients who have not been referred back for specialist review and compared them to a group of patients who had been re-referred. Factors such as patient and doctor characteristics and treatment recommendations at initial consultation were examined.

Methods

A total of 1669 individual patients were referred to the Royal Prince Alfred Hospital Diabetes Centre for assessment and clinical care in a 2-year period. Some of these patients would subsequently have been referred for a repeat assessment. Using the Diabetes Centre computerised database, lists of returned and non-returned patients were generated, ordered by date of attendance, and the clinical status of each patient was retrieved. A stratified sample of 200 returned and 200 non-returned patients was obtained by selecting every 4^{th} patient from each list.

The paper and computer records of the initial visit for each selected patient were audited. Data were collected regarding the patient, the referring general practitioner and the correspondence to and from the referring doctor. For the purpose of this study, values obtained for HbA_{1c}, blood pressure determinations and lipid levels were collected as clinical data. HbA_{1c} had been measured by HPLC (Biorad, CA, USA; CV < 2%). Total cholesterol, HDL cholesterol and triglycerides had been measured using the CHOD-PAP method of enzymatic testing (Boehringer Mannheim. Mannheim, Germany; CV < 1%). Two blood pressure readings had been taken in a sitting position and the mean result reported.

General practitioner data collected included the number of patients they had referred to the Diabetes Centre within the last two years, whether the doctor was enrolled with the Diabetes Shared Care Programme and the type of practice in which they worked (solo practice, group practice or

medical centre). The referral letter was audited for length and content. Correspondence from the Medical Director of the Centre was reviewed to ascertain what specific treatment recommendations had been given to the referring general practitioner. Explicit directives to commence or adjust treatment were taken as a recommendation being given. For example, an instruction to 'please commence this patient on an HMG CoA reductase inhibitor' or 'please continue to increase the Metformin to the maximal dose of 1 Gm tds' was recorded as a treatment recommendation.

For the returned patient group, information recorded at their return assessment was used to assess whether these recommendations had been implemented. For example, the above recommendations were taken as implemented if the patient had commenced an HMG CoA reductase inhibitor or the Metformin had been increased to the maximal dose.

For the non-returned patients, a letter and questionnaire was forwarded to the referring doctor. For those patients in whom a treatment recommendation had been made, the doctor was asked to review the patient's medical records and to provide details regarding whether the recommendation had been implemented. A stamp addressed envelope was included to expedite return of the questionnaire (Appendix 2) and general practitioners were thanked by a promise to have their names put in a draw for a dozen bottles of wine upon receipt of the completed questionnaire. The doctors were not asked to re-refer the patient for a repeat assessment as this would have been a breach of the CSAHS shared

care agreement. The patient may also have moved to the care of another doctor.

To maximise data completion for the non-returned group, a letter was also forwarded to the patients informing them that the staff of the Diabetes Centre would be contacting them in the following week by telephone (Appendix 2). The telephone directory was used to trace patients no longer residing at their last known address. During telephone contact, the patients were questioned regarding the general practitioner(s) they were currently attending. Details were also collected in terms of whether treatment recommendations given at the initial consultation at the Diabetes Centre had been implemented.

Statistical methods

The data were analysed using the Number Cruncher Statistical System software package (Hintze, 1999). Attempts were made to normalise non-parametric data. Where this was not possible, non-parametric tests were used. Continuous data were analysed by unpaired t-tests and Mann-Whitney tests. Categorical data were analysed by χ^2 test. Logistic regression was used to determine independent predictors of patients returning for specialist review, eliminating non-significant variables from a base model which included all variables with a significance of 0.1 on initial analysis. Interaction terms were included in the base model to assess for potential interaction between independent predictors. Results were regarded as significant at the $P<0.05$ (two-tailed) level. Results are

expressed as mean and standard deviation (SD) for parametric data and frequency and percent, median and inter-quartile range (IQR) for non-parametric data.

Results

The 400 patients selected for this study had been initially referred by 216 individual general practitioners. Doctors formally enrolled in the Diabetes Shared Care Programme referred significantly more patients to the Diabetes Centre over the past 2 years (median: 11.5, IQR: 4.8 to 14.5 versus median: 2; IQR, 1 to 5; P=0.00001) than their non-shared care counterparts. However, a higher proportion of shared care doctors (52.5% versus 21.3%; $\chi^2_{(df-1)}$=16.5; P=0.00005) were selective in whom they returned for specialist review, choosing to re-refer some patients and not others.

General practitioners completed 165 questionnaires (82.5%) and 127 patients (63.5%) were successfully contacted via the telephone. Overall, information on 182 of the 200 (91%) non-returned patients could be obtained. Comparison of responses where information was available from both doctor and patient showed 100% agreement. Seventeen of the non-returned patients were deceased, representing 4.5% of the total cohort.

As seen in Table 5-1, there were no significant differences in the glycaemic, blood pressure and lipid levels of returned and non-returned patients at the initial consultation. However, non-returned patients were less likely to have a history of macrovascular disease or risk factor (adjusted OR: 0.4; 95% CI: 0.2 to 0.6) (Table 6-2). Even after adjusting

for the less complicated nature of these patients using a dichotomous variable within the logistic regression model, they were given significantly less treatment recommendations (adjusted OR: 0.5; 95% CI: 0.3 to 0.7). Although there was no differences in the length of the letter from referring general practitioners (50 words, IQR: 31 to 78 versus 48.5 words, IQR: 30 to 70), letters of non returned patients were more likely to contain details of the patients type and/or duration of diabetes (adjusted OR: 4.6; 95% CI: 2.5 to 8.4). Nearly half (47.1%) of non-returned patients changed their general practitioner in the years following their assessment at the Diabetes Centre. In many cases (47.2%), the change was due to the patient or doctor moving their address. This movement between doctors increased by 5 fold the likelihood of a patient not being re-referred (adjusted OR: 5.0; 95% CI: 2.9 to 8.8). These 4 factors accounted for 23% of the variance in determining whether a patient was re-referred. Persons with Type 1 diabetes were also less likely to return for specialist review, however, this was not an independent predictor of a patient's returned status (adjusted OR: 0.7; 95% CI: 0.2 to 2.1).

