An investigation of the relationship between routine care for diabetes and hospital use

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University of Leicester

Elizabeth Claire Goyder

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ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

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GLOSSARY OF ABBREVIATIONS AND TERMINOLOGY

Abbreviations

A&E	Accident and Emergency department
BMI	Body Mass Index (weight in kg/(height in m)^2)
BNF	British National Formulary
CDM	Chronic Disease Management
CI	Confidence interval
CNS drugs	Drugs which act on the central nervous system
CVS drugs	Drugs which act on the cardiovascular system
DSN	Diabetes specialist nurse
FBG	Fasting blood glucose
FHSA	Family Health Services Authority
	(Now merged with the district health authority)
HA	Health Authority
HRT	Hormone replacement therapy
GP	General practitioner
IDDM	Insulin dependent diabetes mellitus, also known as "Type 1"
IQR	Interquartile range (25th percentile to 75th percentile)
Leics	Leicestershire
MAAG	Medical Audit Advisory Group
	(Now renamed the Primary Care Audit Group (PCAG))
NHS	National Health Service
NIDDM	Non-insulin dependent diabetes mellitus, also known as "Type 2"
OR	Odds ratio
PVD	Peripheral vascular disease
SMR	Standardised mortality ratio
UK	United Kingdom
UKPDS	United Kingdom Prospective Diabetes Study
US	United States of America

Terminology used in this thesis

"CDM practices"	General practices which qualified by the end of 1995 for the payments related to provision of structured diabetes care programmes, (known as "chronic disease management" payments)
"Non-CDM practices"	General practices which did not qualify for payments related to provision of structured diabetes care programmes
"Our study"	This always refers to the main study of hospital use on which this thesis is based
"Outpatients"	This refers to a hospital based diabetes clinic
"Survivor cohort"	Individuals with diagnosed diabetes who were alive and registered with the seven study practices on 1/1/96

1. Chapter 1: Introduction

Diabetes mellitus is responsible for a significant proportion of illness, disability and deaths in both developed and developing countries. At current incidence rates, one in ten of the population of Britain will develop diabetes at some stage in their life. As a result of an ageing population and increases in the prevalence of risk factors for non-insulin dependent diabetes, particularly obesity, an increasing prevalence is predicted for the future.[1]

Diabetes is also an expensive burden on health care systems, particularly for hospital based care. 4% of total health service expenditure in England and Wales is estimated to be spent on inpatient treatment of individuals with diabetes. Hospital admissions were estimated to account for 80% of around £1 billion spent on diabetes in 1989.[2] Moreover, estimates of the proportion of hospital admissions attributable to diabetes, both directly and indirectly, have been considerably revised upwards in recent years.[3,4]

Although it has been suggested that every admission to hospital represents a valuable opportunity to optimise diabetic control and educate patients,[5] there is consensus that hospital admissions for diabetic control and complications are expensive and avoidable outcomes that can be minimised by good diabetic management.[6-8] It seems reasonable to assume that use of the accident and emergency (A&E) department by individuals with diabetes could also be minimised by optimal diabetes management.[9]

It is therefore worthwhile taking a closer look at the relative contribution of those potential risk factors for admission and A&E attendance which may be most amenable to intervention, namely those related to the routine care received by an individual patient.

Recent changes in both primary and secondary care have included major changes in the organisation of care for diabetes. The new general practice contract in 1990 offered financial incentives to practices that offered health promotion clinics, more recently replaced by payments related to chronic disease management programmes. Considerable resources have gone into organising structured diabetes care programmes in general practice. An assumption sometimes made was that broadening the responsibilities of the primary care team would not only improve patient care but also reduce demands on secondary care. As the National Health Service (NHS) faces ever increasing costs, particularly in the hospital sector, the issue of whether changes in primary care really can reduce demand for hospital care has become increasingly crucial. There is very limited evidence available on the impact of changes in diabetes care at the interface

between general practice and hospital based services. It seems pertinent to ask whether hospital resources could be saved through earlier identification of problems and better management producing reductions in hospital admissions. An alternative, and equally credible, scenario is that improving identification and surveillance of individuals with diabetes will increase the number of referrals to hospitals for investigation and treatment of identified problems.[10] It is therefore important to critically examine the current predictors of admission. This will help to predict future patterns of demand and the impact of further changes in the organisation of care.

There is currently another reason for interest in factors which predict admission rates. Admission rates for acute and long-term diabetic complications represent a useful, routinely available outcome reflecting overall quality of diabetes services and could be used to assess services.[11,12] The relationship between case mix, admission rates and service provision needs to be better understood before admission rate can be interpreted as a valid measure of service quality.

The major purpose of this thesis therefore is to address the issue of whether a process of routine regular review may influence the risk of hospital admission or attendance at the accident and emergency department for an individual with diabetes. The next chapter sets out the aims and objectives in more detail. The available evidence for suggesting that changes in organisation of diabetes care may influence admission rates and the extensive literature on determinants of hospital admission have been examined (Chapter 3). Initially, a pilot study was conducted which resulted in some significant changes to the study methodology (Chapter 4). For the main study, data from 1120 individuals with diabetes from seven different practices were collected and analysed (Chapters 5 to 10). A comparative study of accident and emergency department use by individuals with diabetes was also conducted (Chapter 11). The final chapter (Chapter 12) brings together some conclusions from these studies and proposes some potentially fertile areas for further research.

2. Chapter 2: Aims and objectives

This study was set up to explore the relationship between routine diabetes review and both hospital admission and A&E attendance, in a cohort of individuals with diabetes. The potential impact on secondary care, through changes in admission rates or A&E use, of changes in the organisation of diabetes care in general practice was the major issue which motivated the setting up of this study. To explore the relationship between routine review and hospital use, it is necessary also to consider the demographic, clinical and social variables that are related to use of health services and could therefore confound the relationship of interest.

2.1 Primary objective

- To investigate whether there is a relationship between receiving routine diabetes review, in the setting of either general practice or hospital outpatient clinic, and risk of hospital admission.

2.2 Other specific objectives

- To describe the distribution of demographic, clinical and social characteristics and to describe the frequency and causes of hospital admission in a cohort of individuals with diabetes.
- To describe patterns of routine diabetes review, and secular trends in these, in a cohort of individuals with diabetes.
- To describe the relationship between routine diabetes care, demographic, clinical and social characteristics and A&E department use in individuals with diabetes.
- To compare a cohort of individuals with diabetes with a matched nondiabetic cohort, in their use of the A&E department.

2.3 Methodological objectives

- To construct a historical cohort of individuals with diabetes from general practice records.
- To validate the collection of information on hospital admission and A&E department use from general practice records, by comparison with routine data sources.
- To develop a statistical model for risk of hospital admission which allows for secular trends in patterns of routine care and for the presence of reverse causality i.e. the setting or frequency of routine diabetes review being the result of an earlier admission rather than the explanation for a subsequent admission.

2.4 General objectives

- To contribute to an understanding of the relationship between the pattern of routine care provided for individuals with diabetes and risk of hospital admission and A&E department use.
- To attempt to predict the impact of current shifts in diabetes care, towards more activity by primary care providers, on the interface between primary and secondary care.

3. Chapter 3: Background

3.1 Introduction

There is an extensive literature on variations in admission rates and on risk factors for hospital admission, relating both specifically to diabetes and to hospital admission in general. Much research has also been published on the organisation of diabetes care and on hospital and primary care use by individuals with diabetes. Much less has been published on their use of A&E departments.

For the purposes of this study, literature searches were conducted using Ovid Medline, BIDS ISI and BIDS EMBASE. References of relevant papers identified were also searched for additional material. The sheer volume of recent work in the area is suggested by the result of a single search on Medline for references published between 1993 and 1997, using the combination of thesaurus terms "diabetes mellitus" and "hospitalisation", which found 270 papers. Particular effort was made to identify all papers which discussed risk factors for hospital admission by individuals with diabetes. However this chapter does not represent a formal systematic review of the field but focuses on the literature which informed the design of this study. Evidence from previous studies informed the choice of study hypotheses and the choice of outcome and explanatory variables used in the main analyses as discussed below.

3.2 Study hypotheses

3.2.1 Recent changes in organisation of diabetes care

The organisation of care for patients with diabetes has changed significantly over recent years in the UK. Changes in the management of diabetes have reflected a general shift in the balance of responsibility for chronic disease from hospital clinics to general practice.[13] Simultaneously, there has been a growing enthusiasm for more structured care of the common chronic diseases such as asthma and diabetes within general practice and for involvement of an expanding primary health care team. Practical initiatives to reorganise care, as well as arguments for the need for change, have come from both hospital specialists and general practitioners over the past twenty years. More recently, the devolution of routine aspects of chronic disease management from secondary to primary care has been taken up as government and NHS policy.[14]

Hospital diabetes clinics were originally set up when treatment for diabetes became available: first insulin, discovered in the 1920s, then oral hypoglycaemic agents, introduced in the 1950s. They became increasingly overstretched as the potential to treat the disease and its complications, and the number of diabetic patients, grew. Demographic changes, including a growing elderly population and an influx of an ethnic minority population with a high prevalence of diabetes (for example, the Ugandan Indians who migrated to Leicester in the early 1970s) together with increasing diagnostic awareness, contributed to rising clinic workloads which were not matched by increasing resources.[15] The dissatisfaction for both patients and doctors which resulted was already evident in the view of a general practitioner (GP) writing in the 1970s:

"....once referred, the patient is kept on the hospital books for life, doomed to take time off work, travel and wait to see a fresh houseman at almost every attendance at the diabetic clinic scrummage."[16]

Some GPs argued that diabetes was best managed by themselves, with support from a hospital clinic for management problems and certain patient groups, namely children, pregnant women and "brittle" (unstable or poorly controlled) diabetes.[17] They argued not only that it was in the patient's and doctor's interests, but that it was most efficient use of limited resources.

It is unlikely that hospital clinics have ever seen every individual with diabetes and there are not enough physicians with a special interest in diabetes to routinely review them all, even if it was clinically desirable. Studies published in the last ten years suggest that in most areas only around half of patients with diagnosed diabetics attend hospital clinics. Only 46% of patients who were on practice diabetes registers in Tower Hamlets were attending a hospital clinic.[18] Similarly, in Norwich, 51% of patients, in practices which did not volunteer to be involved in a shared care scheme, were attending hospital clinics.[19] In Southampton, 47% were seen at the hospital, 33% visited their GP only and 20% had no regular care.[20]

By the early 1990s, randomised controlled trials of "shared care" schemes were demonstrating that interested GPs with hospital support could provide care of a quality equivalent to that of hospital clinics for their patients.[21-23] In 1990, the new General Practice Contract had allowed GPs to claim payment for running Health Promotion Clinics, which could include diabetes clinics.[14] This was the first time a financial incentive for organised chronic disease management (CDM) had been available. In July 1993, this has was replaced by a flat rate payment of £350 per GP annually if a practice

could show that they were providing structured care for diabetes, to the satisfaction of their Family Health Services Authority (FHSA) (now merged with the District Health Authority).[24]

The introduction of financial incentives has undoubtedly accelerated the move to provide structured diabetes care programmes within general practice.[25] Optimism has been expressed that such changes could, in the longer term, make it possible for hospital clinics to become less overburdened with routine reviews, adopting a role instead as an educational and "problem solving" facility.[26] However, in the short term, some feel the hospital clinic workload has been increased as a result of increased referrals.[10,27]

It is still unclear what effects the increasing shift in responsibility for routine surveillance to primary care will have on the demand for outpatient and inpatient hospital care, or on the use of the A&E department. The following section describes the limited evidence available for the impact of changes in diabetes management, in the context of both hospital and primary care settings.

3.2.2 Evaluation of different patterns of diabetes care

Most evidence for the relationship between diabetes care and outcome in the UK has come from the evaluation of schemes which have changed the setting, organisation or educational content of care for diabetes. Two randomised controlled trials of intensified surveillance have recently been reported from the United States (US).[28,29]

3.2.3 Changes to setting and organisation of care

Many of these have been subject to some form of evaluation, although few have been organised as randomised trials.

They fall into three main categories:

1. Patients discharged from hospital clinics to GPs with minimal hospital support.
2. Patients discharged to GPs but with support (usually including a recall system) provided by the hospital.
3. Patient care shared between hospital and GP but patients still seen (at least every one or two years) by the hospital.

These three categories have all been loosely described as "shared care",[13] although schemes differ very widely as to the degree to which care is shared between the hospital and general practice and the intensity of routine review, which may occur every 3 months,[30] 6 monthly[21,31] or annually.[32] The relative contribution of general practitioners

and practice nurses also varied between schemes, with some successfully introducing nurse co-ordinated services.[32]

The first projects were generally instigated by hospital consultants who discharged selected patient groups to the care of their general practitioners.[31,33] In Cardiff, a randomised controlled trial of discharging non-insulin dependent patients to their GP found that, over 5 years, glycaemic control was worse in those discharged, the majority of whom had not in fact been reviewed by their GP at all.[31] The reason for this failure was identified as a lack of support services, and particularly lack of an automatic recall system. Later schemes have sought to rectify this and have also sought more active involvement of GPs. At least two, in Exeter[34] and Norwich[19] began as "grass-roots" initiatives by local GPs.

The main outcomes examined have been frequency of review, frequency of laboratory tests and glycaemic control. Most have demonstrated that these parameters of care are at least as good as in hospital clinics when care is shared by GPs.[21-23,35] Attendance rates have sometimes been better in shared care and a randomised trial which examined patient satisfaction also found that shared care was more popular.[21] A qualitative study has explored the reasons for patient preferences, which include the convenience of attending the general practice and the perceived attributes of the primary health care team.[36] This study also reveals a conflict between the views of patients and the views of their GPs around the most appropriate setting for their care. Very few studies have included admission rates as an outcome of interest. A descriptive account of the shared care scheme started in Stirling in 1981, where patients were still reviewed annually by the hospital and by the GP every three months, reported a four-fold decrease in diabetes related admissions.[30] However the only randomised study of shared care to include admission rate as an outcome did not show any difference in admissions between patients who continued to attend the hospital and those in shared care.[23] An early randomised trial of discharging patients from hospital clinics to "routine general practice care" showed a nonsignificant increase in medical admissions in the general practice group, 25(24%) versus 17(18%).[31]

In 1990 attention was drawn in a review article to the inadequacy of outcome data from such schemes.[37] The only commonly assessed outcomes were frequency of follow-up and metabolic control. Studies reported relatively short term outcomes, only two to five years after the start of an intervention. More recently a comprehensive review of shared care schemes, published by the Royal College of General Practitioners, has examined

both published and unpublished evidence[38] and concluded structured shared care could be effective in the short term but that longer term follow-up was required to assess its true impact.

It cannot be assumed that standards in every practice are equal to those reached in locally co-ordinated "shared care" schemes involving enthusiastic specialists and often the most innovative of GPs. Generalisability of the results of these studies is therefore uncertain. Few studies (and only two of five randomised trials[23,31]) have included hospital admission rates as an outcome measure, so the impact on admission rates of most of these schemes can only be guessed at.

Studies from the US produce similar conclusions. They include both evaluations of new diabetes programmes and a couple of randomised controlled trials which increased the surveillance of patients with diabetes. The "before and after" comparisons yield dramatic reductions in admission rates, but they also raise questions about potential biases in the way subjects are recruited to programmes and the high proportion lost to follow up.[39,40] Unlike the randomised controlled trials, patients generally have to be seen in a hospital clinic, where a clinician decides whether they would benefit from an invitation to join these programmes, before they are recruited. It is possible that the patients recruited are therefore likely to have had diabetes related problems which had led to admission and clinic referral prior to recruitment to the study programme. This will select individuals particularly likely to have had an admission prior to the intervention and make it likely that, even if the intervention has no effect, admission rates will fall over time.

The results of randomised controlled trials of interventions to increase surveillance have been disappointing. A trial in Indianapolis[28] recruited individuals who were already attending a hospital clinic and aimed to reduce admission rates by increasing compliance with planned follow up. Overall admission rates for emergency and elective admissions remained unchanged, although they demonstrated a small and, statistically, non-significant reduction in admissions directly related to diabetes.