Table 5-1. Clinical profile of patients who did and did not return for specialist review

	Returned n=200	**Non returned n=200**
HbA_{1c} (%)	7.8 (6.7-9.2)	7.8 (6.7-9.7)
Systolic BP (mmHg)	137 (120-150)	130 (120-150)
Diastolic BP (mmHg)	80 (70-85)	80 (70-90)
Cholesterol (mmol/L)	5.5 (4.8 to 6.3)	5.6 (4.9-6.2)
Triglyceride (mmol/L)	2.0 (1.4-2.9)	1.9 (1.3-3.1)
HDL cholesterol (mmol/L)	1.18 (0.94-1.40)	1.17 (0.99-1.45)

Results are expressed as median (IQR)

Table 5-2. Demographic profile of patients who did and did not return for specialist review

	Returned n=200	**Non returned n=200**
Age (yrs)	57.7 (SD: 11.9)	57.1 (SD: 13.5)
Male	51.0%	59.0%
Type 2 diabetes *	97.0%	90.5%
Duration of diabetes (yrs)	6 (IQR: 2-10)	4 (IQR: 1-10)
Anglo-Celtic	62.5%	59.5%
History of macrovascular disease or risk factor †	78.0%	49.0%
Duration of contact with referring doctor (yrs)	6 (IQR: 2.5 to 10)	6 (IQR: 3-10)
Changed doctor after Assessment 1 ‡	13.5%	47.1%
Type of practice attended Solo Group Medical Centre	111 (55.5%) 49 (24.5%) 40 (20.0%)	100 (50.0%) 62 (31.0%) 38 (19.0%)

* $\chi^2_{(df-1)}$ =7.2; P=0.007
† $\chi^2_{(df-1)}$ =36.3; P<0.00001
‡ $\chi^2_{(df-1)}$ = 52.1; P<0.00001

Overall, a total of 236 specific treatment recommendations were given in 169 patients (42.3%). Recommendations were given regarding metabolic control, blood pressure treatment and lipid treatment to 109 (27.3%), 49 (12.3%) and 55 (13.8%) patients, respectively, and referral to an ophthalmologist was suggested in 23 (5.8%) patients. As seen in Table 5-3, significantly more treatment recommendations were given for patients

who were subsequently re-referred. The majority of recommendations were implemented in both groups. However, general practitioners implemented more treatment recommendations in the non-returned group, with the difference in implementation rate for metabolic recommendations reaching statistical significance ($\chi^2_{(df-1)} = 4.8$; P=0.03).

Table 5-3. Number of treatment recommendations implemented in returned and non-returned patients

Type of recommendation	Recommendation given		Recommendation implemented	
	Returned	Non returned	Returned	Non returned
Any recommendation	110 (55%) *	59 (29.5%)	86 (78%)	50 (85%)
Metabolic control	76 (38%) †	33 (16.5%)	58 (76%) §	31 (94%)
Blood pressure	30 (15%)	19 (9.5%)	22 (73%)	15 (79%)
Lipids	38 (19%) ‡	17 (8.5%)	17 (45%)	12 (71%)
Eyes	15 (7.5%)	8 (4%)	4 (27%)	7 (88%)

* χ^2 (df-1) =26.7; P<0.00001
† χ^2 (df-1) = 23.3; P<0.00001
‡ χ^2 (df-1) = 9.3; P=0.002
§ χ^2 (df-1) = 4.8; P=0.03

Discussion

It is a reality that most health systems around the world need to provide care to the growing number of people with diabetes without corresponding increases to their budget. It is therefore important to establish models of care that optimise the use of finite resources. In Australia, as in many other countries, specialist services are less accessible and more expensive than those provided by generalists. Therefore models that share the care of diabetic patients between general practitioners and specialists have become increasingly popular. However, there are no fixed criteria of what constitutes shared care and, in particular, how often the specialist should see the patient. In many systems, a yearly review by the specialist is standard. However, when resources continue to contract, even providing this could be difficult. It is estimated that in the Central Sydney Area, which serves a population of about 300,000 people, 40 specialist sessions per week would be required for each patient to receive a specialist review once a year. Therefore, rather than providing a strict protocol for re-referral, the CSAHS has adopted a differential approach that is dependent on general practitioners providing the majority of diabetes management and referring to specialist care only those patients they consider to require it. The results of this study suggest many general practitioners are comfortable with this approach and are already caring for patients with variable levels of diabetic control and vascular risk factors in a differential manner. Most importantly, they distinguish the level of care that patients require. As shown by these findings, general practitioners differentiate

between the ‘more complicated’ patients, choosing to re-refer those with macrovascular disease, while maintaining the care of ‘less complicated’ patients. Although control of blood glucose levels can reduce microvascular complications, it is the aggressive treatment of macrovascular risk factors that significantly reduces the morbidity and mortality associated with diabetes (Pyorala et al, 1997; UK Prospective Diabetes Study (UKPDS) Group, 1998[c]). Referral of patients with macrovascular disease would therefore seem an appropriate use of specialist services.

In addition to the patients’ macrovascular status affecting re-referral for specialist care, multivariate analysis identified several doctor-related factors as also having an affect. Interestingly, general practitioners were more likely to include details regarding type and duration of diabetes in the referral letters of patients who were not re-referred for specialist review. This may reflect that these patients have less vascular risk factors, thus issues relating to glycaemic control become more eminent in the doctor’s mind. Re-referral for specialist review was also dependent on the patient remaining under the care of their original doctor. A disturbingly large proportion of the patients changed their general practitioner in the years following their assessment at the Diabetes Centre. The Central Sydney Area has a highly mobile population and in many cases this change in doctor was associated with change in the patients’ or doctors’ address. Due to the Australian health system, patients can also move from one area to another to seek medical care. While many patients like to

develop a relationship with their doctor over time, others are happy to attend the most convenient doctor at the time of their need. The practical implication of this finding is, of course, that areas of diabetes management may remain neglected. Fortunately, in the majority of cases the treatment recommendations had been implemented by the referring general practitioner before the patient left their care. This study sought information from both the referring general practitioner and patient. Comparison of responses showed 100% agreement, thus it is unlikely that the results have overestimated the rate at which these recommendations were implemented. These findings emphasise the importance of sending correspondence to the referring doctors as soon as possible. The Diabetes Centre now also routinely sends a copy of the letter to the patient to increase the chance of any new doctor becoming familiar with the patient's diabetic status and treatment requirements.