The Veterans trial[29] aimed to prevent readmissions in individuals with a range of chronic diagnoses by employing intensive primary care follow up. The unexpected result was a statistically significant increase in admissions in the intervention group. Patients in the intervention group were also more satisfied with their care, which raises interesting questions as to the relative importance attached to increasing patient satisfaction and reducing hospital admissions as desirable outcomes.

The striking difference between observational "before and after" comparisons and randomised controlled trials may be due to selection biases operating in the non-randomised comparisons. It may also be partly because the level of care before the new programmes were introduced was much lower for the control group than would ever be acceptable in a randomised controlled trial.

3.2.4 Educational initiatives

Programmes offering diabetes related education to GPs have often been initiated by GPs themselves. They have rarely been evaluated and what evaluation there has been has concentrated on organisation of diabetes clinics, treatment choice and clinical parameters.[41,42] They have not attempted to assess whether GP education has any impact on diabetes related admission rates.

In contrast, educational initiatives for patients have often been based in hospitals, sometimes with reduction of hospital admission rate as an explicit objective. Randomised trials are rare and the evidence for reduction in admission rates is often based on historical comparisons.

Beaven and Scott claimed that an education centre saved 500% of its running costs in reduced admissions[43] and schemes involving nurse run clinics and integration of education and care in a "diabetes centre" have been demonstrated to reduce admissions for ketoacidosis and hypoglycaemia.[7,44] Although one New Zealand study[45] showed no relationship of admissions to access to educational and outpatient services, an earlier study in the same area had shown those who had attended specific education programmes were less likely to be admitted.[46] The interpretation of such observational studies must be guarded as the attenders are a self-selected population. A randomised controlled trial of a home based education program was unable to show any impact on diabetes related hospitalisation or emergency room visits.[47] It may be that to be effective educational interventions need to be targeted at receptive individuals.

The main message of these studies is that there might be scope to reduce admission rates, at least for the acute metabolic complications of diabetes, in selected patient populations. Employing diabetes specialist nurses and replacing traditional clinics with diabetes centres, which aim to provide a focus for educational activities, are two ways this has apparently been achieved, but it is difficult to identify whether a change in admission rates can be ascribed to any one element of an integrated system of diabetes care, such as educational programmes.

3.2.5 Management of children with diabetes

The management of children with diabetes in the UK, and the impact on admission rates, has been investigated in studies conducted in Oxford[48,49] and Leicester.[8] The proportion of children admitted at diagnosis appears largely to depend on local service organisation and admission policy. In Oxford, 79% of children were admitted[49] whilst in Leicester the proportion was only 42%.[8] In Leicester, those not admitted at diagnosis were also less likely to be admitted later on. Whether this is a causal relationship, or due to differences in clinical or social characteristics, is uncertain. There is widespread consensus that all children with diabetes should be regularly reviewed by a specialist service.[50,51] Since the changes in diabetes management in primary care have not directly affected the management of children, our study excluded children under 16 years.

3.2.6 Why was a study of the relationship between routine care and hospital use by individuals with diabetes needed?

Admission rates are complex phenomena, influenced by a wide range of variables. Differences in admission rates in observational studies may be confounded by differences in casemix and, in population studies, by differences in prevalence.[52]

Better evidence of the relationship between routine care and admission rates comes from intervention studies. However very few such studies have been randomised, relying on comparison of dissimilar groups or historical comparisons. Observational studies using "before and after" comparisons have shown dramatic reductions in admission rates with changes in routine diabetes services, but are fraught with methodological problems which limit both the validity and generalisability of their findings. The selection of intervention groups is particularly prone to bias and it is impossible to rule out selection biases or other explanations of time trends. Randomised controlled trials of changes in the setting of care in the UK have not been designed to examine the impact on admission rates and have not been large enough to draw any conclusions where admission rates have been reported.[23,31] Randomised controlled trials conducted in the US have not shown a reduction in admissions with intensified care.[28,29] A major trial of an intervention designed to reduce readmissions actually produced an increase in admissions in the intervention group.[29]

There is a lack of clear evidence whether, or how much, changes in the frequency or setting of routine care influence admission rates. It is still possible that there is a group of patients, currently not receiving routine diabetes review, whose use of A&E and inpatient facilities would be reduced by regular review. We therefore believed a study was needed to examine whether there was any relationship between routine review and use of hospital services, in a population which included a range of patterns of care, from no routine reviews at all to regular review in either general practice, a hospital clinic or both. The choice of outcome and explanatory variables are crucial to the design of such a study and the following sections discuss the choice of variables, in the context of the existing literature in this field.

3.3 Choice of outcome variables

3.3.1 Use of inpatient facilities by individuals with diabetes

Many studies have focused on quantifying the use of inpatient facilities by patients with diabetes in the UK.[4,53-56] Similar studies have been done in Denmark,[57] Finland,[58,59] the US,[60] Australia,[61] New Zealand,[46,62] Ethiopia,[63] Saudi Arabia[64] and Trinidad.[65] Some studies have focused on specific age groups,[66] ethnic groups[67] or diagnoses.[67,68]

Most studies have examined admission rates or length of stay. Those that have compared populations with diabetes with the general population have invariably found that individuals with diabetes are admitted more often and have longer hospital stays.[4,58,59] The actual and relative rates of admission and bed occupancy appear to vary widely between countries. In Finland, average bed occupancy for a drug-treated diabetic patient was 13 days per year (occupying 13% of all hospital beds and six times more than the general population),[59] whilst from Saudi a rate of 3 days a year (twice the rate for the general population) was reported. Comparisons must be interpreted with great caution however, since methodology, study populations and ascertainment vary widely.

A UK study using routine hospital data to identify admissions related to diabetes identified 5.6% of beds as occupied by individuals with diabetes in East Anglia.[53] More recent evidence, using record linkage of admissions to individuals with diabetes, gave an estimate of 9.4% of beds occupied by individuals with diabetes in South Glamorgan.[4] At least some of the difference between estimates is likely to be due to the different methodologies employed.

None of the UK studies discussed have examined the contribution of admissions to non-NHS hospitals, although more than 20% of elective operations were estimated to be

done in the private sector in 1989.[69] This is presumably due to the lack of comparable routine data sources to those available within the NHS.

3.3.2 Defining "diabetes related" admissions

A major difficulty when comparing studies of admissions is that there is no standard definition or criteria for identifying a "diabetes related" admission. The relative significance of different explanatory variables is likely to be strongly dependent on the categories of admission included in the analysis.

Commonly, only admissions for the acute metabolic complications of diabetes are included and these could be expected to be the admissions most strongly related to standards of diabetes care.[8,44] However, they only represent a minority of admissions related to diabetes. In a population of patients with known diabetes only 23% of those admitted had "diabetes" as the principle cause of admission, while for a further 27% diabetes was a secondary cause of admission.[58] For this reason other studies include all admissions in which diabetes can be identified as a discharge diagnosis.[70] This will be highly dependent on the completeness of discharge summaries and coding practices.[55,71]

Other authors have studied all admissions, regardless of cause, of individuals with diabetes.[46,58] This can only be done where a diabetic population can be identified and usually involves studying a register population. This tends to limit studies to insulin treated, or drug treated, populations. Such a broad definition can be justified by the observation that individuals with diabetes have a higher risk of admission, even for indications not obviously related to diabetes.[4,58] It may be difficult to decide, even at the time of admission, to what extent diabetes contributed to precipitating a specific admission.

This variety of different categories of admissions and different diabetic subgroups studied limits the comparability of studies.

3.3.3 Difficulties in defining "optimum" admission rates

It should be noted that including all admissions by individuals with diabetes makes it impossible to assume that there is an "optimum" admission rate or that lower admission rates (or higher admission rates) represent a "desirable" outcome. The thorny question of what the "optimum" admission rate might be is less problematic for acute diabetic admissions. There is unlikely to be unmet need for admission and it may be reasonable to attempt to minimise such admissions. Although hypoglycaemic episodes may be an

inevitable consequence of tighter glycaemic control, these should very rarely be so severe as to warrant admission. However, for chronic complications of diabetes, the level of unmet need for treatment has not been fully established. A relatively high admission rate may reflect a genuinely higher prevalence of complications related to poor diabetic control or be due to a higher level of detection and referral of complications.

3.3.4 Admission as an outcome variable

The definition of "diabetes related" hospital admission has varied widely between studies. The choice has depended largely on the aim of the study and data availability. Since the aim of this study was to examine the overall relationship between pattern of care and admission it was important to consider all categories of admission for individuals with both insulin dependent diabetes mellitus (IDDM) and non-insulin dependent diabetes mellitus (NIDDM). It was also considered how this relationship would be expected to differ for different categories of admission. It was also important to choose a classification which would allow comparison with other published results.

Day-cases were included in order not to exclude those procedures that, during the period of the study, may have represented either admissions or day cases. A recent study classified day-cases as admissions of duration zero days.[4]

Other factors such as bed-days, length of admission, or frequency of re-admission were not examined. Although they are important (particularly in assessing costs of hospital care), it is the overall risk of admission which would be anticipated to be the variable most strongly related to an individual patient's experience around the time of admission. Organisational variables and events during and after the admission are likely to have a greater influence on length of admission and chance of readmission.[72,73]

Since it is likely that the presence of diabetes will influence to some extent every hospital admission for an individual with diabetes, and the increase in admissions seen in diabetes includes many categories of admission not directly related to diabetes, "all cause admissions" was our primary outcome of interest. For our current study, enough information was available from general practice notes to classify admissions by primary reason for admission (as given on the discharge letter). It was not possible to distinguish elective and emergency admissions as the type of admission was not always specified. According to their theoretical relationship with diabetes care, causes of admissions were classified as shown in Table 3.1, according to the main diagnosis given on the discharge

letter. International Classification of Disease (Ninth Revision) codings are given to facilitate comparison with other studies.

Table 3.1: Categories of admission and related ICD 9 coding

Category of admission	Type of admission	ICD9 coding
Diabetes related		
Diabetes control	Hyperglycaemia	250.0, 250.1, 250.2
	Hypoglycaemia	251.0, 251.2
Chronic complications (adapted from Jacobs et al[74] and Aro et al[58])	Venous	451-453, 457.1-457.9, 454
	Arterial	250.6, 707, 785.4, 440-442, 444, 447.1, 443.8
	Neurological	358.1, 713.5, 731.8, 354, 355, 337.1, 357.2, 458.0, 458.9, 250.5
	Cerebrovascular	430-438
	Cardiac	410-414, 425-429
	Renal	250.4, 580-586, 588,
	Retinopathy	362.0 -362.6, 362.8-362.9, 250.4
	Other	250.7, 250.9
Cataract and glaucoma	Cataract	366
	Glaucoma	365
Infections	Renal	590, 595, 599.0
	Respiratory	460-466, 480-487
	Other (inc TB)	001-139, 680-686, 730
Not diabetes related		All other codes

Admissions in a cohort of individuals with diabetes can be usefully conceptualised as a hierarchy of categories which would be expected to have an increasingly strong relationship to diabetes and therefore to previous diabetes care. Examples of classifications used are given in Table 3.2.

Table 3.2: Published classifications of diabetes related admissions

Types of admission	Examples of use	Comment
All admissions of population with diabetes (including day cases)	Currie et al[4] (UK)	Diabetes related to increased admissions for all ICD 9 chapters with sufficient admissions for analysis.
All emergency admissions	Smith et al[75,76] (US)	Admissions increased and related to clinical characteristics (but not for all individual causes and not influenced by increased review frequency)
All admissions coded for diabetes either as primary or secondary diagnosis	Williams[53] (UK) Isaacs et al[70] (New Zealand)	Frequency dependent on coding practices and accuracy. Likely to underestimate admissions by individuals with diabetes.
All admissions for chronic complications of diabetes grouped as: Neurological, Cardiovascular, Renal, Ophthalmic, Other	Jacobs et al [74] (US) Adapted by Aro et al[58] (Finland)	All probably reduced by better control in long term but in the short term may increase. Ophthalmic admissions may increase with better care due to earlier diagnosis and surgical treatment of cataract and glaucoma.
Infections	Aro et al [58] (Finland) O'Connor et al[77] (US)	Increased admissions. Would expect to be related to both clinical characteristics and standard of control.
Hyperglycaemia and hypoglycaemia	Sugarman et al[78] Kovacs et al[79] (US) Beaven et al[43] (New Zealand)	Most strongly related to diabetes control, but also other clinical, social, psychological characteristics. Influenced by access to different types of diabetic care and educational interventions.

3.3.5 Use of A&E facilities by individuals with diabetes

In contrast to the wealth of information relating to hospital admission for individuals with diabetes, the literature related to use of A&E departments by individuals with diabetes is much more limited. The management of patients with diabetes appears only to be perceived as relevant to A&E services in the context of acute metabolic emergencies, particularly hypoglycaemia.[9,80] Those studies that have looked at overall use of the A&E department have generally suggested that diabetic individuals visit A&E no more often than the nondiabetic population in either the UK[81] or in the USA.[82] One Swedish study found a relative increase in A&E use, but this was not statistically significant.[83] These results suggest that, after excluding problems directly related to diabetes, individuals with diagnosed diabetes visit the department significantly less often than expected.

It is plausible that individuals with diabetes might be more likely to use alternatives to A&E, due to more regular contact with their general practice or greater reliance on selfcare for health problems. The study cohort was therefore used to examine a relatively unexplored question: do individuals with diabetes have a different pattern of A&E use from the general population (Chapter 11)?

3.3.6 A&E use as an outcome variable

Previous studies looking at admission and emergency department use have interpreted emergency department use as a predictor of admission.[75,76] However, it seems likely that many of the risk factors for admission would also be risk factors for A&E attendance. It also seems plausible that the setting of routine diabetes care might influence A&E use through changing individual behaviour. It is possible that those who regularly attend a hospital diabetes clinic would be more likely to feel the hospital A&E department was an appropriate source of care, whilst those who regarded general practice as their main source of routine diabetes care would perceive access to primary care as an appropriate source of urgent health care needs. Moreover those without experience of routine diabetes review in either setting, might be more likely to end up in the A&E department. Therefore the risk factors for A&E use by the diabetes cohort were examined in order to explore the question: is the risk of A&E attendance related to the setting of routine diabetes review?

3.4 Explanatory variables

3.4.1 Theoretical models of health service use

According to the theoretical framework developed by Andersen and Newman,[84] admission risk for an individual is related to "predisposing", "need" and "enabling" characteristics. Predisposing factors are patient related variables such as age, sex and lifestyle. Need relates to clinical characteristics such as chronic morbidity and acute illness. Enabling factors are those related to access to medical care.

Within this framework, routine review of diabetes may theoretically influence "need" through early intervention to reduce morbidity, but also act as an "enabling" factor, by increasing the chance that complications are detected and admission for treatment arranged. Similarly, in this model, marital status and ethnic origin are included as "predisposing" factors, although they may influence admission rates via both social "enabling" effects and an association with morbidity or "need". This model has been developed into a framework for the study of policy influences on access to medical care.[85] However the difficulties posed in ascribing explanatory variables to its three categories, limits the model's value in unravelling individual influences on admission rates.

In contrast, a framework developed by Brown emphasised organisational factors in predicting health service utilisation.[86] The four important "themes" identified were service provision, characteristics of service providers, individual characteristics and geographical variables. This framework has been applied to the study of predictors of hospital admission for individuals with diabetes in New Zealand.[45] This study demonstrated the importance of geographic variation in service provision and the characteristics of service providers in explaining variation in hospital admission rates.

The research hypothesis of our study focuses instead on the characteristics and health care experience of individuals in explaining their individual risk of hospital admission. This required a model of service use which included individual demographic, clinical and social variables which might be causally related to service use at an individual level. Clues as to which variables may be relevant come from studies of both population based and individual predictors of hospital utilisation. The following section discussed the information available from ecological and cohort studies.

3.4.2 Studies of factors associated with admission

There is a vast literature dealing with geographical variations in admission rates for different causes. A database compiled in 1989 for a literature review[69] included 350 relevant papers and interest in the field remains undiminished, as the explanation of variations remains incomplete. The papers were classified by the causes of variation investigated into 38 different categories, reflecting the huge range of explanatory variables investigated. Although most studies have concentrated on surgical procedures, it is for medical diagnoses that variations are widest. A study of the full range of admission diagnoses classified adult diabetes as a "very high variation" cause of admission.[69] There must therefore be geographically heterogeneous variables influencing risk of admission in diabetes.

The relative importance of different variables will depend on the size and nature of areas or populations being compared.[87] The contribution of variables in an ecological analysis depends on their variability between areas as well as their importance in increasing risk in an individual. Moreover, the observation of an association at an ecological level does not necessarily imply an association at the individual level (the "ecological fallacy").

Studies have reported interesting correlations, for example between deprivation index and admission rates,[88] but have lacked information on associated variables which may well explain the correlation, such as differences in prevalence.[89]

Two important concepts which arose from early ecological studies[90,91] were "supply driven demand" and "physician uncertainty" as explanations for variations not explained by difference in morbidity. As a result, more recent ecological studies have often included consideration of variation in provision of and access to services[92] and variations in clinical practice[93] as well as variations in morbidity.

In contrast, most cohort studies which have examined risk factors for hospital admission at an individual level have concentrated on clinical, social and demographic variables which could identify individuals at increased risk of admission. The generalisability of such studies is often limited because they have been based on clinic populations[76] and will therefore not include individuals who do not attend the clinic. The validity of studies based on medical records are dependent on the completeness and accuracy of recording of information and questionnaires will also be limited by their response rates.[94]

For the purposes of the following discussion, explanatory variables investigated in the published literature have been broadly classified into three groups: patient related, doctor related and service related variables.

3.4.3 Patient related factors

Admission rates in a general population will be related to the prevalence of diabetes in the population. Prevalence is known to be related to age and sex,[95] social deprivation[89] and ethnicity.[96,97]

Evidence for variation in admission rates within diabetic populations comes from hospital admission surveys and a few detailed studies of diabetic populations. In all age groups, individuals with diabetes have more frequent admissions and longer stays than the general population. An analysis of routine data for East Anglia[53] shows relative bed usage by individuals with diabetes was highest amongst the under 14 age group (11 fold that of the general population under 14 in males and 22 fold in females). In every age group, bed usage was greater in females. Overall admission rates rise with age, particularly in the over 65 age groups.

There is a wealth of evidence that differences in morbidity are related to socioeconomic indicators specifically in diabetes[98,99] and more generally.[100] It is therefore not surprising that a study using routine data found a strong correlation between diabetes related admission rates and Townsend Deprivation Score by ward.[88] This study in Sheffield used age adjusted admission rates but was unable to control for confounding by differences in diabetes prevalence or other risk factors for hospital admission. Ethnic differences in complication rates have been observed[101,102] and could also contribute to differences in admission rates.

Cohort studies of patient related factors have looked mainly at clinical parameters. A US study demonstrated that, amongst members of a Health Maintenance Organisation with diabetes, 39% of hospital days were attributable to cardiovascular disease.[103] This suggests that cardiovascular co-morbidity must be an important predictor of overall admission risk. A historical cohort study of Navajo Indians over 12 years showed that, for subjects with NIDDM, risk of admission was related to increasing age, poorer metabolic control and presence of diabetic complications.[77] A population based cohort study of individuals with NIDDM, designed to identify high risk individuals for subsequent intervention studies,[104] suggested age group (above and below 65), sex and the presence of heart disease, retinopathy and proteinuria were the main identifiable

determinants of admission. A New Zealand observational admission study was able to compare insulin treated and non-insulin treated cases and showed higher admission rates in the insulin treated group.[62]

A study to examine "unexpected" urgent or emergency admissions in the US identified six characteristics which predicted admission in diabetes: frequent emergency room visits, low albumin, cardiomegaly, anaemia, hypotension and hyperglycaemia.[76] These combined criteria were used to predict admission with sensitivity 43% and specificity 77%. Some of these clinical variables may lie on the causal pathway between quality of care received and admission. Relatively low sensitivity suggests that there are other important factors precipitating admission apart from these identifiable clinical parameters.

Examples of psychosocial factors come mainly from studies of admissions for acute metabolic complications of diabetes. In a survey of adolescents attending a diabetes clinic,[105] five individuals admitted with hyperglycaemia during the study period showed greater emotional difficulty with diabetes and a more negative attitude on psychometric testing than controls. Despite the small number of cases the differences were highly significant, suggesting that, at least in this age group, psychological difficulties may be an important precipitant of admission. A larger study found behaviour problems, as well as younger age at diagnosis and socioeconomic status, predicted readmission in the young.[79] A study of adults admitted with poor diabetic control showed an excess of psychiatric morbidity, social problems and life events.[106]

3.4.4 Doctor related factors

In the search for explanation for variations in admission rates, differences in the characteristics of the doctors responsible for making the decision to request admission or to admit the patient have been considered in small area analysis in the United States,[93,107,108] in Canada[109] and in New Zealand.[45] Some North American studies were motivated by concerns that financial incentives were encouraging doctors to admit a higher proportion of less severe cases where payment was on a per case basis without adequate adjustment for case mix. They found that where admission rates were high there did seem to be less severe cases being admitted and fewer investigations done on admission.[107] This scenario may be less relevant to the UK where the need for admission is generally determined by the GP. The New Zealand study,[45] restricted to insulin-treated patients, found a relationship with GP age, practice type and caseload. In

general young doctors, those not in solo practice and those with fewer diabetic patients were more likely to have their patients with diabetes admitted.

Wennberg is the major proponent of the argument that variation in admission rates reflects differing levels of professional uncertainty, which influences both evaluation of a patient and perception of the need for admission in given circumstances.[91] This explanation is supported by the evidence from New Zealand that it is possible to characterise doctors with high diabetes related admission rates.

3.4.5 Service related factors

Research in the UK has considered facilities and organisational factors, rather than personal characteristics of doctors. A relationship between facilities for routine diabetes care available in general practices and admission rates for diabetes has been demonstrated, although the variation was small.[110] Although rates were standardised using 3 agebands, the study did not examine any other possible confounders such as prevalence or deprivation.

Roemer argued more than 30 years ago that the demand for hospital services was directly related to the supply of hospital beds[90] and, to a lesser extent, to the supply of doctors.[111] The relationship between bed supply and admission rate has been labelled "Roemer's Law" and demonstrated for diabetes using routine data in New Zealand.[45] Although this may explain variation between areas with different access to hospitals, it cannot contribute to explanations of differences between neighbouring GPs, where access is similar.

A significant relationship between admission rates and practice characteristics has been demonstrated for asthma admissions in east London,[112] with smaller practices having higher rates. It seems possible that an observed relationship between attending for diabetes review in general practice and admission could be confounded by other aspects of practice organisation (for example, existence of a diabetes recall policy associated with clear referral policies) or practice culture (for example, practices which organise the majority of diabetes care in house may also prefer to manage problems that others would refer for admission).

3.4.6 Choice of explanatory variables for this study

For our study, potential confounding by doctor and access related variables was dealt with by restricting the study population to a geographically defined population

registered with a limited number of different general practices. Information on individual demographic, clinical and social variables could be derived from patient records and postal questionnaires.

The choice of explanatory variables is given in Table 3.3. Several variables are included because they have previously been shown to be related to risk of admission. Other variables were included because they were significantly associated with admission in the pilot study univariate analyses or because there is a plausible theoretical reason why they should influence admission risk.

Table 3.3: Explanatory variables and justification for inclusion

Variable	Justification for inclusion in analysis		
	Theory	Previous studies	Pilot study
Demographic factors:			
Age	√	√[94,104]	√
Sex	√	√[94,104]	
Clinical factors:			
Duration diabetes	√	√[48,113]	
Treatment type	√	√[62,66]	√
Co-morbidity/complications	√	√[77,103,104]	√
Pattern of care factors:			
Setting of routine care		√[113]	√
Practice characteristics	√	√[110,112]	√
Social factors:			
Smoking	√		
Access to car	√		√
House ownership	√		√
Townsend index	√	√[88]	

The model assumes that admission risk is related both to patient and general practice characteristics. It also assumes that treatment and duration of diabetes (which may be related to the risk of both acute and chronic complications) and the presence of co-

morbidity (measured by repeat prescriptions and recorded diagnoses) will influence admission risk. In addition, it assumes that social and demographic factors may influence admission independent of their association with clinical variables. Great care is needed in interpreting the significance of explanatory variables which are related to admission risk, and explanations other than causality have to be considered.

3.5 Glycaemic control - a variable on the causal pathway?

Poorer glycaemic control has been shown to be directly related to an increased risk of development of complications in insulin dependent diabetes[114] and may also be a reason for referral to a hospital diabetes clinic, so might be considered a confounder of the relationship of interest. Glycaemic control has also been shown to be related to some aspects of the quality of general practice diabetes care, specifically care in a large and well equipped practice, from a GP with a declared special interest in diabetes, with access to a dietician.[115] Glycaemic control may therefore be considered to lie on the causal pathway between the quality of routine care and reduced risk of diabetes related admissions. This hypothesis was tested by examining the effect of introducing a measure of control into the model for risk of admission. If it is an independent risk factor it will not influence the relative risk associated with different patterns of care. If it lies on the causal pathway, including it in the model will change the relative risk associated with different patterns of care towards unity.

We defined control as "good", "acceptable" or "poor" on the basis of the mean HbA1 for the two year period before admission. The cut-off values was chosen on the basis of guidelines published locally in 1993[51] and are given in Table 3.4.

Table 3.4: Definition for glycaemic control

Test	Normal range	good control	acceptable control	poor control
HbA1	4 - 8.5	< 8.5	8.5 - 10.0	>10.0

3.6 Conclusions

An understanding of the context of the changes that have led to current patterns of care is important to the understanding and interpretation of an observational study of patterns of routine diabetes review and hospital use. It is also impossible to examine the relationship between patterns of care and hospital use, using an observational study design, without consideration of the multitude of interrelated confounding factors which

are known to be related to admission rates and which may vary systematically between groups receiving different patterns of care.

Variables and methods of analysis must be selected, precisely specified and justified prior to analysis. Otherwise the indiscriminate analysis of a wide array of subgroups and a range of different outcome variables inevitably leads to the phenomenon of "data dredging" which increases the possibility that interesting or statistically significant results have arisen by chance. Therefore explanatory and outcome variables of interest and the appropriate statistical analyses were chosen in advance, on the basis of theory, previous published studies and the pilot study.

3.7 Key points

- **In a research setting, routine care for diabetes provided in general practice can produce outcomes comparable to that provided by hospital clinics.**
- **Observational studies demonstrate that there is a wide range of patient related, doctor related and organisational factors which are related to hospital admission rates.**
- **Dramatic reductions in admission rates have been reported in observational studies of diabetes care programmes, but these have not been achieved by randomised controlled trials.**
- **Explanatory and outcome variables for the main study were chosen on the basis of a theoretical model of admission risk, supported by evidence from the published literature and the pilot study results.**

4. Chapter 4: The Pilot Study

4.1 Introduction

It may be impossible to design an appropriate study to address a specific hypothesis if there is uncertainty surrounding the magnitude of important parameters or the practicality of the proposed methodology. In particular, we did not know what proportion of individuals currently had routine diabetes reviews in different settings. Under these circumstances a pilot study was essential. More generally, conducting a pilot study may save time and resources in the long run by leading to improvement in the design and conduct of a major study.

4.2 Pilot objectives

- To assess the feasibility of using general practice computerised prescribing data to establish a historical cohort of individuals with diabetes
- To establish whether the Leicestershire Diabetes Register could be used to identify a historical cohort
- To assess data available from general practice notes and postal questionnaires for:
  - completeness and quality
  - concordance with each other and with routine data sources
- To establish the approximate magnitude of parameters including:
  - prevalence of diagnosed diabetes in Leicestershire practices
  - proportion of individuals lost from and joining a cohort within a 4 year period
  - proportion reviewed in a hospital diabetes clinic within a 4 year period
  - proportion with diabetes reviewed within general practice within a 4 year period
  - proportion of individuals admitted and number of admissions over a 4 year period by cause (diabetes, diabetes related, unrelated to diabetes)
- To analyse the dataset to determine the possible major risk factors for hospital admission in a cohort of individuals with diabetes

4.3 Pilot methodology

4.3.1 Selection of pilot practices

A random sample of 25 practices for the main study was drawn from the 150 practices covered by Leicestershire FHSA. 21 of these practices used five different commercial

software information and prescribing systems: Meditel (seven practices), AMSYS (five practices), EMIS (four practices), Microdoc (three practices), VAMP (two practices). The remaining four practices were recorded by the FHSA as using Genisys, Exeter GP system, GP records and "no computer system".

An opportunistic sample of seven practices, that were not included in the random sample but were known to use the five most commonly used software systems listed above, were contacted and invited to take part in the pilot study. One practice did not wish to participate and one was prepared to answer questions, but did not allow direct access to its database. The other five practices allowed access to their computer databases. In these practices the identification of individuals with diabetes was attempted using the practice software to search the repeat prescribing system.

4.3.2 Establishing a historical cohort

Clinical and prescribing information was used to identify individuals with diabetes. Patient information was collected, on a sample of 100 individuals from three pilot practices, from the patient computer record, the patient notes and postal questionnaires (Appendix 1). As several parameters of interest (eg admission rates, organisation of diabetes care) may be related to practice setting, one inner-city three partner practice, one suburban five partner practice and one single-handed rural practice were selected for the pilot data collection.

4.3.3 Comparison with the Leicestershire Diabetes Register

The characteristics of those members of this pilot cohort who were on the Leicestershire Diabetes Register were compared with those who could not be identified on this register, in order to assess whether the register might be useful in identification of a historical cohort for examining patterns of care.

4.3.4 Completeness and concordance of data from notes and questionnaires

The completeness of data from notes and questionnaires was established. Concordance between different sources was compared using both the percentage agreement and the Kappa score (which gives the proportion agreement minus the agreement expected by chance, as a fraction of the total possible agreement over chance).

The case has been argued for used sensitivity, specificity and predictive values rather than Kappa for assessing validity.[116] This is appropriate if one source is regarded as a

"gold standard" to which a second source is to be compared. Kappa is more appropriate as a measure of agreement between two sources where neither is regarded as entirely sensitive or specific. Kappa is dependent on both the number of categories and prevalence of the variables and this should be borne in mind if results are generalised to different populations.

4.3.5 Estimation of parameters

Information from the pilot practices was used to estimate the magnitude of parameters of interest, particularly the proportion of individuals admitted and proportion receiving routine care in different settings, which were needed for the main study sample size calculation.

4.3.6 Risk factors for admission

In order to examine the relationship between the variables collected and risk of a hospital admission, or a "diabetes related" hospital admission, subjects were classified on the basis of whether they had had such an admission recorded in GP records between 1991 and 1994 inclusive. The working definition of a diabetes related admission was any admission with a diagnosis that was a recognised complication of diabetes or for which diabetes was a known risk factor, including infections, cardiovascular and peripheral vascular disease. "Number of items on repeat prescription" (excluding diabetes related items) was used as a proxy measure of co-morbidity, since recording of chronic diagnoses in notes was found to be incomplete and to vary between practices.

A comparison of explanatory variables for those admitted and those not admitted demonstrated that the most significant risk factor was the number of items on repeat prescription. Therefore the relationship between admission and pattern of routine care was further explored by stratifying by presence or absence of co-morbidity.

4.4 Pilot results

The characteristics of the pilot practices are shown below in Table 4.1

Table 4.1: Characteristics of the six participating pilot practices

Practice	Location	No. of GPs	Computer software
P	Suburban	5	VAMP
Q	Inner city	3	Microdoc
R	Rural	1	Microdoc
S	Suburban	5	EMIS
T	City	6	Meditel
U	City	3	Amsys

4.4.1 Feasibility of establishing a historical cohort

All five computer systems had a facility for searching on prescriptions and on clinical factors. The main limitations on identifying all individuals with diabetes within the practice between 1.1.91 and 31.12.94 were

- Practice only recently computerised, so only current cases recorded
- Only current repeat prescriptions accessible
- Manual register still used for diabetic clinic
- Problems limiting searches to specific dates

On VAMP in Practice P, it was possible to search both repeat prescriptions and all acute prescriptions. Using acute prescriptions yielded a few extra cases (8/164, 5%).
Searching on clinical history fields also yielded some additional cases not receiving repeat prescriptions (15% (25/164) in Practice P, 11% (25/219) in Practice T, none in Practice S).
In order that the cohort should include all patients that had died or left the practice, the study would need to be limited to practices using computerised repeat prescribing since 1990. Only two of the pilot practices fully met this criterion; the number of individuals lost from the cohort since 1990 could not be calculated for the other practices.