Also of interest is the finding that the doctors involved in the formalised shared care programme referred more patients but were selective in whom they re-referred for specialist care. They provided ongoing management for the majority of their patients following the initial specialist review but re-referred those with macrovascular disease. On the other hand, 'non-shared care' general practitioners tended to re-refer all their patients, regardless of whether they had a co-morbidity. This 'selectivity' in referral behaviour may be partly due to continued education, an assumption supported by earlier work that suggested referral could be influenced by the training and skills of general practitioners (Mudge

1993). However, doctors who choose to formally register with the shared care programme may also be self selected in their commitment to the shared care philosophy and may have more experience with diabetes care.

While there are limitations of any diabetes care model, this study has shown that a system of differential shared care can provide flexibility so that patients can receive the level of care they and their general practitioner require. Through encouraging selective referral to specialist services, shared care can help to maximise the use of limited health care resources, without compromise to standards of care.

Chapter 6

Continuity of care

Introduction

Over the past few decades, general practice has changed with the advent of increased competition, more stringent government control and the demand for faster patient throughput to keep general practice economically viable. While general practitioners remain the best placed health professional to take an overall view of the health of person with chronic disease, it takes a great deal of time to care for these patients. These combined factors mean that the provision of best practice medicine is not easy to accommodate within a single appointment. In this pressured environment, continuity of care becomes an important issue. This is especially so for patients with a chronic disease such as diabetes as they require ongoing monitoring of glycaemic, lipid and blood pressure control and adjustment of medication to deter the development or slow the progression of diabetes complications. A study of patients attending the Royal Prince Alfred Hospital Diabetes Centre, Sydney, conducted in the late 1980s, found that as many as 31% of people with diabetes attend more than one general practitioner; some attending as many as 3 or 4 different practices (Constantino et al, 1991). The staff of the Diabetes Centre has since taken every opportunity to emphasise to patients the importance of continuity of care. In light of this, it is important to assess the current status. This study therefore sought to compare the

demographic profile and clinical outcomes of patients attending one versus multiple general practitioners. The profiles of patients who had recently changed their general practitioner, compared to patients under the care of their general practitioner longer term were also examined.

Methods

Clinical assessment

In the system of diabetes care provided by the Royal Prince Alfred Hospital Diabetes Centre, patients are referred by general practitioners for clinical assessment, including assessment of diabetic complications. For the purpose of this study, all data were collected on a standardised assessment form (Appendix 3). Venous blood was taken for measurement of HbA_{1c}, total cholesterol, HDL cholesterol and triglycerides. A spot sample of urine was collected and assayed for urinary albumin and urinary protein. Two blood pressure readings were taken in the sitting position and the mean result used in the analysis. Vibration perception was measured in a semi-quantifiable manner using a biothesiometer. The dorsalis pedis and posterior tibial pulses were palpated, and if absent, a hand held Doppler was used for detection. Optic fundus was examined with pupils dilated using a direct ophthalmoscope.

For the purpose of statistical calculation, retinopathy was defined as evidence of any retinopathy due to diabetes. Microalbuminuria and overt proteinuria were defined as urinary albumin concentration greater than 50 mg/L and 0.3 Gm/L respectively. Neuropathy was defined as a biothesiometer reading of greater than 40 volts. Any complication of diabetes was defined as having at least one of the following:

cerebrovascular disease, ischaemic heart disease, peripheral vascular disease, retinopathy, neuropathy, nephropathy or microalbuminuria.

Patients

Assuming 31% of patients attended more than one general practitioner (Constantino et al, 1991), it was estimated that a sample size of 470 patients had 86% power of detecting a 15% difference in the proportion of patients with a diabetes-related complication at the 0.05 significance level. This sample size also had 85% power of detecting a 0.6% difference in HbA_{1c} concentration (ie. an HbA_{1c} of 8.0% versus 7.4%), at the two sided 5% significance level, given a standard deviation of 2.0. Consequently, 479 consecutive patients newly or re-referred to the Diabetes Centre in a 6-month period were studied and underwent the clinical assessment described above. In addition to the assessment, the patients were questioned regarding the number of general practitioners they attended and the length of time they had been under the care of the referring doctor.

Statistical methods

Statistical analysis was performed using the Number Crunching Statistical System software package (Hintze, 1999). Attempts were made to normalise non-parametric data. Where this was not possible, non-parametric tests were used. Separate analyses were performed for the 2 outcome variables of interest: the number of general practitioners attended and the length of time under the referring general practitioner. For the purpose of analysis, patients were characterised as seeing either single or multiple general practitioners. Length of time under the care of the

referring doctor was categorised into 3 groups: less than 12 months, 1 to 10 years and more than 10 years. Continuous data were analysed by unpaired t-tests, Mann-Whitney tests and One Way Analysis of Variance (ANOVA). Categorical data were analysed by χ^2 test. The Mantel-Haenszel trend test (Armitage and Berry, 1990) was used to examine the relationship between the proportion of persons with complications of diabetes and length of time under the referring doctor. Logistic Regression was used to adjust for confounding variables. Results were regarded as significant at the $P<0.05$ (two-tailed) level. Results are expressed as mean and standard deviation (SD) for parametric data and percent or adjusted odds ratio (OR) and 95% confidence interval (95% CI) and median and inter-quartile range (IQR) for non-parametric data.

Results

Single versus multiple general practitioners

Most patients (87.7%) attended only one general practitioner and had been under the care of the referring doctor for a median of 6.2 years (IQR: 2.3-12.1). As seen in Table 6-1, patients who reported attending only one general practitioner were older (median of 59.9 years versus 54.0 years; P=0.02). However, they were comparable with those attending multiple general practitioners in terms of type and duration of diabetes as well as length of time under the care of the referring doctor. Their HbA_{1c}, lipid, blood pressure and treatment profiles were also similar. Moreover, there was no significant difference in the proportion of patients with the micro- or macro-vascular complications associated with diabetes (Table 6-2).