4.4.2 Comparison with the Leicestershire Diabetes Register

The names, dates of birth and addresses of 100 individuals identified were checked against the Leicestershire Diabetes Register. 41 were found on the register, including 80% of those on insulin, 17% of those only on tablets and 7% of those currently controlled by diet. 85% of those seen in diabetes outpatients, 44% of those reviewed by GP or hospital, and only 22% of those reviewed by neither were on the register.

4.4.3 Completeness and concordance of data from notes and questionnaires

Complete information on surname, first names, address, date of birth, sex and computerised repeat prescriptions were available for all 100 patients and postcodes for all but two patients, and NHS number for all but five patients. All this information was found on practice computers.

Information from GP notes was available for 96 of 100 patients identified by a computer search as current patients. (In practice Q the partnership was in the process of being dissolved at the time of the study and four patients had apparently changed their GP, despite still appearing on the computerised register.) An estimation of date of diagnosis was possible from all but one set of notes. Total number of contacts was difficult to establish as often notes made no distinction between a visit to a GP or nurse, telephone advice or a repeat prescription.

Presence of complications was the most difficult information to ascertain from the notes. Entries such as "feet ✓" are ambiguous and open to varying interpretations. Only 51 sets of notes included both height and weight, enabling calculation of BMI. Recording of complications was generally only adequate for those seen regularly for general practice checks, since information from hospital clinic letters was sometimes limited to "no other problems" or mentioned blood tests done without communicating results. Blood pressure and HbA1 were the only parameters recorded regularly (in 94% and 95% of notes respectively) and were often recorded even if there was no written evidence of a diabetes review in the previous four years.

Other components of diabetes review were variably recorded between practices. Overall recording frequencies were: lipids 60%, proteinuria 69%, creatinine 71%, fundi examination 83%, foot pulses 73%.

It is likely that all these practices are well above average in conducting and recording diabetic checks, since they were chosen as practices likely to be interested in involvement in the pilot study. Randomly selected practices are likely to have lower levels of recording.

Questionnaire completion

Several problems with individual questions were identified from responses. Few patients could distinguish between a diabetes specialist nurse ("a nurse with special training in diabetes who may have given advice about diabetes") and a practice or district nurse involved in diabetic clinics. Many patients from practice Q answered "yes" to "have you ever seen a diabetes specialist nurse" but claimed to have seen the nurse at their GP surgery (where the practice nurse ran clinics and had indeed completed some diabetes training).

It seemed that an additional question was needed about regular nurse contact as in some practices patients may only see the nurse, and not the GP, for diabetes related review. Questions about admissions and A&E visits were answered incompletely with little information given about diagnoses.

The question about complications was too broad to yield useful information. One respondent expressed uncertainty about whether "kidney infection" was relevant, another included "new glasses" as treatment for an eye problem. Many did not complete this question, or indicated "yes" but failed to give any details.

The question about household size caused difficulty for those in residential homes. All respondents completed the ethnic origin question. One individual expressed confusion about the smoking question, and non-smokers did not all answer the question about giving up, possibly due to misunderstanding or not thinking it relevant.

The employment question yielded some ambiguous job descriptions. One respondent mentioned that he was on long term invalidity benefit. Several offered explanations of why the question about partner's job was not applicable, explaining that they were single, widowed or divorced.

Comments on services

There was praise for GP services, regular checks, clinics and free prescriptions. Criticisms included GP knowledge level, lack of continuity of care at hospital, lack of information about test results, insufficient back-up, waits/overcrowding in clinic, loss of evening clinic, lost notes, need for more education/information on management/new developments, waits for referrals, lack of financial help with diabetic diet/dental treatment, insufficient access to clinics and a non-diabetic diet received in hospital.

Comments on questionnaires

One respondent noted that much of the information asked for in the questionnaire might be available from GP notes. One commented on the lack of clarity of the smoking question. One questionnaire was returned uncompleted with the comment "does not speak English".

Comparison of pilot questionnaire results and general practice records

It was possible to assess concordance of questionnaires and GP records for several items. Sex and date of birth were compared to check the accuracy of records and also to check that the questionnaires had been completed by the correct individuals. Duration of diabetes, type of diabetes treatment and whether an individual had been admitted to hospital or attended A&E in the previous 4 years was also compared. Respondents generally gave too little detail to allow comparison of frequency or cause of admissions. 66 respondents confirmed their gender as registered by the practice. One female respondent (as confirmed by telephone) mistakenly identified herself as male, giving 99% agreement. Four respondents gave dates of birth which differed by one digit or involved the transposition of two digits, although no dates differed by more than one year, giving 94% agreement.

Agreement over current diabetes treatment is shown in Table 4.2.

Table 4.2 : Comparison of treatment of diabetes

	GP repeat prescription			
Questionnaire				
	insulin	tablets	diet	total
insulin	26	1	-	27
tablets	-	23	-	23
diet	-	4	13	17
total	26	28	13	67

There was 93% agreement (Kappa = 0.89) with the commonest disagreement being over oral hypoglycaemics which appeared on the repeat prescribing record but respondents either did not currently take or did not record they took.

There was reasonable agreement over duration of diabetes (Table 4.3) which was defined on the questionnaire as an ordered categorical variable. There was agreement for 84% of subjects (Kappa = 0.76).

Table 4.3: Comparison of duration of diabetes

Questionnaire	GP records				
	<1yr	1-5yrs	5-10yrs	>10yrs	Total
<1yr	1	1	-	-	2
1-5yrs	1	12	2	2	17
6-10yrs	-	-	17	2	19
>10yrs	-	-	2	21	23
Total	2	13	21	25	61

Concordance on A&E attendances was remarkably poor (Table 4.4), reflecting failure to find hospital letters in GP notes and apparently poor recall on the part of respondents over a 4 year period. There was 75% agreement (Kappa = 0.38).

Table 4.4: Comparison of A&E attendance

Questionnaire	A&E letter in notes		
	Yes	No	Total
Yes	38	7	45
No	9	10	19
Total	47	17	64

Examination of the reasons for attendances without a letter in the notes showed that four of these were medical causes that might well have been admissions through the A&E department (two cases of "angina", "heart attack" and "epilepsy"). These may have bypassed the A&E registration system and failed to generate an A&E letter. A&E visits may not be recalled by respondents because they are less significant events than admissions and four years is a relatively long recall period to remember over. Postal questionnaires asking about previous use of health services have generally been limited to three months recall by concerns over the accuracy of recall.[117]

Better concordance was achieved for hospital admission (Table 4.5) and there was 90% agreement (Kappa = 0.81).

Table 4.5: Comparison of hospital admission

	hospital discharge letter in notes		
questionnaire	Yes	No	Total
Yes	33	3	36
No	3	24	27
Total	36	27	63

The admissions not recalled by patients included two brief admissions for routine procedures ("knee ganglion removal" and "maxillary clearance") and one admission for "detoxification". The admissions not recorded in the notes may have occurred after notes had been examined, but no dates were given. Causes were given as "renal failure", "operation" and "new insulin trial".

Questionnaire response rate and response bias

Within 4 weeks of sending out 100 pilot questionnaires, 67 had been both completed and returned. The response rate varied between the three practices (71% in the suburbs, 50% in the inner-city and 80% from the single-handed rural practice).

Only one telephone inquiry was received, from an individual who believed she was no longer diabetic, although still on a sugar-free diet and intermittently checking for glycosuria. She agreed to complete the questionnaire and has been included in the analysis.

The characteristics of respondents and nonrespondents were compared on details available from notes, for the 96 individuals for whom notes were available. There was no significant difference by sex or treatment. 67.2% respondents were male versus 66.7% of nonrespondents. Respondents were marginally more likely to be on insulin or diet (39% versus 33% and 19% versus 12% respectively) and less likely to be on oral hypoglycaemics only (42% versus 54%).

Other variables are compared in Table 4.6 below; respondents were older, had better glycaemic control and had twice as many GP routine diabetes reviews.

Table 4.6: Comparison of respondents and non-respondents

Mean	Respondents (n=64)	Non-respondents (n=32)	t-test: p=
Age/yrs	62.4	53.2	0.001
BMI(kg/m^2)	27.6	29.7	0.2
HbA1 (most recent)	8.97	9.99	0.01
Time since diagnosis/yrs	12.1	7.93	0.1
No. drugs on repeat	2.28	2.75	0.4
No. GP reviews	3.63	1.65	0.002
No. diabetes outpatients	1.52	1.75	0.7
No. admissions	0.70	1.13	0.1
No. A&E visits	0.34	0.53	0.3

4.4.4 Estimation of parameters

The prevalence of diabetes by practice is shown in Table 4.7. Prevalence of diagnosed diabetes varied widely between practices from 1.24% to 2.34%.

Table 4.7: Prevalence of diabetes in selected Leicestershire practices (on 1/1/95)

practice	population	prevalence of diabetes	
		Number	%
P	8705	164	1.88
Q	5473	128	2.34
R	2123	35	1.65
S	10314	128	1.24
T	9862	219	2.22
total	36477	674	1.85

The number of individuals with diabetes lost from and joining a practice cohort could only be accurately established in two practices using VAMP and EMIS, where searches for patients no longer registered were possible. In Practice P, 24 died and 21 transferred, out of total of 209 (22%) over four years. In Practice S, seven died and five left out of 140 (9%) in one year.

For those patients for which date of diagnosis was established 30 out of 96 (31%) had been diagnosed during the previous four years (between 1991 and 1994).

Pattern of diabetes care

Table 4.8 shows the proportion of individuals seen in the diabetes out patient clinic or reviewed within general practice within a 4 year period. The proportion of patients who had been reviewed in general practice varied widely from 35% to 73%. Overall 17% of patients had not been seen in a diabetes outpatient clinic or had a routine diabetes review in general practice (see Appendix 2 for the full definition of a routine diabetes review).

Table 4.8: Setting of routine diabetes review 1991 to 1994

practice	Seen in outpatients No. (%)	Seen in general practice No. (%)	Seen in neither setting No. (%)
P (suburban)	9/45 (20)	33/45 (73)	5/45 (11)
Q (inner-city)	10/26 (38)	9/26 (35)	9/26 (35)
R (rural)	14/25 (56)	15/25 (60)	2/25 (8)
Total	33/96 (34)	57/96 (59)	16/96 (17)

The proportion of individuals admitted is shown by practice, and by cause of first admission, in Table 4.9.

Two people had five admissions, three had four admissions, four had three admissions, eight had two admissions and 27 had only one admission recorded. Table 4.10 shows the frequency of different causes of admission by practice.

Table 4.9: Proportion of individuals admitted 1991 to 1994 (by cause of first admission)

practice	dm/dka/ hypo* No. (%)	dm related** No. (%)	not dm related No (%)	Total No. (%)
P	0/45 (0)	7/45 (16)	13/45 (29)	20/45 (44)
Q	0/26 (0)	3/26 (12)	13/26 (50)	16/26 (62)
R	1/25 (4)	3/25 (12)	4/25 (16)	8/25 (32)
total	1/96 (1)	13/96 (14)	30/96 (31)	44/96 (46)

* Included admissions directly related to hyperglycaemia, diabetic ketoacidosis or hypoglycaemia

** Included all admissions for conditions for which diabetes is a recognised risk factor

Table 4.10: Proportion of total admissions for different causes by practice

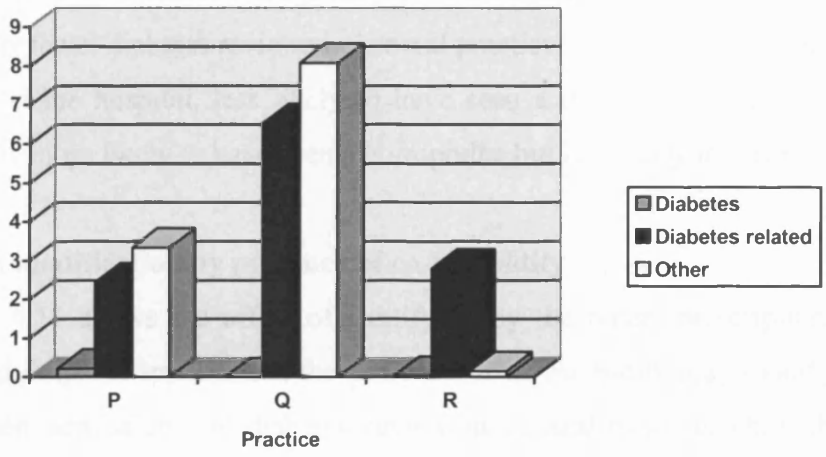
practice	dm/dka/ hypo*	dm related**	not dm related
	No. (%)	No. (%)	No (%)
P	1/27 (4)	11/27 (41)	15/27 (56)
Q	0/38 (0)	17/38 (45)	21/38 (55)
R	1/12 (8)	7/12 (58)	4/12 (33)
total	2/77 (3)	35/77 (45)	40/77 (52)

* Included admissions directly related to hyperglycaemia, diabetic ketoacidosis or hypoglycaemia

** Included all admissions for conditions for which diabetes is a recognised risk factor

Admission rates varied very widely between practices, being lowest for the rural practice and highest in the inner-city practice (Graph 4.1).

Graph 4.1 Admission rate (admissions between 1991 and 1994 per 10 individuals with diabetes) by practice and cause



4.4.5 Risk factors for admission

The characteristics of those with and without an admission, and those with and without a diabetes related admission, are given in Appendix 3 (Tables 15.1 to 15.4). The relationship between variables and admission is similar for all admissions and for diabetes related admissions, with number of drugs on repeat prescription and total number of outpatient visits (all specialties) being the variables most closely related to admission risk.

Age and sex were not strongly related to admission; risk of all cause admission is slightly higher in the over 70s and risk of diabetes related admission slightly higher in the under 60s.

Those admitted tended to have had diabetes for longer and to be receiving repeat prescriptions for blood testing equipment. Diabetes related admission was associated with treatment with insulin. The number of non-diabetic drugs on repeat prescription was strongly related to admission. However recorded complications and glycaemic control were not consistently associated with admission.

Only six individuals who completed questionnaires gave an ethnic origin other than "White British", so it was not possible to gather any information about the relationship between ethnic origin and admission. Those admitted were more likely to live alone, less likely to have access to a car and less likely to be home owners. They were also more likely to be unemployed (although numbers were small).

Those admitted visited their GP and the A&E department more often and had significantly more visits to non-diabetic outpatient clinics. Those with diabetes related admissions had attended marginally more diabetes outpatient clinics, but had received slightly fewer diabetes reviews in general practice. They were more likely to have seen a nurse at the hospital, less likely to have seen a nurse in general practice. They were slightly more likely to have seen a chiropodist but less likely to have seen a dietician.

Effect modification by presence of co-morbidity

Table 4.11 shows the effect of stratifying by the repeat prescription of non-diabetes related drugs. It appears that the presence of co-morbidity may modify the relationship between admission and diabetes review in general practice. Only those without co-morbidity who have had a diabetes review in general practice have a reduced risk of admission. In fact, none of the 17 individuals without co-morbidity who had received a review in general practice had a diabetes related admission. However it is notable that only a third of individuals are without co-morbidity (31/96, 32%) and few of these have a diabetes related admission (4/31, 13%), regardless of their diabetes care.

Table 4.11: Proportion having had a diabetes review (stratified by whether they have any non-diabetic drugs on repeat prescription):

	Having a diabetes related admission	No diabetes related admission	Fisher's exact
No co-morbidity			
GP diabetes review (%)	0/4 (0)	17/27 (63)	p=0.03
diabetes outpatients (%)	2/4 (50)	17/27 (63)	p=0.6
Co-morbidity			
GP diabetes review (%)	9/15 (60)	32/50 (44)	p=0.8
diabetes outpatients (%)	5/15 (33)	9/50 (18)	p=0.3

4.5 Discussion of pilot results and implications for the main study

4.5.1 Feasibility of establishing a historical cohort

The possibilities for using computer held information to identify a cohort with diabetes depends on:

- the type of software used
- what information the practice routinely records on the computer
- the length of time that the practice has been computerised.

A fully computerised search strategy was not universally feasible and, in order to maximise the identification of all individuals with diagnosed diabetes, it was decided that searches of prescribing records and computerised clinical data should be combined with a search of any manual register available for the main study. As there was a Medical Audit Advisory Group (MAAG) co-ordinated diabetes audit in progress at the time of data collection, most practices were confident that their diabetic registers were relatively complete. Since it has been demonstrated that registers may include people who do not have diabetes,[118] the eligibility for inclusion of each subject identified by a search should be checked at the time of examination of their GP medical records, and those without diabetes excluded.

If a complete historical cohort of prevalent cases over a four year period is assembled, the notes will be unavailable for up to 15% of the cohort because of a change in GP. Questionnaires can only be sent to around 70% of the original cohort who are still alive and registered with the practice.

4.5.2 Comparison with the Leicestershire Diabetes Register

The Leicestershire Diabetes Register was set up in 1987 using details of insulin treated patients from hospital clinics, consultants' patient indexes, health visitor, dietician and general practice records. It is maintained with the aid of record linkage checks for duplications, migrants and deaths.[119] Registration of individuals who are not insulin-treated (those treated with oral hypoglycaemics or diet alone) has only recently started and is known to be incomplete. The observed association between setting of diabetes review and chance of being on the register supports the hypothesis that the district register would be a biased and therefore inappropriate sampling frame for studying the service contact of a diabetic population. Even if a study was restricted to insulin-treated individuals, the 80% of this population included are likely to over represent those in contact with hospital clinics. It is therefore not a suitable population for a study which aimed to include the full spectrum of individuals with diabetes in terms of both disease severity and pattern of routine care. A general practice based cohort was therefore more appropriate for our study.

4.5.3 Completeness and concordance of data from notes and questionnaires

In view of the response rates from practices and patients, a number of methods of improving response rates in the main study were considered. The possibility of demonstrating the potential value of the information collected to individual practices was explored as a method of improving practice response.

The differences between respondents and non-respondents demonstrated the need for an improved response rate to reduce response bias. Use of a covering letter from the individual's GP was considered, in order to improve patient response rates. Use of repeat mailings and telephone contact with non-respondents were also considered. Shortening the questionnaire was made possible by removing some questions which could be answered using GP records and some of the open questions which yielded few useful responses. The need to translate the questionnaire into languages other than English was considered to be an issue to be decided in collaboration with the study practices.

Several data items, such as BMI, were dropped because of inadequate records. The information on complications was made more specifically related to treated (and therefore likely to be recorded) diabetic complications. Total GP contacts and outpatient visits (all specialties) were thought to be markers for levels of both morbidity and

service use, but were dropped from the main study questionnaire as being difficult to enumerate and not candidate risk factors for admission.

For details of A&E visits, the option of using data from the A&E department was considered. A search of the A&E department database suggested that this was a more complete source of information, available retrospectively for up to twelve years and this source was used in the main study.

4.5.4 Estimation of parameters

The parameter values given above were used in the sample size calculation for the main study (Chapter 5). A striking finding was the extent to which prevalence of diabetes, patterns of diabetes care and admission rates varied between practices. The clustering of practice characteristics makes the interpretation of individual differences difficult, unless general practice is controlled for in the analysis. The occurrence of only two admissions directly due to diabetes (one an insulin overdose and one diabetic ketoacidosis) highlighted the fact that most admissions in a population diabetic cohort will not be directly due to diabetes. The large number of other drugs on repeat prescription highlights the fact that such a cohort will have a very high level of other chronic diseases.

4.5.5 Risk factors for admission

The strongest predictor of admission was the number of non-diabetic drugs on repeat prescription, which was interpreted as a proxy for the presence of chronic co-morbidities. Admissions are also highly correlated with number of non-diabetes outpatient visits, but this relationship was felt to be due to outpatient visits and admissions sharing the same risk factors, rather than being a causal relationship.

It is plausible that the relationship between routine review and admission is influenced by co-morbidity, as when diabetes is the main risk factor for admission, routine diabetes reviews are more likely to significantly influence admission risk. This difference is apparently demonstrated by comparison of those with and without co-morbidity. The power of the comparison was much reduced by the small number of individuals with diabetes related admissions who were also without co-morbidity. The association of diabetes outpatient visits with an increased risk of admission (which was not statistically significant) could be explained by the casemix seen by the hospital clinic which is likely to include a high proportion of "high risk" patients with complications and co-morbidity likely to lead to admission.

In view of the wide variations between practices, for the main study general practice was included, as a potential confounding variable, in the multivariate analyses. It was also decided to limit the main study to practices within the city catchment area, as rural practices have fewer admissions and have access to peripheral clinics and cottage hospitals.

The pilot sample was too small to detect all risk factors for admission with confidence. It appeared that the main risk factors were similar, whether diabetes related admissions, or all cause admissions were considered. This provided justification for using all cause admissions as the primary outcome variable in the main study. Surprisingly, certain expected risk factors such as age, duration of diabetes and glycaemic control were very similar in the admitted and not admitted groups. The analysis showed that the presence of co-morbidity (as assessed by number of items on repeat prescription) is strongly related to admission and may modify the association with routine reviews in general practice or outpatient clinic visits. Number of non-diabetic drugs on repeat prescription were identified as an available proxy measure of co-morbidity which is independent of completeness of general practice notes, where computerised repeat prescriptions were issued.

4.6 Conclusions

Although the pilot study of risk factors for hospital admission took only a few weeks and involved a limited data collection exercise, it led to a number of changes in the design and practical methodology of the main study. The pilot analyses demonstrated the major importance of co-morbidity in predicting admissions and suggested that a relationship with routine care may only exist for individuals without co-morbidity.

4.7 Key points

- Using a range of strategies including repeat prescription records, a historical prevalence cohort of individuals with diabetes registered with a group of general practices can be identified.
- In recently computerised practices, complete identification of cases who have died or migrated may not be possible.
- The district diabetes register is incomplete, particularly for individuals who are not treated with insulin.
- The pilot study produced parameter estimates on the basis of which the sample size for the main study could be determined.
- Few admissions in a diabetic population were directly due to diabetes. The main predictor of admission in the pilot study was the number of non-diabetic drugs on repeat prescription.
- The presence of co-morbidity modified the relationship between general practice review and risk of diabetes related admission.

5. Chapter 5: Main Study - Identification of the study cohort

5.1 Introduction - Choice of study setting

The city of Leicester was chosen as the setting of this study. It was thought that, since there is no formal shared care programme, there were likely to be patients with clinically similar disease receiving care in different settings. The results of a local multi-practice audit involving 48 practices and co-ordinated by the local Medical Audit Advisory Group (MAAG) demonstrated that the provision of care varied widely between practices (Barklie S. Personal communication). It was also known that a significant minority of practices did not provide a structured diabetes programme which qualified for CDM payments.[52] It seemed likely that whether an individual patient attended a hospital clinic or received diabetes reviews in general practice would be dependent on the preferences of the patient and general practitioner as well as the patient's clinical status.

An advantage of restricting the study to the city of Leicester was the ability to minimise the need to control for the large number of organisational factors which influence hospital admission rates. Since all general practices around the city have access to the same three hospitals (all separate NHS trusts) and all requests for nonelective admission go through a single bed bureau, access to hospital services were unlikely to differ greatly within the study cohort.

5.2 Organisation of diabetes services in Leicestershire

The diabetes service in Leicester was set up by Dr Joan Walker in 1945 and several current features of the service reflect her early interests. Her distinctive contributions included the pioneering of treatment for newly diagnosed children at home, still an important feature of the service today.[8] She also worked with the first specialist health visitor ever appointed to a hospital clinic, who started work in 1950, and was responsible for the first diabetes population survey of an entire community conducted in Ibstock, a rural Leicestershire community, in 1957.[120]

The current service is based at two separate acute hospitals, each of which have two consultant physicians with a specialist interest in diabetes. There are now 11 diabetes specialist nurses based at the hospitals. Although GPs can refer patients directly to them, the majority of their referrals still come from within the hospitals. GPs can refer patients to any hospital clinic and can also make direct referrals to community dieticians and chiropody. As well as a number of diabetes clinics held in peripheral hospitals, there are

diabetes foot clinics held at both hospitals. Both GPs and hospital clinics have access to a retinal photography screening service.

5.3 Methodology

5.3.1 Sample size estimation

The sample size was based on parameter estimates from the pilot study:

Estimated proportion of cohort admitted to hospital over a four year period = 50%

Estimated proportion of cohort with no routine care = 20%

There would be major resource implications if the difference in admissions between those receiving some and those receiving no routine care was 50% or more.

To detect this difference, analysing as a cohort study, with power 95% and significance 5%:

Minimum number of admissions by those receiving routine care needed = 275.8

(from sample size tables)[121]

Define admission rate for those receiving routine care = r

Overall admission rate = 0.5 = (0.8 * r) + (0.2 * 1.5 * r)

Solving this gives r = 0.45

Total cohort required = 1.25 * number receiving routine care required

= 1.25 * admissions required/admission rate

= 1.25 * 275.8/0.45 = 766

To allow for an 80% response rate, a initial cohort size of 958 would be needed.

A cohort size of 1000 was felt to be a practical study size in terms of previous experience of extracting information from general practice records and known time constraints. Assuming an average list size of 1800 per principal and a 1.8% diabetes prevalence, all individuals with diabetes on the lists of approximately 31 GPs needed to be recruited.

This sample size calculation assumes that the sample is a random sample of individuals with diabetes. It does not take account of the sample being a cluster sample based on general practices. If, within the population sampled, an appreciable proportion of the variation in admission rates is due to variation between the practices rather than the characteristics of the individual patient, a larger sample is needed to achieve the stated power. By choosing a study population within an urban area with access to the same secondary care services, it was assumed inter-practice variation would be mainly due to

variation in socioeconomic and demographic differences between individuals, rather than intrinsic differences between practices.

5.3.2 Practice recruitment

Before recruitment, ethical approval for both the pilot study and the main study was obtained from the Leicestershire Health Authority Ethics Committee. The Leicestershire Local Medical Committee (LMC) was also informed about the study.

From 25 randomly selected practices, chosen before the pilot study, 11 outside the Leicester area with access to other hospitals, including cottage hospitals, were excluded. This exclusion criterion was justified by the need to prevent confounding by differential access to hospital services, for which it would be complex to develop and validate measures. Since concern amongst those responsible for providing diabetes services focused on city practices which have higher admission rates and are perceived to have poorer services relative to clinical needs, it seemed appropriate to exclude rural or small town practices and limit the study to those in the city and its suburbs.

The remaining practices were listed in random order and the first ten (with a total of 33 GP partners and therefore an estimated diabetic population of 1069) were asked to participate.

In order to maximise the practice response rate, strategic approaches to practices were developed and it was decided to offer a token fixed payment in recognition that the practice staff would be spending practice time helping the researcher to identify patients with diabetes and locating records. General practitioners, particularly in large group practices, receive a large number of requests to participate in research and audit projects. The response of some approached during the pilot phase suggested that even practices with an interest in research and diabetes care felt that they had insufficient resources to accede to yet another request for co-operation where the benefit to the practice might not be immediate and tangible.

Initial contact was made, if possible, with a partner with an interest in diabetes rather than practice manager or senior partner. If the practice nurse had an interest in diabetes (or had attended local diabetes courses), she was also contacted in order to discuss the project, with the hope of eliciting support. If possible, a brief appointment with a partner was then made to explain what would be involved, before the practice was asked to make a decision. Explanation to the practice team through the practice manager was avoided where possible as personal contact with the members of the clinical team with an interest in diabetes care was thought to be more likely to elicit a positive response. It

was made clear that the study was not an audit and was not related to the local MAAG or the health authority and that there was no intention to look at individual practices' clinical performance. If a practice wished to do so, they could use the information collected to assist their own diabetes audit, or to update their diabetes register. At least two practices used the study data in this way.

5.3.3 Cohort identification

Experience with the pilot study suggested that a range of strategies would be needed, depending on practice organisation. At each practice computerised prescriptions were searched for insulin, insulin syringes, oral hypoglycaemic agents and blood and urine testing equipment. Clinical information fields on computer patient records were also searched to identify any patients with diabetes related conditions. In one practice, where computerised prescribing was not used at the branch surgeries, a manual search for notes marked "diabetes" or "DM" was needed.

Patients aged under 16 on 1/1/96 were excluded, as the hospitalisation of children with diabetes has been studied separately and is likely to be influenced by different factors.[8] Individuals who had only had gestational diabetes or for whom there was no supportive evidence for the diagnosis in the notes were excluded. As a strict diagnostic definition would have excluded those with poor documentation (who might well have included those with least routine care), an inclusive definition requiring some evidence of a raised blood glucose or glycosylated haemoglobin, or mention of the diagnosis in hospital letters or GP records was accepted. Explanations were sought for anomalies in the records. For example, one individual identified on computerised records as having diabetes was excluded because there was no evidence for the diagnosis in the written notes and there was another patient with the same name who genuinely had diabetes, suggesting a likely source of confusion.

5.4 Results

5.4.1 Practice response rate

Out of ten practices approached, seven agreed to be involved in the study. The reasons given by the other three practices for declining were: one practice was already collecting information by questionnaire from their diabetic patients and did not wish to overload them, a second had a practice policy not to agree to any research projects involving patients in the practice unless the study was entirely hospital based and the third had

concerns relating to confidentiality of their patient list. One was a single-handed GP and the other two group practices; all were inner-city practices.

5.4.2 Practice characteristics

The seven practices were highly heterogeneous in their size, organisation of diabetes care and in the characteristics of their patient populations.

Practice size ranged from single handed (one practice) and two partner (two practices) to four or five partners (four practices). The total population registered was 48,500, including 1,094 with diagnosed diabetes (2.3%). Prevalence varied between practices from 1.3% to 3.5% (see Table 5.1).

Table 5.1: Prevalence of adult diabetes by whether practice receives CDM (Chronic Disease Management) payments for their diabetes care

Practice	No with diagnosed diabetes	Practice size	Prevalence of diabetes (%)
A	173	8,800	2.0
B	163	9,700	1.7
C	133	7,700	1.7
D	61	4,600	1.3
E	24	1,800	1.3
CDM practices (n=5)	**554**	**32,600**	**1.7**
F	398	11,800	3.4
G	142	4,100	3.5
Non-CDM practices (n=2)	**540**	**15,900**	**3.4**
Total	**1094**	**48,500**	**2.3**

All seven provided diabetes care to some extent, all had a practice nurse with some diabetes training and had direct access to chiropody and dietetics. Only five had a blood glucose meter on the practice premises. Six had a diabetes register but of these two were very incomplete when compared with prescribing data. Five had some system for regular review by the practice nurse or a doctor and these five all received CDM diabetes payments and had therefore satisfied the health authority that they were running structured diabetes care programmes. In only one of these practices was a doctor involved in seeing patients in diabetes clinic sessions. Only four had some kind of recall system for regular review, the others relying on patients to make appointments for

review. The two practices with the highest prevalence did not run clinics or qualify for CDM payments during the study period.

5.4.3 Cohort characteristics

1094 individuals with diabetes were identified who were alive and registered with seven general practices on 1/1/96. Only 26 individuals with diabetes who died between 1/1/91 and 31/12/95 could be identified. This was mainly because computerised practice registers had been linked with the FHSA register which automatically deleted records when patients die or leave a practice.

For the same reason, little information was available on the migrants out of the study practices. Although patient turnover varied, all the practices had fairly stable practice sizes according to the practices (no figures are available). The proportion of the cohort who had joined the practice since the start of 1990 are given in Table 5.2.