Table 6-1. Demographic and clinical profiles of patients under the care of one versus multiple general practitioners

	Attends one general practitioner n=430	**Attends multiple general practitioners n=49**
Age (yrs) †	59.9 (50.7 to 67.0)	54.0 (48.7 to 61.5)
Male	51.6%	46.9%
Anglo-Celtic	35.6%	36.7%
Time under referring doctor (yrs)	6.3 (2.4 to 12.2)	5.3 (1.2 to 10.2)
Duration of diabetes (yrs)	5.4 (1.6 to 11.2)	5.2 (1.6 to 9.8)
Type 2 diabetes	95.1%	100%
Diabetes treatment		
Diet	18.6%	18.4%
Tablets	63.7%	67.3%
Insulin(+/- tablets)	17.7%	14.3%
Antihypertensive treatment	43.0%	36.7%
Lipid treatment	28.6%	28.6%
HbA_{1c} (%)	7.8 (6.6 to 9.1)	7.5 (6.6 to 9.6)
Systolic BP (mmHg)	135 (121 to 148)	130 (120 to 141)
Diastolic BP (mmHg)	80 (70 to 85)	79 (70 to 84)
Cholesterol (mmol/l)	5.2 (4.6 to 6.0)	5.3 (4.9 to 6.0)
Triglyceride (mmol/L)	1.9 (1.3 to 2.9)	2.4 (1.6 to 3.1)
HDL cholesterol (mmol/L)	1.1 (0.9 to 1.3)	1.0 (0.8 to 1.2)

Results are expressed as percent (%) and median (IQR)
† Wilcoxin Rank-Sum; P=0.02

Table 6-2. Complication profile of patients under the care of one versus multiple general practitioners

	Attends one general practitioner n=430	**Attends multiple general practitioners n=49**
Cerebrovascular disease	6.5% (4.2% to 8.8%)	6.1% (-0.6% to 12.8%)
Ischaemic heart disease	18.8% (15.1% to 22.5%)	16.3% (6.0% to 26.7%)
Peripheral vascular disease	1.4% (0.3% to 2.6%)	0
Retinopathy	16.0% (12.6% to 19.5%)	16.3% (6.0% to 26.7%)
Neuropathy	15.5% (12.1% to 19.0%)	12.2% (3.1% to 21.4%)
Nephropathy (>0.3 Gm/L)	11.8% (8.2% to 15.4%)	9.8% (0.7% to 18.8%)
Microalbuminuria (>50 mg/L)	23.3% (19.2% to 27.5%)	22.9% (11.0% to 34.8%)
Any complication	50.7% (46.0% to 55.4%)	51.0% (37.0% to 65.0%)

Results are expressed as proportion (95% CI)

Time under the care of the referring general practitioner

There was also a relationship between the age of the patients and the length of time they had been under the care of the referring doctor. As seen in Table 6-3, patients who had been attending the referring doctor for one year or more were older than those patients who had only recently changed their general practitioner (P=0.0002). There was also a progressive increase in duration of diabetes, although this did not reach significance.

There were no differences in HbA_{1c}, lipid, blood pressure and treatment profiles for patients attending referring doctors for the different lengths of time (Table 6-4). However, the proportion of patients with a history of cerebrovascular disease (test for trend: $\chi^2_{(df-1)} = 6.2$; P=0.01), ischaemic heart disease (test for trend: $\chi^2_{(df-1)} = 10.0$; P=0.002) or any complication of diabetes (test for trend: $\chi^2_{(df-1)} = 7.5$; P=0.006) increased in a step-wise fashion with each incremental increase in the length of time the patients had been under the referring doctor's care (Table 6-5). As seen in Figures 6-1 to 6-3, these upward trends remained continuous even when the length of time under the care of the referring doctor was categorised into smaller increments.

Table 6-3. Demographic profile of patients under the care of the referring doctor for less than 12 months, 1 to 10 years and more than10 years

	Under the care of the referring doctor for less than 12 months n=67	**Under the care of the referring doctor for 1 to 10 years n=221**	**Under the care of the referring doctor for more than 10 years n=169**
Age (yrs) †	52.2 (SD 13.6)	59.1 (SD 12.9)	59.3 (SD 10.8)
Duration of diabetes (yrs) *	3.4 (0.4 to 9.2)	5.1 (2.0 to 10.4)	6.7 (1.5 to 12.1)
Type 2 diabetes	92.5%	96.4%	95.9%
Male	46.3%	53.4%	52.6%
Anglo-Celtic	35.8%	33.9%	36.7%
No. of general practitioners	1.2 (SD 0.4)	1.2 (SD 0.5)	1.1 (SD 0.3)
Diabetes treatment			
Diet	22.4%	18.6%	16.6%
Tablets	61.2%	64.7%	66.3%
Insulin (+/- tablets)	16.4%	16.7%	17.2%
Antihypertensive treatment	34.3%	43.0%	44.3%
Lipid treatment	25.4%	30.3%	27.8%

Data regarding length of time under the referring doctor is missing for 22 patients
† ANOVA P=0.0002
* Results are expressed as median (IQR)

Table 6-4. Clinical profile of patients under the care of the referring doctor for less than 12 months, 1 to 10 years and more than 10 years

	Under the care of the referring doctor for less than 12 months n=67	**Under the care of the referring doctor for 1 to 10 years n=221**	**Under the care of the referring doctor for more than 10 years n=169**
HbA_{1c} (%)	7.3 (6.3 to 9.0)	7.8 (6.6 to 9.1)	7.8 (6.6 to 9.4)
Systolic BP (mmHg)	130 (120 to 140)	135 (120 to 147)	135 (123 to 147)
Diastolic BP(mmHg)	80 (70 to 89)	79 (70 to 84)	80 (70 to 85)
Cholesterol (mmol/l)	5.5 (4.5 to 6.1)	5.3 (4.8 to 5.9)	5.2 (4.5 to 6.2)
Triglyceride (mmol/l)	2.0 (1.4 to 2.8)	1.9 (1.3 to 3.0)	1.9 (1.3 to 3.1)
HDL cholesterol (mmol/l)	1.1 (0.9 to 1.4)	1.1 (0.9 to 1.3)	1.1 (0.9 to 1.3)

Data regarding length of time under the referring doctor is missing for 22 patients
Results expressed as median (IQR)

Table 6-5. Complication profile of patients under the care of the referring doctor for less than 12 months, 1 to 10 years and more than 10 years