Table 5.2: Migration of diabetic patients into study practices

General Practice	Practice size (1/1/96)	Joined since 1/1/90 Number	%
A	173	39	23
B	163	35	21
C	133	10	8
D	61	19	31
E	24	5	21
F	398	12	3
G	142	44	31
Total	1094	164	15

5.5 Discussion

5.5.1 Practice response rates

The practice response rate of seven out of ten practices approached (70%) being willing to be involved in the project was probably favourably influenced by a high level of interest in the impact of changes in the organisation of diabetes care. Direct comparison with other studies is difficult; reports of studies involving general practices do not always state their response rate and often only involve those practices who actively express interest in a project. A recent study which recruited general practices to a study of ethnicity recording used only 15 out of an initial sample of 80 practices, suggesting a minimum response rate of only 20%.[122] Practice response rates locally have varied from 100% (when practices were selected on the basis of previous research collaboration)[123] to 32% when randomly selected from amongst practices with a high prevalence of ethnic minorities.[124]

5.5.2 Practice characteristics

It was the two practices with the highest prevalence (over 3%) who did not run clinics or qualify for CDM payments at any time during the study period. These practices have a high proportion of Indian patients (as defined by responses to the question on ethnic origin from the 1991 census, asked on the postal questionnaire for this study). Ethnic minority patients, who make up 28% of the population in the city of Leicester, tend to be clustered in certain practices both because of geographical clustering of minority populations and because patients choose practices run by staff with whom they share a common language or ethnic background. The clustering of patients of Indian origin provides an explanation for the wide range of prevalences between practices. High prevalence may also be a practical barrier to the introduction of structured programmes for chronic disease management.[52] Since routine reviews within general practice were effectively not available to any individuals in these two practices, these "non-CDM practices" were analysed separately from the five "CDM practices" in Chapter 9.

5.5.3 Use of a cohort with diagnosed diabetes

The ideal cohort for studying the relationship between diabetes care and admission would probably be a population based cohort including every individual in a population from the time that diabetes developed to death. Since diabetes may be present for ten years or more before diagnosis[125] and only around half the prevalent cases of diabetes

may be diagnosed,[126] diagnosed cases are not representative of all cases of diabetes. It seems likely that poorer health (through increased symptoms, contact with health services and hospital admission) will be one of several factors that increase the probability that a diagnosis is made. Relatively healthy individuals, without symptoms or co-morbidity, will be more likely to remain undiagnosed.

Since diabetes care can only be accessed by those in whom the diagnosis has been made, it seemed logical to study this subgroup of all individuals with diabetes. Caution is required if results are to be extrapolated to a population being screened for diabetes, since the impact of regular review for screening detected cases may be different, since they may have less co-morbidity and a lesser degree of hyperglycaemia.

5.5.4 Use of a survivor cohort

The practical obstacles to reconstructing a cohort which included all those patients who had died or left the practice after a diagnosis of diabetes was made and during the period over which admissions data was collected, meant that the main analyses were based on a cohort chiefly composed of those who survived up to 1996. It is likely that prevalent cases at the start of 1996 are healthier and younger than cases who died during the study period (1992-1995) would have been. The characteristics of the group of 26 patients who died between 1992 and 1995 and for whom notes were located confirm this assumption (see Chapter 8).

Estimates of the number of deaths expected within the cohort and the number of admissions by individuals who died are calculated in Appendix 4. About 278 deaths could be expected, so the 26 identified only represent 10% of the total. These would contribute a total of around 898 admissions, compared to 1217 admissions by the survivor cohort. The survivor cohort therefore may only represent about 58% of all admissions by individuals with diabetes, although it represents 80% of the total population who had a diagnosis of diabetes during this period.

Ideally follow-up, as stated above, should be from diagnosis to death. Any cohort that includes prevalent, rather than incident cases of diabetes will be prone to bias related to survival. In the context of the main hypothesis, there will be bias introduced if the proportion or type of admissions not survived by patients is related to their pattern of care. Bias may be introduced if hospital outpatient attenders die during admission more often than GP reviewed individuals. However, any such relationship would probably be mediated by the severity of disease or co-morbidity and these have been included in the analysis as potential confounders.

In generalising results it is relevant to consider whether the results are applicable to all diabetic individuals. Caution would prevent generalisation to individuals that had a terminal illness or had severe complications, unless the findings could be shown to be consistently similar for this subgroup and not influenced by presence of co-morbidity or complications.

The great advantage of analysing information from a survivor cohort is the detailed information available from general practice notes and questionnaires. However it must be borne in mind that it represents a selected, relatively healthy population.

5.5.5 Migration within the cohort.

15% of the survivor cohort had registered with a study practice between 1/1/90 and 31/12/95, and were still registered at the start of 1995. The cohort excludes individuals who left the study practices during the study period. Individuals who change their GP may have different patterns of morbidity and different patterns of care from those who are less mobile.[127] However, it was assumed that the experience of migrants into a randomly selected group of practices would be similar to the experiences of migrants out of the practices and so the experience of the migrants who joined study practices between 1990 and 1995 were included in the analysis, even though they were initially registered with a different general practice.

5.6 Key points

- **The response rate from practices was seven out of ten practices approached (70%).**
- **The practices included varied widely in terms of practice size, diabetes prevalence and organisation of diabetes care.**
- **Structured diabetes care was organised, by the end of 1995, by all practices except the two with the highest prevalence.**
- **The cohort of 1120 individuals recruited was incomplete because details of individuals who had died or migrated from study practices was unavailable. 20% of the cohort may have died between 1991 and 1995, but information was available on only about 10% of these.**

6. Chapter 6: Main Study - Data collection

6.1 Introduction

The study data was mainly collected from general practice records and patient questionnaires. Information was also gathered from other sources, including health authority activity data, the A&E department database and diabetes specialist nurses' record cards.

6.2 Methodology

6.2.1 Data collection from general practices

The collection of information from general practice records was completed between 16/2/96 and 21/7/96. For individuals who had died before data collection, records were retrieved from the health authority. The data collection was done using a data extraction form (Appendix 5) by one individual in order to reduce practice concerns relating to confidentiality of patient information. A general practice diabetes review was recorded if at least three of the following were recorded as having been done: examination of fundi, blood pressure check, foot examination, injection site examination, weighing and urinalysis. Detailed definitions and explanations of variable definitions are given in Appendix 2.

At one practice a second researcher, with experience in collecting data from clinical records, repeated the collection of data from a random sample of 15 sets of notes to check for inter-observer variation. It was not possible to blind the data collection process as information on both the pattern of care and hospital admissions was collected from the same notes. Consistent and standardised data extraction was therefore very important to reduce the potential for bias. Comparison with results of the postal questionnaire and health authority records was also used to check the validity of the data collection process. The results of these comparisons are discussed in Chapter 7.

6.2.2 Data collection from postal questionnaires

1091 English questionnaires were sent with a covering letter on 3/6/96. 396 Gujarati and 59 Punjabi translations (professionally translated and then back translated and revised with the help of a Gujarati GP and a Punjabi general practice researcher) were also enclosed after consultation with practice staff as to which patients might find them helpful. After six weeks a reminder letter was sent with another copy of the

questionnaire to each individual who had not responded. English versions of questionnaires and covering letters sent to cohort members are included in Appendix 5.
Eight individuals were excluded from the cohort after mailing, since their general practice records did not support a diagnosis of diabetes (for example, despite urinalysis strips dispensed there was no evidence of diabetes within their notes).

6.2.3 Data coding and data entry

All data items were coded according to the criteria given in Appendix 2. The data were then enter into a database using SPSS data entry software.[128] Accuracy of data entry was ensured by entering the data twice and rechecking any discrepancies.
Each individual was allocated a Townsend score by linking their 1996 postcodes to ward based Townsend deprivation indices[129] calculated using 1991 census data (using SASPAC).[130]

6.3 Results

6.3.1 Data collection from general practice records

Information was available in all practices from computerised registers (names, addresses, NHS numbers and dates of birth). Repeat prescribing software on practice computers was used for most repeat prescribing.[131] Current computerised repeat prescription information was available for all but 176 (16%) of the survivor cohort, all of who attended two branch surgeries. Other data items were collected from notes. Date of diagnosis, taken as the first mention of diabetes as a definite diagnosis, was available for all except four individuals, for whom notes appeared to be incomplete.

6.3.2 Questionnaire response rate

Questionnaires were sent to all members of the cohort excluding any who were known to have died or changed GP between the start of 1996 and the time the questionnaire were sent in June 1996. Two individuals were excluded at the request of their GP, one who was seriously ill and another whom the GP felt might be caused excessive anxiety.
The overall response rate (after one postal reminder) was 83.3%. The categories of response and response rates for individual practices are shown in Table 6.1.
Those who had died before the questionnaire was received and those whose notes provided no evidence to confirm the diagnosis of diabetes (in those whose notes were not examined before the questionnaire was sent) were excluded from the denominator.

Table 6.1: Response rate by practice

	Practice							
	A	B	C	D	E	F	G	Total
Questionnaire not sent	3	1	3	1	0	1	2	11
Total questionnaires sent	171	162	130	60	24	398	146	1091
Excluded from cohort after mailing because respondent not diabetic	1	0	0	0	0	1	6	8
Excluded because patient died before mailing	0	1	0	0	0	1	0	2
Valid questionnaires sent (living diabetic recipient)	**170**	**161**	**130**	**60**	**24**	**396**	**140**	**1081**
Returned completed after 1st mailing (a)	141	131	102	52	19	207	66	718
Returned completed after 2nd mailing (b)	10	13	16	4	2	97	41	183
Total completed (a+b)	**151**	**144**	**118**	**56**	**21**	**304**	**107**	**901**
Returned "not at this address"("ghosts") (c)	0	1	1	0	0	1	9	12
Returned blank or patient declined in writing ("refusers") (d)	0	2	1	0	0	2	1	6
No response (includes ghosts and refusers) (e)	19	14	10	4	3	89	23	162
Total non-respondents (c+d+e)	**19**	**17**	**12**	**4**	**3**	**92**	**33**	**180**
Response rate (%) (a+b/a+b+c+d+e)	**88.8**	**89.4**	**90.8**	**93.3**	**87.5**	**76.8**	**76.4**	**83.3**

Response rates varied significantly between practices (chi-squared: $p<0.00001$). The main difference was between the two city practices with a high proportion of Indian patients (practices F and G: response rate 77%) and the other five practices (response rate 90%).

6.3.3 Characteristics of questionnaire non-respondents

Non-respondents include both those who did not receive questionnaires because the address on their notes or general practice computer was incorrect (sometimes called "ghosts") and those who received the questionnaire but chose not to complete and return it (so called "refusers"). There may be demographic and clinical differences between the two types of non-responder[127] but since the total number of non-responders is relatively small, and these two groups are difficult to accurately differentiate, they have been grouped together for the analysis of characteristics of non-responders.

Because information was available from the general practice notes of all non-responders it is possible to look in some detail at possible biases introduced by the lack of questionnaire derived variables in this group. Demographic and clinical variables are compared in Tables 6.2 and 6.3 and service use is compared in Table 6.4. Non-respondents are registered at addresses in more deprived wards. They are less likely to have blood testing strips on repeat prescription (16% v 31%) despite being only marginally less likely to be on insulin (24% v 29%) . They are much less likely to have had a diabetes review in general practice (11% v 26%).

Table 6.2: Demographic and clinical characteristics of respondents and non-respondents (continuous variables)

	Respondents	Non-respondents	
Age (on 1.1.96)	(n=901)	(n=180)	
median	64.0	61.8	MannWhitney: p=0.2
mean	62.8	61.8	
Townsend score	(n = 889)	(n=175)	
median	2.34	3.49	MannWhitney: p=0.01
mean	2.10	2.85	
Years since diagnosis	(n=898)	(n=179)	
median	7.6	8.0	MannWhitney: p=0.7
mean	10.0	9.4	

Table 6.3: Demographic and clinical characteristics of respondents and non-respondents (categorical variables)

	Respondents (n=901)	Non-respondents (n=180)	
Male (%)	492 (55)	94 (52)	chi^2 : p=0.6
Diabetes treatment			
Insulin (%)	264 (29)	43 (24)	
Oral only (%)	466 (52)	98 (54)	
Diet only (%)	171 (19)	39 (22)	chi^2 : p=0.3
Testing strips			
Blood testing (%)	276 (31)	29 (16)	
Urine testing (%)	336 (37)	74 (41)	
Neither (%)	289 (32)	77 (43)	chi^2 : p<0.0001
Other drugs			
cvs drugs (%)	453 (50)	77 (43)	chi^2 : p=0.07
analgesics (%)	299 (33)	63 (35)	chi^2 : p=0.6
cns drugs (%)	128 (14)	34 (19)	chi^2 : p=0.1
all nondiabetic drugs	666 (74)	121 (67)	chi^2 : p=0.07

Table 6.4: Service use by respondents and non-respondents

	Respondents (n=901)	Non-respondents (n=180)	chi^2
Visited A&E (%)	274 (30)	57 (32)	p=0.7
Admitted (all cause) (%)	489 (54)	88 (49)	p=0.2
Admitted (diabetes related) (%)	328 (36)	60 (33)	p=0.4
Reviewed by GP (%)	238 (26)	20 (11)	p<0.0001
Attended hospital clinic(%)	408 (45)	68 (38)	p=0.06

6.4 Discussion

6.4.1 Data collection from general practice records

The quality and completeness of information collected from records were dependent on the standard of filing and record keeping within a practice. Particular difficulty was experienced with the identification of treated complications and co-morbidities. Individuals with a repeat prescription for a particular drug often did not have a relevant diagnosis recorded. The number of non-diabetic drugs on repeat prescription was therefore identified as a proxy measure for co-morbidity, since it did not appear to be subject to the same recording biases.

6.4.2 Questionnaire response rates

Two recent local surveys which involved individuals with diabetes, contacted by letter through general practitioners, had questionnaire response rates of 91%[123] and 60%.[124] The questionnaire response rate in the present study, 83%, was felt to be reasonable, particularly as information was available from medical records of questionnaire non-respondents. The differences in the deprivation scores and number of GP reviews between respondents and nonrespondents show that an analysis based on questionnaire respondents only would underestimate the level of material deprivation and overestimate the proportion receiving routine reviews in general practice.

6.4.3 Examining records without obtaining patient consent

Ethical approval for both the pilot study and the main study was obtained from the Leicestershire Health Authority Ethics Committee on the basis that the protocol stated that general practitioners would be asked to allow access to their patients' records. Whether patient consent was obtained before notes were examined was left to the individual practices. In fact all the practices involved allowed access without patient consent. Their decision was probably influenced by the fact that the individual examining the notes (EG) was a GP by training and had completed her training in the area, so was known to some local GPs. A medical student collecting patient information for a BSc project found that many practices required written patient consent before access to patient notes was allowed.[132]

Use of medical records for the purpose of health services research is included as an acceptable use of patient information in the most recent guidance issued by the

Department of Health.[133] Obtaining patient consent before examining medical records for research purposes is not universal and is currently controversial.[134]

The original justification for not obtaining patient consent in this study was, principally, that a request to examine notes that was not linked to any medical intervention could cause worry and confusion for patients. An additional consideration was that a group of patients of great importance to the study were those receiving no routine diabetes care. These were a group who might not perceive the study to be relevant to them and therefore might not respond to a request for consent. However, this argument has to be reconsidered in the light of response rates for the patient postal questionnaire. Although patients who had not had routine diabetes reviews within general practice were significantly less likely to respond, overall response rates were sufficiently high that this group were still represented. Concerns about response rates cannot represent a valid justification for not obtaining patient consent in this instance.

6.4.4 Giving information about the study and feedback on results

Whether general practices or individual patients are involved in research, the ethical principle of informed consent means that they must be given sufficient information about the study before they can make a decision about participation. A balance must be reached between avoiding providing precise information about study hypotheses that may bias individual responses and giving sufficient information for valid informed consent. For our study we only gave brief information that the purpose of the study was to look at risk factors for hospital use by individuals with diabetes, but offered more detailed information on request. Once the study data collection had been completed, both practices and individual respondents (the majority of respondents requested information on the questionnaire results) were sent summarised results. The value of giving participants feedback after the completion of a study includes the possibility that it will sustain their interest in contributing to health services research in the future and that their response to the study findings may be helpful in suggesting explanations for findings and in qualitative validation of findings. If it is felt, as in this case, that giving too much information about a study's hypothesis could adversely influence validity, a pragmatic solution of giving more information after data collection is completed seems a reasonable compromise.