	Under the care of the referring doctor for less than 12 months n=67	**Under the care of the referring doctor for 1 to 10 years n=221**	**Under the care of the referring doctor for more than 10 years n=169**
Cerebrovascular disease †	1.6% (-1.5% to 4.7%)	5.0 % (2.1% to 7.8%)	9.5% (5.0% to 13.9%)
Ischaemic heart disease ‡	7.9% (1.3% to 14.6%)	17.2% (12.2% to 22.2%)	24.9% (18.3% to 31.4%)
Peripheral vascular disease	1.7% (-1.6% to 4.9%)	0.9% (-0.3% to 2.2%)	1.8% (-0.2% to 3.9%)
Retinopathy	17.5% (8.1% to 26.8%)	14.5% (9.8% to 19.1%)	17.8% (12.0% to 23.5%)
Neuropathy	9.7% (2.3% to 17.0%)	16.9% (11.9% to 21.9%)	14.4 % (9.1% to 19.7%)
Nephropathy (>0.3Gm/L)	9.5% (0.6% to 18.4%)	12.1% (7.0% to 17.2%)	12.7% (6.9% to 18.5%)
Microalbuminuria (>50 mg/L)	17.2% (8.9% to 29.1%)	24.2% (18.3% to 30.0%)	25.2% (18.5% to 31.8%)
Any complication §	38.7% (26.6% to 50.8%)	51.1% (44.5% to 57.7%)	56.8% (49.4% to 64.3%)

Data regarding length of time under the referring doctor is missing for 22 patients
Results are expressed as proportion (95% CI)
† Test for trend: $\chi^2_{(df-1)} = 6.2$; P=0.01
‡ Test for trend: $\chi^2_{(df-1)} = 10.0$; P=0.002
§ Test for trend: $\chi^2_{(df-1)} = 7.5$; P=0.006

Figure 6-1. The proportion of patients with a history of cerebrovascular disease, stratified by the time they had been under the referring general practitioner

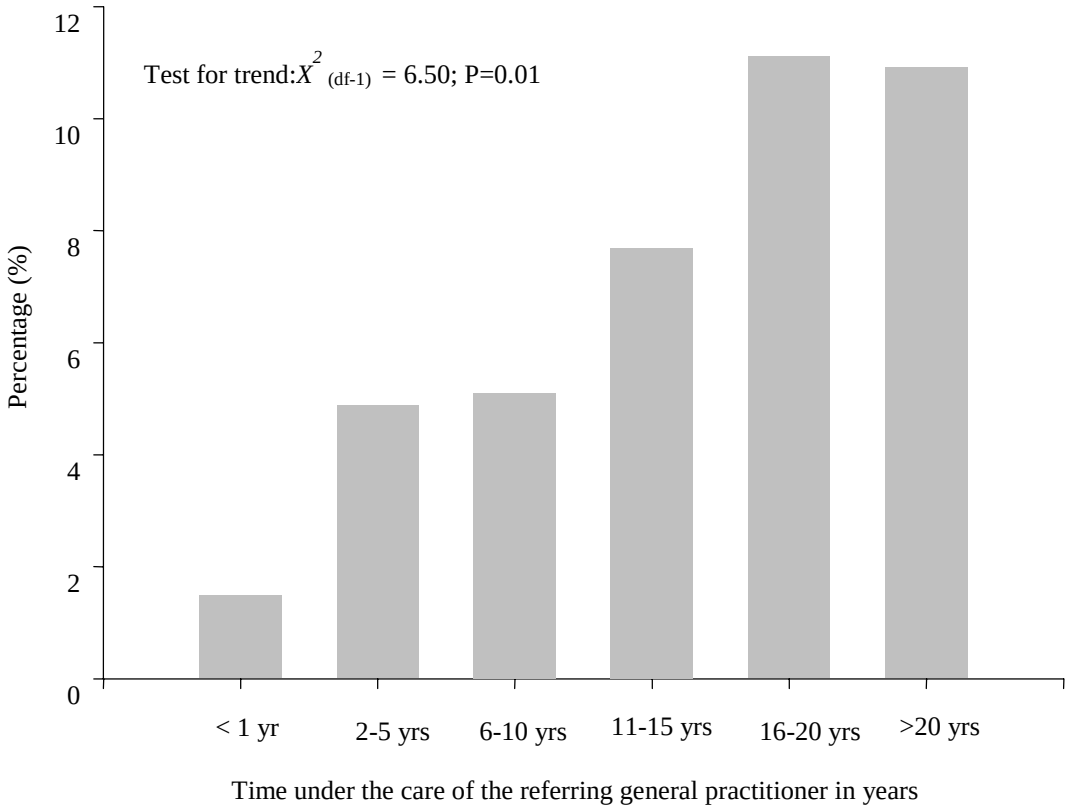


Figure 6-2. The proportion of patients with a history of ischaemic heart disease, stratified by the time they had been under the care of The general practitioner

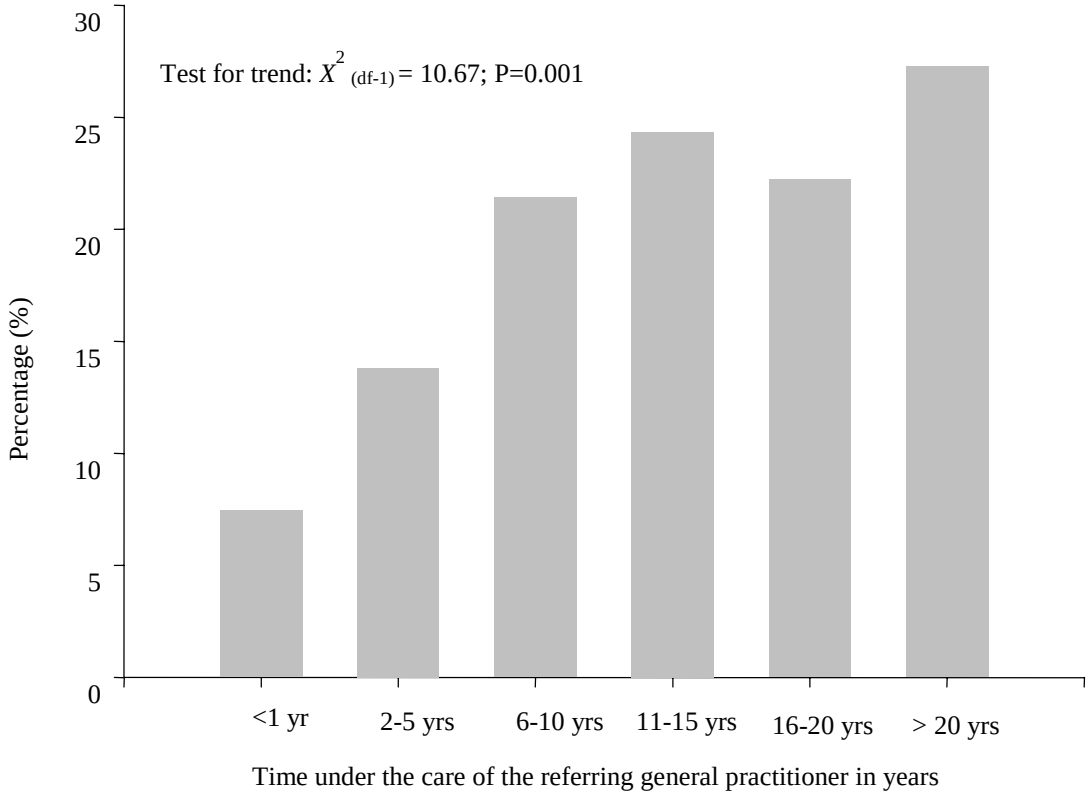
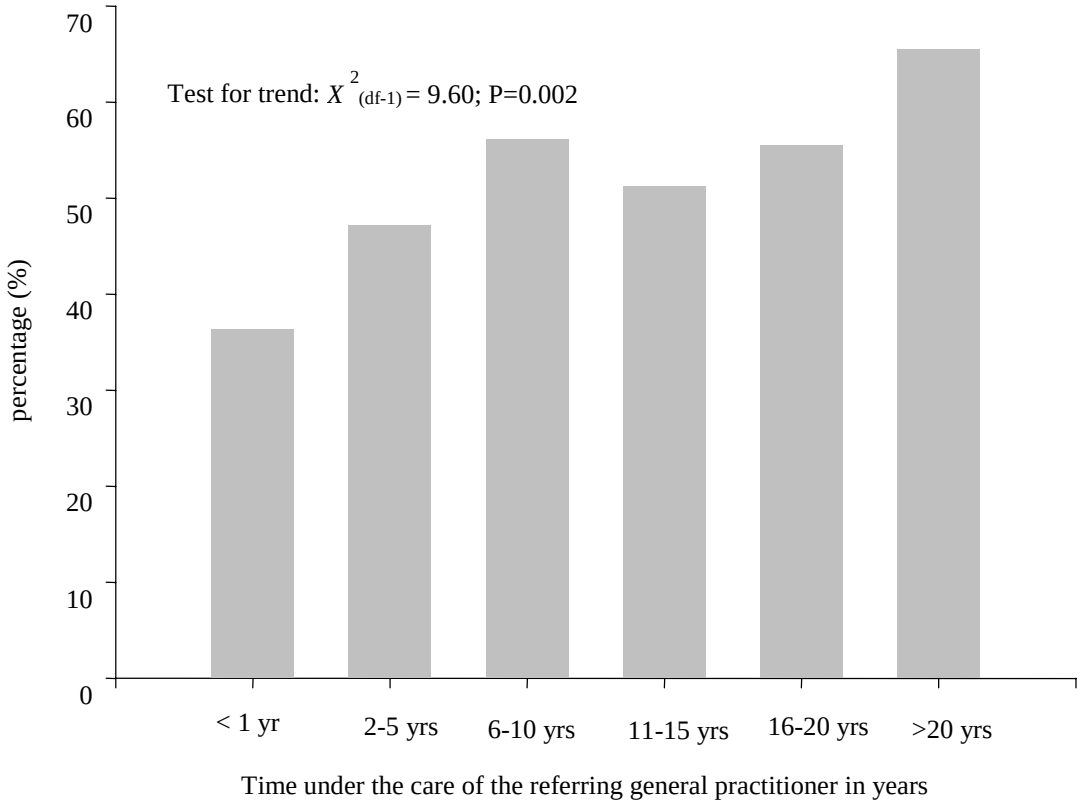


Figure 6-3. The proportion of patients with any complication, stratified by the time they had been under the care of the referring general practitioner



Logistic regression models were performed to adjust for differences in the patient's age and duration of diabetes. Both variables confounded the trends associated with cerebrovascular disease or any complication of diabetes. However, even when adjusted, there was a 3 fold increase (adjusted OR: 3.23; 95% CI: 1.19 to 8.74) in the number of patients attending the referring doctor for more than 10 years with a history of ischaemic heart disease (Table 6-6).

Table 6-6. The OR (95% CI) of a patient having a history of cerebrovascular disease, ischaemic heart disease or any complication of diabetes, adjusted for age and duration

	Cerebrovascular disease	**Ischaemic heart disease**	**Any complication of diabetes**
Under the care of the referring doctor for less than 12 months	1	1	1
Under the care of the referring doctor for 1 to 10 years	2.42 (0.29 to 19.78)	1.95 (0.72 to 5.30)	1.48 (0.81 to 2.70)
Under the care of the referring doctor for more than 10 years	4.83 (0.61 to 38.29)	3.23 (1.19 to 8.74)	1.75 (0.94 to 3.26)

Discussion

Within the Australian health system patients are relatively free to move around to seek medical care. While some patients like to develop a relationship with their doctor over time, many frequently change their general practitioner or regularly attend more than one general practitioner for the same health problem (Commonwealth Department of Health and Family Services, 1996). The perception that many patients with diabetes shop around for a doctor was confirmed by a study conducted by the Royal Prince Alfred Hospital Diabetes Centre in the late 1980's (Constantino et al, 1991). The finding from the current study that the overwhelming majority of patients were under the care of a single general practitioner and had been so for many years indicated that continuity of care had improved. The Central Sydney Area, in which this study was conducted, is serviced by over 400 general practitioners. In this relatively open medical market, patients can readily use their exit option and seek care elsewhere if incompatibility problems between patient and doctor existed. Hjortdahl and colleagues (1992) found that continuity of care and patient satisfaction are bi-directionally related. This would imply that there is a reasonable degree of satisfaction with the service patients in this study received.