6.5 Key Points

- **Data was collected from general practice computers, general practice written records and from postal questionnaires.**
- **Data from general practices records was available for 1120 individuals and from questionnaires for 901 individuals.**
- **Questionnaire respondents lived in less deprived wards, were more likely to have a repeat prescription for blood testing strips and more likely to have had a routine diabetes review than non-respondents.**

7. Chapter 7: Main Study - Data validation and comparison of data sources

7.1 Introduction

The main analyses in this study are largely based on data collected from general practice records which, in order to assure confidentiality, was extracted by a single researcher (EG). Particularly as the data extractor was not blind to the research hypotheses, there is a risk of information bias being introduced by, for example, more diligent searching of the notes of those thought likely to have been admitted. To investigate the validity of the data used, several other sources of data on service use and clinical characteristics were compared to the information derived from patient notes.

7.2 Methodology

To evaluate inter-observer agreement when data extraction from GP records was started, the data recording of a random sample of notes in one practice was repeated by a second individual with experience in data extraction from medical records.

Information derived from GP records was compared to the information from postal questionnaires. Both the overall level of concordance and any systematic differences between sources were examined.

It was possible to use a locally developed data linkage programme to match the study cohort to the admission data recorded centrally by the health authority. The details of cohort members were matched using a record linkage programme which matches on names, date of birth and postcode, to NHS numbers on the Leicestershire Health Information Department central register of individuals registered with Leicestershire general practices. The NHS numbers identified were then linked to Leicester hospital admission episodes. This information was used to compare the admissions data derived from notes on admissions to Leicestershire hospitals to the routine data collected.

7.3 Results

7.3.1 Inter-observer agreement

For the 15 sets of notes reviewed by a second data extractor, data forms were compared (Table 7.1). Information collected was often similar but not identical. Agreement was particularly poor for dates of general practice reviews, A&E visits and admissions. Discussion revealed that the definition of GP reviews had been differently interpreted by

the second extractor, highlighting the importance of consistency in definition. Most other differences were relatively minor, however this exercise highlighted the need to seek validation from alternative data sources.

Table 7.1:Comparison of recording by data extractors

Item	Number of pairs of forms	
	Identical on both forms	Different on both forms
Date of birth	14	1 (notes different from computer data)
Sex	15	0
Date of diagnosis	10	5 (2 >2 years different)
Date started insulin	13	2 (1 missing)
GP reviews	10	5
Outpatient reviews	15	0
A&E visits	11	4
Admissions	12	3
Mean HbA1	11	4
Chronic diagnoses/ complications	11	4

7.3.2 Comparison of questionnaire and general practice information

Information on date of birth and sex was used to check that questionnaires had been completed by the individual to whom they were sent. If individuals at the same address had completed each other's questionnaires they were included and assigned to the cohort member with the same sex and date of birth as the respondent. In two cases it appeared that another individual, not in the original cohort, had completed a questionnaire and the questionnaires were discarded. Information was collected from both medical records and questionnaires on duration of diabetes and type of treatment, contacts with health professionals for diabetes care, casualty visits and admissions. Some differences were expected, as the questionnaires were sent after most of the data extraction from records was complete and the time period referred to was slightly different. These variables were compared to establish whether there were systematic differences between sources.

Information about treatment and duration of diabetes showed reasonable agreement (Tables 7.2 and 7.3), but patient contact with dieticians, chiropodists and specialist nurses was often not recorded in general practice records (Tables 7.4 to 7.6).

Table 7.2: Comparison of treatment of diabetes

Questionnaire	GP repeat prescription			
	insulin	tablets	diet	total
insulin	260	13	1	274
tablets	2	433	19	454
diet	3	19	145	167
total	265	465	165	895

Kappa = 0.90, % agreement = 94%

Table 7.3: Comparison of duration of diabetes

Questionnaire	GP records			
	0 to 5 yrs	6 to 10 yrs	10+ yrs	Total
0 to 5 yrs	316	31	15	362
6 to 10 yrs	37	124	30	191
10+ yrs	15	45	261	321
total	368	200	306	874

Kappa = 0.69, % agreement = 80%

Table 7.4: Comparison of whether seen by dietician

Questionnaire	Dietician referral mentioned in notes		
	Yes	No	Total
Yes	124	449	573
No	21	292	313
Total	145	741	886

Kappa = 0.11, % agreement = 47%

Table 7.5: Comparison of whether seen by chiropodist

Questionnaire	Chiropody referral mentioned in notes		
	Yes	No	Total
Yes	21	365	386
No	4	498	502
Total	25	863	888

Kappa = 0.05, % agreement = 58%

Table 7.6: Comparison of whether seen in general practice or hospital

Questionnaire	GP records				
Regularly sees:	GP review	Outpatients	Both	Neither	Total
GP/practice nurse	135	69	24	153	381
Hospital doctor	-	88	16	3	107
Both	3	98	14	47	162
Neither	16	44	4	82	146
Total	154	299	58	285	796

Kappa = 0.23, % agreement = 40%

The greatest discrepancies in description of patterns of care (Table 7.6) lie where the respondent said they saw their GP or practice nurse for regular "diabetes checks" but there was no record of a routine examination as defined for the data extraction from notes. This suggests that the lay understanding of "diabetes check" may relate specifically to checking diabetes control rather than a more general review for risk factors and developing complications. Almost two-thirds (252/409, 62%) of those who had any record of attending a hospital diabetes clinic responded that they regularly saw a hospital doctor for diabetes care.

Information on hospital admission shows a reasonable level of agreement. If only admissions involving an overnight stay are included (ie daycases are excluded) the level of agreement improves further (Tables 7.7 and 7.8).

Table 7.7: Comparison of whether admitted to hospital

Questionnaire	Discharge letter in notes		
In last 5 years	Yes	No	Total
Yes	334	33	367
No	122	392	514
Total	456	425	881
	Kappa=0.65, % agreement = 82%		

Table 7.8: Comparison of whether admitted to hospital (excluding day cases)

Questionnaire	Discharge letter in notes		
In last 5 years	Yes	No	Total
Yes	300	67	367
No	58	456	514
Total	358	523	881
	Kappa=0.71, % agreement = 86%		

For A&E attendance both questionnaires and records appeared equally incomplete (Table 7.9). Information on A&E attendance was also available from the hospital database, which was searched manually for records with details matching cohort members (Table 7.10). Best agreement was between notes and the A&E database (82%), with no source providing complete information on casualty department attendance.

Table 7.9: Comparison of A&E letters and questionnaires

Questionnaire	A&E letter in notes		
In last 5 years	Yes	No	Total
Yes	129	96	225
No	117	536	653
Total	246	632	878
	Kappa=0.4	% agreement =76%	

Table 7.10:Comparison of general practice A&E data with hospital dataset

A&E database	Questionnaire -			GP records -		
Seen 1991-1996	seen in casualty in last 5 years			A&E discharge letter		
	Yes	No	Total	Yes	No	Total
Yes	123	92	215	169	98	267
No	31	335	366	28	401	429
Total	154	427	581	197	499	696
Kappa=0.5, % agreement = 79%				Kappa=0.6, % agreement = 82%		

Information on nurse contacts were was also available from a manual search of the record cards completed by the diabetes specialist nurses (DSN). Again no single source provided complete information (Table 7.11). The record cards are not always used as the nurses also record contact in hospital medical records and referrals may come from both hospital staff and GPs. The comparison with questionnaire responses highlights the fact that patients may be confused about the precise designation of the wide range of health professionals who provide advice and treatment relating to their diabetes.

Table 7.11: Contact with diabetes specialist nurse (DSN)

Questionnaire -	GP records -		
seen nurse at hospital or home	mention referral to DSN		
	Yes	No	Total
Yes	69	285	354
No	30	476	506
Total	99	761	860
	Kappa = 0.15		% agreement = 63 %

DSN record card	Questionnaire -			GP records -		
records contact	seen nurse at hospital or home			mention referral to DSN		
	Yes	No	Total	Yes	No	Total
Yes	70	52	122	46	98	144
No	284	454	738	73	877	950
Total	354	506	860	119	975	1094
	Kappa = 0.1			Kappa = 0.3		
	% agreement = 61%			% agreement = 84%		

7.3.3 Comparison of general practice admission data with health authority dataset

An initial comparison compared those with any local NHS admissions (between 1991 and 1995 inclusive) recorded in their records with those that could be linked to routine admission data. Because of uncertainty about the accuracy of the linkage procedure, the episodes were rematched against the cohort members on sex, surname, year of birth and postcode (a combination which uniquely identified each cohort member).

After this process, 280 episodes remained unmatched due mainly to differences in postcode and year of birth (Table 7.12). These episodes were examined in detail and all but 46 could be allocated to cohort members as probably representing the same individual. (Table 7.13). 146 episodes were matched to cohort members with different postcodes, 47 to those with a different year of birth and 14 to those with a different spelling of their surname. 27 episodes were matched to individuals with two differences in the four matching parameters.

Table 7.12: Initial rematching of episodes to cohort members (based on exact match of surname, sex, year of birth and postcode)

	GP records	
	Not admitted	Admitted
No episodes matched	558	*156*
Episodes matched	*24*	382

NB: 280 out of 1808 episodes (15%) could not be matched exactly

Table 7.13: Final matching of episodes to cohort members

	GP records	
	Not admitted	Admitted
No episodes matched	533	*35*
Episodes matched	*49*	503
	Kappa = 0.85	

NB: only 46 out of 1808 episodes (3%) remained unmatched

Having determined that the linking of cohort members to the routine dataset was accurate, the episodes were then grouped into admissions. Admissions were only excluded if the surname of the individual to whom a match had been made was entirely different (20 different names, 30 admissions excluded). The number of admissions to

NHS hospitals for each individual identified from GP records and from the linked health authority data (HA records) were compared (Table 7.14).

Table 7.14: Comparison of number of admissions identified by GP and Health Authority records

HA records	GP records							
	0	1	2	3	4	5	6+	Total
0	**533**	*40*	*19*	*7*	*5*	*4*	*5*	613
1	*32*	**169**	*12*	*3*	-	-	-	216
2	*5*	*20*	**83**	*6*	*3*	-	-	117
3	*4*	*7*	*16*	**30**	*9*	*1*	-	67
4	*4*	*4*	*4*	*11*	**10**	*2*	*1*	36
5	*1*	-	-	*1*	*9*	**11**	-	22
6+	*3*	*1*	*6*	*1*	*5*	*10*	**23**	49
Total	582	241	140	59	41	28	29	1120

Table 7.15 shows which individuals would be classified differently by the two data sources. 88% of individuals were classified similarly (as having had at least one admission or not) by both data sources (Kappa = 0.8).

Table 7.15: Comparison of individuals identified as having at least one admission

HA records	GP records		
	Not admitted	Admitted	Total
Not admitted	533	80	613
Admitted	49	458	507
Total	582	538	1120

The individuals who had been classified differently by the two data sources were examined more closely. 80 of the cohort had an admission only identified from GP records and 49 individuals had an admission identified only from Health Authority data. The number of such admissions as a proportion of total admitted individuals (identified from either record) in different groups was compared and is shown in Table 7.16. This table shows no evidence for systematic bias in terms of a more complete ascertainment

of admissions from GP records by practice, type of diabetes care, sex or diabetes treatment.

Table 7.16: Comparison of proportion of individuals identified as having an admission, but identified by only one source, by practice and by individual characteristics

	Identified by HA records only		Identified by GP records only	
		%		%
General practice				
A	11/99	11	11/99	11
B	4/77	5	12/77	16
C	4/81	5	15/81	19
D	4/35	11	5/35	14
E	2/12	17	4/12	33
F	17/200	9	24/200	12
G	7/83	8	9/83	11
		chi^2: p=0.6		chi^2: p=0.3
Reviewed by				
Neither	17/218	8	31/218	14
GP only	5/96	5	13/96	14
Hospital only	21/237	9	33/237	14
Both	6/36	17	3/36	8
		chi^2: p=0.2		chi^2: p=0.8
Sex				
Male	23/315	7	44/315	14
Female	26/272	10	36/272	13
		chi^2: p=0.3		chi^2: p=0.8
Treatment				
Insulin	17/203	8	32/203	16
Oral	24/280	9	38/280	14
Diet	8/104	8	10/104	10
		chi^2: p=1.0		chi^2: p=0.3

7.4 Discussion

7.4.1 Agreement between questionnaire data and general practice records

The general practice record is potentially a uniquely useful research resource for retrospective examination of health service use or treatment for an individual and largely overcomes the problems of recall bias, response bias and interviewer bias which may arise with interview or postal questionnaire studies. We therefore compared the questionnaire responses with the records to look at whether the methods yield similar information or whether one seemed significantly more complete.

There is a limited body of research which has examined the level of agreement between interviews or questionnaire data and medical records. This includes relatively little data on the validity of medical data derived from postal questionnaires. A review published in 1989 identified only two (out of 29 studies comparing records to questionnaires) which compared a self-administered questionnaire with general practice records.[135] One study compared reported operations from a postal questionnaire with GP records in a single practice and concluded "surgical operations are relatively well-remembered events" but there was also evidence that a few operations recalled by patients were absent from notes.[136] In these studies, medical records have usually been regarded as a "gold standard" for assessing questionnaire validity.[137]

More recently the potential for using general practice records as a source of research data has been recognised. Data from the UK National Case-Control study of the relationship between oral contraceptives and breast cancer was used to demonstrate that if only GP notes, rather than interviews, had been used, the study conclusion would have been the same and costs could have been halved.[138] It was suggested that the significant under-recording of oral contraceptive use in GP records could be assessed by interviewing a subgroup of cases and controls. This might also allow collection of potential confounding variables not available from records. The researchers commented on the very variable quality of general practice notes and expressed optimism that over time the quality was improving. In contrast, a comparison of childhood vaccination history suggested that neither records nor mothers' reports were adequate and an alternative source of data was required.[139]

Although results from interviews regarding hospital admission have been compared to medical records, most research has been conducted in the US where information is mainly derived from hospital records and a lifelong medical record of the type

maintained within UK general practice does not exist. Recall, when compared to medical records, has been shown to deteriorate rapidly after 10 months.[117]

We are aware of no studies which have examined concordance of general practice records and postal questionnaires on duration or treatment of current chronic disease, use of general practice facilities, hospital admission or A&E department attendances in the UK. A study in Norway,[140] which used medical records to validate postal questionnaires, found that agreement was good for the presence of diabetes and diabetes treatment (insulin or tablets), but that individuals tended to overestimate the duration of diabetes. We also found that agreement was better for treatment than for duration of diabetes and that individuals slightly overestimated duration, in comparison with medical records. The Norwegian study also found much better agreement on diagnosis than a recent UK survey.[141] It may be that these findings are specific to the countries or populations in which the studies are conducted. Hence there is a need to pilot postal questionnaires, even if they have previously been validated in other populations, particularly if these are in different countries.

Our results show that either general practice records or postal questionnaires will give comparable information on sex, age, duration of diabetes and whether insulin or hypoglycaemics are taken. They give similar overall rates for A&E attendance despite significant differences in classification, suggesting both sources will produce significant misclassification. Routine A&E databases are another possible source of information which is not subject to recall bias; their use in retrospective ascertainment of visits depends on an effective method for linking records to individuals.

Concordance between notes and questionnaires was reasonable for hospital admission and since more information on dates, duration and cause of admission is available in notes, this appeared to be an appropriate source to use for the present study. Using record linkage of patient details to routine hospital activity data is a viable alternative source of this information.

7.4.2 Comparison of routine hospital activity data and general practice records

The comparison of admission data with routine data has two applications. Firstly, it provides reassurance that the data collected from notes is not significantly biased. Secondly, if analyses using routine data sources yield similar results, the use of routine data sources in further research can be justified.

Only 7% of individuals with admissions identified in their general practice records did not link to admissions recorded by the routine hospital activity data. This may be a less

complete source for identification of admissions, but has the advantage of being available for large populations without the need for further time consuming data extraction and coding.