Obviously the importance of diligent and continuous care increases as the patients' needs become more complex with increasing age and the clustering of macrovascular risk factors such as dyslipidaemia and hypertension. It makes sense that younger patients who are relatively healthy apart from the presence of diabetes, and are more likely to be working, would visit the closest doctor to minimise work disruption, attending more than one general practitioner or

frequently changing the regular doctor they see. The lack of continuity seemed to make little difference to acute outcomes such as glycaemic and blood pressure control. Presumably treatment of these areas is easier to address within several consultations if the patients are relatively uncomplicated. On the other hand, older, more complicated patients generally need multiple drugs and considerable efforts from both the patient and health care provider are required to achieve maximal therapeutic benefit. This increased patient-doctor dependency is most clearly illustrated in this study by the relationship between longer duration of contact and the increasing prevalence of diabetes complications, mainly macrovascular disease. Of note is the absence of a similar relationship in regard to the complications specific to diabetes such as retinopathy and nephropathy. Although general practitioners play an important role in the prevention and detection of these complications, their treatment is often outside the general practitioners' domain. As such, these patients are likely to be under the care of one or more specialist practitioners and therefore have less of a dependency on the general practitioner for ongoing medical care.

The data used in this study has been derived from patients referred by general practitioners to a diabetes centre located within a major teaching hospital. This sample may be biased as patients who do not seek continuity of care from a general practitioner may have less opportunity to be referred and are more likely not to attend appointments which they had made (Sweeney and Gray, 1995). Therefore the extent to which patients continue to doctor shop may be greater than reported by this study. However, this effect is probably quite small as previous work has shown the patients referred to the Royal Prince Alfred

Hospital Diabetes Centre are representative of persons with diabetes in the area as a whole.

While the data are only observational in nature, they provide useful information on the relationship between diabetes outcomes and continuity of care. As seen in this study, both patients and doctors are working appropriately, with continuity of care improving especially once the patients' medical requirements become more complicated. This is not only important medically, but also economically. Without this continuity of care, the use of health care resources is likely to increase (Hjortdahl and Borchgrevink, 1991) and therefore health costs.

Chapter 7

Concluding remarks

Diabetes is certain to be one of the most challenging health problems facing all nations this century. However, mounting research is providing us with the tools to reduce the personal and economic burden of this chronic disease. Routine monitoring of clinical status to promote optimal diabetes control and regular screening to facilitate the early detection and appropriate management of diabetes complications are now recognised as important cornerstones of effective diabetes management. As shown in the earlier Chapters of this thesis, large proportions of people with diabetes are still not routinely monitored in regard to diabetes and its complications. While there have been improvements over time, most notably for patients living in rural areas, further strategies will be required to continue this momentum. The development of innovative models of care together with the provision of mechanisms such as ongoing medical education to support practitioners manage patients with chronic disease are possible vehicles with which to drive further improvements.

Although it is probably inevitable that general practitioners would supervise most aspects of the patient's diabetes management, as seen in Chapters 2 and 3 of this thesis, large proportions of patients with diabetes currently receive care at the consultant physician level. The importance of access to this level of care for some aspects of diabetes treatment is difficult to dispute. Therefore, initiatives capable of optimising access to specialist care need to be established. The debate about

how to do so must be strengthened by research into different models and ways of organising care. As shown in Chapters 4 and 5, although some models of 'shared' diabetes care are based on strict protocols, this is not an absolute pre-requisite. Rather, models of shared care can be organised so that they are tailored to the patient's and doctor's individual needs and preferences. Shared care can also take into account the presence of specific complications or co-morbidities as well as the level of training and commitment of the general practitioner. With a flexible organisation structure, together with close co-operation and open communication between general practice and specialist care, models such as shared care can offer an efficient way in which to manage the increasing number of patients with chronic disease while promoting improved standards of care.

However, there is still a potential for patients to receive either haphazard duplication of care or neglected care. At least in Australia, many patients are able to seek care from multiple doctors or regularly change the doctor they see. Under the current health system it is the role of the general practitioner to mediate the movement of patients from primary to secondary care. Thus, the absence of continuity of care may lead to a group of patients missing out on the level of care that they need. The results of the study reported in Chapter 6 of this thesis showed that those patients with complications relating to diabetes, mainly macrovascular disease, who require specialist review, are more likely to seek continuous care from a single general practitioner. This would suggest that both patients and general practitioners recognise the importance of establish a long term relationship once diabetes management becomes more complex.

The current challenge is to continue to improve the standard of care patients with diabetes in Australia receive, taking into consideration available resources. To meet this goal the ongoing collection of relevant information to monitor future trends in standards of care and diabetes service provision is of paramount importance. As shown in earlier Chapters, Australia's universal health insurance system, known as Medicare, offers a sustainable and reliable system that may play a vital role in this regard. Medicare occasions of service data have already provided unique information on both standards of care and health service utilisation for people with diabetes living in NSW. Its ability to provide an almost complete snap shot of the total picture means it has considerable potential in regard to ongoing monitoring of both diabetes and other chronic disease. Moreover, with minor modifications to item code numbers, extensive epidemiological and public health data could be collected at virtually no cost.

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Appendix 1

The letters and questionnaires sent to the General managers and Directors of Pathology of all NSW public hospitals to estimate the correction factor for State funded services not captured by Medicare occasions of service data.

The Diabetes Centre
Royal Prince Alfred Hospital
Level 10, Queen Mary Building
Grose St
Camperdown 2050
Australia

DK Yue, Director and Professor in Medicine **Tel: 61 2 95153737** **Fax: 61 2 9515 3750**

«Date»

General Manager
«Hospital»
«Address1»
«City» «State» «PostalCode»

Dear Sir/Madam,

We are currently constructing a profile of diabetes care for people living within NSW using Medicare occasions of service data. Unfortunately, this data does not account for people receiving care entirely through hospital based services. While we suspect the number of people retained under the traditional hospital model is likely to be small, assessment of the extent to which diabetes care remains hospital based would allow for 'correction' of the Medicare data. We are therefore writing to seek your help with this process. We would appreciate you passing this letter to the most appropriate person within your organisation and asking them to complete the short questionnaire enclosed. An envelope is also enclosed so that the completed questionnaire can be returned to us at your earliest convenience.

Any information you give us will be treated as strictly confidential. If you would like any further information regarding our study please do not hesitate to contact us on 9515 3737.

Thank you for your help.

Yours sincerely,

Professor Dennis Yue Ms Jane Overland

Return address:

Jane Overland
Diabetes Centre
Level 10, Queen Mary Building
Grose St
Camperdown 2050

Thank you for your help. Please complete the following question(s) and return this page in the envelope provided.

1. Does «Hopsital» have a diabetes clinic:

   [ ] yes (please go to question 2)
   [ ] no

2. If yes, can you please provide an estimate of the number of **individual patients** (not services) seen at the diabetes clinic last year:

   _____

Thank you

The Diabetes Centre
Royal Prince Alfred Hospital
Level 10, Queen Mary Building
Grose St
Camperdown 2050
Australia

DK Yue, Director and Professor in Medicine **Tel: 61 2 95153737** **Fax: 61 2 9515 3750**

«Date»

Director of Pathology Services
«Hospital»
«Address1»
«City» «State» «PostalCode»

Dear Doctor,

We are currently constructing a profile of diabetes care for people living within NSW using Medicare occasions of service data. Unfortunately, this data does not account for services provided by hospital based services. Assessment of the extent to which diabetes related pathology is performed through hospital based laboratories would allow for 'correction' of the Medicare data. We are therefore writing to seek your help with this process. This will involve you completing the short questionnaire enclosed and returning it in the envelope provided.

Any information you give us will be treated as strictly confidential. If you would like any further information regarding our study please do not hesitate to contact us on 9515 3737.

Thank you for your help.

Yours sincerely,

Professor Dennis Yue Ms Jane Overland

Return address:

Jane Overland
Diabetes Centre
Level 10, Queen Mary Building
Grose St
Camperdown 2050

Thank you for your help. Please complete the following question(s) and return this page in the envelope provided.

1. Does «Hospital» have a pathology laboratory:

[ ] yes (please go to question 2)
[ ] no

2. Does your laboratory perform HbA1c assays:

[ ] yes (please go to question 3)
[ ] no

3. a) If yes, can you please provide an estimate of the number of HbA1c assays your laboratory performed last year:

_____

b) To assist us calculate the correction factor for the Medicare data can you please indicate what proportion of these assays are funded by the Federal Government through Medicare rather than by the NSW health budget *(this information will be treated as strictly confidential)*:

_____ % Federally funded (Medicare)

_____ % hospital (State) funded

Thank you

Appendix 2

The letters and questionnaires sent to doctors and patients for those shared care patients who had not returned for specialist review. The questionnaires to the doctors were ‘individualised’ to only include questions regarding treatment areas where a recommendation had been given.

ENDOCRINOLOGY

The Diabetes Centre
Royal Prince Alfred Hospital
Level 10, Queen Mary Building
Grose St
Camperdown 2050
Australia

DK Yue, Director and Professor in Medicine **Tel: 61 2 95153737** **Fax: 61 2 9515 3750**

«Date»

Dr «Doctor name»
«Address 1»
«Address 2»

Dear Dr «Doctor name»,

As a doctor who has referred patients to our Diabetes Centre, you may be aware that we do not routinely provide regular follow-up. While we are happy to see your patients every year or so, we leave re-referral to your discretion. Many doctors and patients have asked us to provide a recall service. We are currently looking at the feasibility of offering a system to remind general practitioners of when their patients were last seen by the Diabetes Centre. With this in mind, we are contacting a group of doctors and a group of patients who used our services between 1993 and 1995.

On review of our records we noted that your patient «Name» last attended an assessment on «Date 2». We are interested to know what has happened to this patient since then. We would appreciate you completing the questions below and returning this letter to us in the stamp addressed envelope provided.

To thank you for your time your name will be put in a draw for a mixed dozen of wine upon receipt of your reply.

Yours sincerely,

Dennis Yue Jane Overland

1. Is this patient still in your care?

[ ] Yes
[ ] No

2. If no, please specify the reason

[ ] The patient has moved
[ ] The patient has died
[ ] Don't know
[ ] Other.....(please specify)

Thank you very much for your help

ENDOCRINOLOGY

The Diabetes Centre
Royal Prince Alfred Hospital
Level 10, Queen Mary Building
Grose St
Camperdown 2050
Australia

DK Yue, Director and Professor in Medicine **Tel: 61 2 95153737** **Fax: 61 2 9515 3750**

«Date»

Dr «Doctor name»
«Address 1»
«Address 2»

Dear Dr «Doctor name»,

As a doctor who has referred patients to our Diabetes Centre, you may be aware that we do not routinely provide regular follow-up. While we are happy to see your patients every year or so, we leave re-referral to your discretion. Many doctors and patients have asked us to provide a recall service. We are currently looking at the feasibility of offering a system to remind general practitioners of when their patients were last seen by the Diabetes Centre. With this in mind, we are contacting a group of doctors and a group of patients who used our services between 1993 and 1995.

On review of our records we noted that your patient «Name» last attended an assessment on «Date 2». After the assessment, a report was sent to you with treatment recommendations regarding blood pressure treatment to implement at your discretion. We are interested to know what has happened to this patient since then. Therefore, we would appreciate you completing the short questionnaire enclosed and returning it to us in the stamp addressed envelope provided. We have enclosed a copy of the original report to help you complete the questions. This information will help us establish the appropriateness of a reminder system.

To thank you for your time your name will be put in a draw for a mixed dozen of wine upon receipt of your reply.

Thank you very much for your help.

Yours sincerely,

Dennis Yue Jane Overland

1. Is «Name» still in your care?

[ ] Yes (please answer questions 3)
[ ] No (please answer questions 2 and 3)

2. If no, please specify the reason

[ ] the patient has moved
[ ] the patient has died
[ ] Don’t know
[ ] Other.....(please specify)

3. Did you implement the recommendation regarding blood pressure treatment?

[ ] Yes
[ ] No

Comment:

Thank you for your help

ENDOCRINOLOGY

The Diabetes Centre
Royal Prince Alfred Hospital
Level 10, Queen Mary Building
Grose St
Camperdown 2050
Australia

DK Yue, Director and Professor in Medicine **Tel: 61 2 95153737** **Fax: 61 2 9515 3750**

«Date»

«Name»
«Address 1»
«Address 2»

Dear «Name»,

We are currently thinking about establishing a system to remind your doctor that it may be time for your diabetes to be reviewed. With this in mind, we are contacting a group of doctors and a group of patients who used our services between 1993 and 1995.

Our records tell us that we last saw you for a full diabetes check-up on «Date 2». We are interested to know how you have been since then. Over the next week, one of the staff of the Diabetes Centre may contact you to ask you a few questions. This should only take a few minutes of your time, so we hope that you will be able to help us.

If you have any questions regarding this letter please do not hesitate to contact Jane Overland on 9515 3757 Monday to Wednesday.

Yours sincerely,

Dennis Yue Jane Overland

Appendix 3

The standardised form used to perform the clinical assessment for the continuity of care study.