There is no evidence that the chance of discrepancy between the two sources (in either direction) was related to the characteristics examined. Therefore any bias introduced by misclassification or incomplete recording of admissions will be non-differential bias. This will reduce the power of the study to detect specific associations with risk of admission, but associations found will not be invalidated.

7.5 *Conclusions*

The comparison of data sources provides reassurance that the results of our study are not invalidated by using data extracted from GP records by an individual who was aware of the study hypotheses. It also highlights some striking differences between the information derived from records and from postal questionnaires. Both incomplete records and incomplete recall are likely explanations for discrepancies observed. Other differences could be due to differences in the interpretation of questions. Even questionnaires requesting factual information should be validated before widespread use in health services research.

7.6 *Key points*

- **General practice records are a useful source of information on service use that is not available from other sources.**
- **Where information available from routine sources can be linked to individual patients, this may represent a source that is more cost effective and less subject to bias than either medical records or questionnaires.**
- **In the past, medical records have been used as a "gold standard" for validating other data sources. However, for some variables, records may not be more complete than either routine data collection or patient questionnaires.**

8. Chapter 8: Main Study - Descriptive analyses

8.1 Introduction

In order to understand the relationship of potential explanatory variables to admission risk, and before a multivariate analysis was performed, the distribution of individual variables, and their relationships to pattern of routine care and admission risk were examined.

8.2 Methodology

The complete cohort of individuals with diabetes whose notes were examined was subdivided for the purposes of describing their characteristics as shown (Table 8.1).

Table 8.1: Definition of groups used for descriptive analyses

	Date of diagnosis			
	Before 1990	1990 to 1995	Unknown	Total
Alive on 1/1/96	**620**	471	3	**1094** "Survivor cohort"
Died 1992-1995	15	10	1	**26** "Died 1992 to 1995"
Total	**635**	**481**	**4**	**1120**

The distributions of all variables collected from general practice records were examined separately for the survivor cohort and for the 26 individuals who had died, all of whom died between 1992 and 1995. Questionnaire information was only available for the 901 members of the survivor cohort who completed questionnaires.

Secular trends in patterns of care were examined, after dividing the cohort into those with access to review in general practice (in "CDM practices") and those without (in "non-CDM practices"). For those diagnosed during the period studied, pattern of care for the twelve months since diagnosis was studied to see if there were also secular changes in the care of the newly diagnosed. The results are described in Sections 8.3.5 and 8.3.6.

Pattern of diabetes care from 1990 to 1995 and risk of admission from 1991 to 1995 could only be described for the subgroup of the survivor cohort diagnosed before 1990 and so these analyses include only these 620 individuals (Section 8.3.7).

Admissions for those diagnosed between 1991 and 1995 were analysed separately because, for this group, time of admission could be related to the time of diagnosis (Section 8.3.8).

8.3 Results

8.3.1 Characteristics from general practice records

In this section, results are shown for both survivors and those who died; comments relate mainly to survivors. Demographic characteristics are shown in Table 8.2. The survivor cohort was predominantly middle-aged to elderly (50 to 79 years) whilst those who had died were elderly (58% were over 80 years). Age and duration of diabetes were calculated with reference to 1/1/96.

Table 8.2: Demographic characteristics

	Survivor cohort		Died between 1992 and 1995	
	Number	%	Number	%
Age distribution				
16-29	27	2.5	-	-
30-39	53	4.8	-	-
40-49	103	9.4	1	3.8
50-59	242	22.1	-	-
60-69	321	29.3	6	23.1
70-79	244	22.3	4	15.4
80+	104	9.5	15	57.7
Total	1094	100	26	100
Sex				
male	591	54.0	11	42.3
female	503	46.0	15	57.7
Total	1094	100	26	100

Tables 8.3 to 8.5 show the age at diagnosis, type of diabetes, and testing equipment on repeat prescription. Most were diagnosed between the ages of 40 and 70. 13% of the survivor cohort had insulin dependent diabetes and 29% overall were treated with insulin. Two thirds of the survivor cohort had some kind of testing equipment on repeat

prescription, 49% had urine testing strips and only 28% blood testing equipment. A third had been prescribed no testing equipment.

Table 8.3: Age at diagnosis

	Survivor cohort		Died between 1992 and 1995	
	Number	%	Number	%
0-15	41	3.7	-	-
16-29	39	3.6	1	3.8
30-39	110	10.1	-	-
40-49	233	21.3	3	11.5
50-59	293	26.8	4	15.4
60-69	235	21.5	5	19.2
70-79	110	10.1	10	38.5
80+	30	2.7	2	7.7
Unknown	3	0.3	1	3.8
Total	1094	100	26	100

Table 8.4: Type of diabetes and treatment

	Survivor cohort		Died between 1992 and 1995	
	Number	%	Number	%
IDDM* diagnosed <30yrs	70	6.4	-	-
IDDM* diagnosed ≥30yrs	74	6.8	-	-
IDDM* total	144	13.2	1	3.8
NIDDM-Insulin treated	171	15.6	7	26.9
NIDDM-Tablet treated	571	52.2	12	46.2
NIDDM-Diet treated	208	19.0	6	23.1
NIDDM total	950	86.8	25	96.2
Total	1094	100	26	100

* IDDM was defined as diabetes treated with insulin within 1 year of diagnosis

Table 8.5: Testing equipment on repeat prescription

	Survivor cohort		Died between 1992 and 1995	
	Number	%	Number	%
Blood tests	193	17.6	3	11.5
Urine tests	415	37.9	7	26.9
Blood & urine	117	10.7	1	3.8
Neither	369	33.7	15	57.7
Total	1094	100	26	100

81 individuals in the entire cohort (7%) had no record of HbA1, HbA1c or fasting glucose (from 1990 to 1995) recorded in their records.

The HbA1 result, or mean result for patients who had more than one test recorded, is given in Table 8.6. Overall mean control was within the "acceptable" range, although 357 (37%) of the survivor cohort had a mean HbA1 over 10 (indicating poor control).

Table 8.6: Glycaemic control (HbA1 1990 to 1995)

	Survivor cohort (n=965)			Died between 1992 and 1995(n=22)		
	mean	median	IQR	mean	median	IQR
HbA1	9.6	9.4	8.3 to 10.7	8.9	9.0	7.9 to 10.0

The number of tests done will be related to the time since diagnosis and was expected to be related to diabetic control, so the analysis of number of tests done was restricted to those diagnosed before 1990. In this group, 89% had at least one HbA1 result and, of these, 42% had poor mean control. Table 8.7 shows the number of tests done by level of control. Even amongst those with a "poor" mean result, 31% had only had one or two test results recorded over a 6 year period. There did not appear to be any trend in number of tests with worsening mean control (chi squared test for trend: p=0.8).

Table 8.7: Relationship between control and test frequency over 6 year period

(only survivors diagnosed pre1990 with at least one HbA1 recorded 1990-1995)

	Mean HbA1			
No of tests	"good" (<8.5)	"acceptable" (8.5 to 10)	"poor" (>10)	total
1-2	46 (33%)	40 (22%)	72 (31%)	158 (29%)
3-4	43 (31%)	55 (31%)	68 (29%)	166 (30%)
5+	50 (36%)	83 (47%)	92 (40%)	225 (41%)
total	139 (100%)	178 (100%)	232 (100%)	549 (100%)

Complications and co-morbidity

The number and British National Formulary (BNF) classification of all non-diabetic drugs on repeat prescription are shown in tables 8.8 and 8.9. Overall 73% of the survivors and 92% of those who died were on other drugs, suggesting a very high incidence of treated co-morbidity. The most commonly prescribed drugs were cardiovascular drugs (50%), followed by analgesics (34%).

Table 8.8: Number of non-diabetes drugs on repeat prescription

	Survivor cohort		Died between 1992 and 1995	
No. of drugs	Number	%	Number	%
0	292	26.7	2	7.7
1 to 2	335	30.6	3	11.5
3 to 9	442	40.4	21	80.8
10+	25	2.3	-	-
total	1094	100	26	100

Table 8.9: Categories of non-diabetes drugs on repeat prescription

	Survivor cohort		Died between 1992 and 1995	
	No (n=1094)	%	No (n=26)	%
Cardiovascular	542	49.5	20	76.9
Analgesics	368	33.6	8	30.8
Neurological	169	15.4	11	42.3
Gastrointestinal	213	19.5	10	38.5
Nutritional	126	11.5	5	19.2
Respiratory	106	9.7	3	11.5
Ophthalmic	88	8.0	4	15.4

Information on treated complications and number of chronic conditions recorded given in Tables 8.10 and 8.11 indicates a high prevalence of diagnosed hypertension (36%) and of recorded co-morbidity (57%) in this population. However the recording of co-morbidity and complications varied widely between practices and was not closely correlated with the computerised prescribing records.

Table 8.10: Recorded treatment for complications

	Survivor cohort		Died between 1992 and 1995	
	No (n=1094)	%	No (n=26)	%
Hypertension	398	36.4	10	38.5
Retinal laser therapy	78	7.1	2	7.7
Hyperlipidaemia	31	2.8	1	3.8
Peripheral vascular disease	35	3.2	1	3.8
Chronic renal failure	9	0.8	-	-

Table 8.11: No of other chronic conditions recorded

	Survivor cohort		Died between 1992 and 1995	
	Number	%	Number	%
None	469	42.9	1	3.8
1-2	546	49.9	21	80.8
3-4	76	6.9	4	15.4
5+	3	0.3	-	-
total	1094	100	26	100

8.3.2 Hospital clinic attendance and general practice reviews

The overall frequency of visits for those 635 individuals diagnosed before 1990 is shown in Table 8.12. Table 8.13 shows the setting of routine care for survivors in practices which qualify for CDM payments and those who do not. Over a third of individuals had neither been seen in a diabetes outpatient clinic or had a routine diabetes review in general practice over the six year period, whilst 11% had had more than ten visits to an outpatient clinic. Overall, more patients were seen in hospital clinics (53%) than had routine reviews in general practice (20%). 51% of those registered with practices which do not organise routine diabetes reviews, were not seen at all in the hospital diabetes clinic.

Table 8.12: Number of outpatient visits and GP routine reviews 1990 to 1995

	Survivor cohort		Died between 1992 and 1995	
Outpatient visits	Number	%	Number	%
None	288	46.5	8	53.3
1	33	5.3	2	13.3
2-5	120	19.4	4	26.7
6-10	110	17.7	-	-
11-15	52	8.4	-	-
15+	17	2.7	1	6.7
Total	620	100	15	100
GP reviews	Number	%	Number	%
None	496	80.0	11	73.3
1	36	5.8	1	6.7
2	28	4.5	2	13.3
3	13	2.1	-	-
4+	47	7.6	1	6.7
Total	620	100	15	100

Table 8.13:Outpatient visits and GP reviews (1990 to 1995) by practice type

	GP review (%)	Outpatients (%)	Both (%)	Neither (%)	Total (%)
CDM practices	73 (26)	115 (41)	51 (18)	43 (15)	282 (100)
NonCDM practices	-	166 (49)	-	172 (51)	338 (100)
All practices	73 (12)	281 (45)	51 (8)	215 (35)	620 (100)

Hospital admissions (including daycases)

Tables 8.14 and 8.15 give the primary diagnoses for admissions and the type of hospital respectively. In the survivor cohort, 543 (50%) had at least one admission from 1991 to 1995. Almost half of admissions were for diagnoses unrelated to diabetes and only 5% were related to diabetes control (including admissions at the time of diagnosis). Only 4% of admissions were to non-NHS hospitals.

Table 8.14: Admissions by primary diagnosis for admission

Admissions	Survivor cohort		Died 1992 - 1995	
	Number	%	Number	%
Diabetes control	61	5	2	2
Infections	111	9	7	8
Chronic diabetic complications	340	28	37	43
Elective eye surgery	139	11	1	1
Other causes	566	47	38	45
All causes (total)	1217	100	85	100

Table 8.15: Admissions by hospital category

Admissions	Survivor cohort		Died between 1992 and 1995	
	Number	%	Number	%
Leics NHS hospitals	1141	93.8	83	97.6
Other UK NHS hospitals	16	1.3	-	-
Admitted abroad	12	1.0	-	-
Private (within the UK)	44	3.6	2	2.4
Unknown	4	0.3	-	-
Total	1217	100	85	100

8.3.3 Characteristics from postal questionnaire data

Information was only available for the 901 individuals who completed questionnaires and denominators represent the number of respondents who provided a response for an item. Social characteristics are given in Table 8.16 to 8.18.

Table 8.16: Social characteristics from postal questionnaires

Household size:	Proportion of respondents	%
Living alone	160	17.8
Living with 1-4 others	610	67.8
Living with >4 others	88	9.8
Living in a residential home	42	4.7
Total	900	100
Ethnic group:		
White	446	50.3
Indian	382	43.1
Black African/Caribbean	47	5.3
Other	11	1.2
Total	886	100
Smoking habit:		
Never smoker	678	76.1
Ex-smoker	85	9.5
Pipe/cigar smoker	21	1.3
<10 a day	51	4.9
10-20 a day	44	5.7
20+ a day	12	2.4
Total	891	100
Access to car		
Yes	456	51.6
No	428	48.4
Total	884	100
House owner		
Yes	598	67.8
No	284	32.2
Total	882	100

5% lived in residential homes and 18% lived alone. Only 50% of the respondents described themselves as white, whilst 43% describe themselves as Indian. 76% claimed they had never smoked. Although two thirds were home owners, only a half had access to a car.

Table 8.17 shows the employment of respondents and their partners. Although the cohort included slightly more men than women, individuals with diabetes were less likely to be in full-time or part time work than their partners. 18% were on invalidity benefit.

Table 8.17 : Employment of respondents and their partners

	Self		Partner	
Employment	Number	%	Number	%
Full-time	161	18.4	142	24.8
Part-time	39	4.5	62	10.8
Retired	442	50.5	278	48.5
Unemployed	45	5.1	46	8.0
Student	7	0.8	3	0.5
Housework	24	2.7	42	7.3
On invalidity/sickness benefit	157	17.9	-	-
Total	875	100	573	100

Table 8.18 shows the age of immigration for respondents who were not born in Britain. 94% of Indian and all black African and Caribbean respondents came to Britain after the age of 16.

Table 8.18: Place of birth and age of immigration by ethnic group

Ethnic group No (%)	Born in Britain	Came <16yrs	Came >16yrs	Total
White	417 (94)	2 (-)	26 (6)	445 (100)
Indian	8 (2)	13 (4)	342 (94)	363 (100)
Black African/Caribbean	-	-	45 (100)	45(100)
Other	-	1 (13)	7 (88)	8 (100)
Total	425	16	420	861

Table 8.19 shows self reported service use. Two thirds of respondents saw their GP regularly and a third attended a hospital diabetes clinic regularly. 18% did not regularly attend either in general practice or a hospital clinic. Only 65% had seen a dietician at any time and 44% had seen a chiropodist. Only 2% had been seen privately by a diabetes specialist. 26% recalled having been to A&E in the previous 5 years, and 42% having been admitted to hospital.

Table 8.19: Self reported service use

	Proportion of respondents	%
Regularly sees: GP	562/859	65.4
Practice nurse	310/829	37.4
Diabetologist at hospital	308/858	35.9
None of the above	146/796	18.3
Seen a nurse at: Home	110/506	21.7
Hospital	323/611	52.9
GP surgery	336/645	52.1
Seen dietician	573/886	64.7
Seen chiropodist	386/888	43.5
Seen private diabetologist	19/885	2.1
Been to A&E in past 5 years	225/878	25.6
Been admitted in past 5 years	367/881	41.7

Table 8.20 shows the main responses to an open question about what aspect of diabetes services should be changed. The majority of responses related either to unmet needs for information and advice or to a need for more frequent "check ups".

Table 8.20: Comments on diabetes services

Main comments on "what should be changed"	**Number of replies**
More advice or information (for public and/or patients)	93
More regular check ups	75
Better access to clinics/ other services	28
Financial help for diet/equipment/glasses/cold weather etc	16
Changes to doctors' attitudes	12
Better co-ordination of services	7
Better continuity of care	5

8.3.4 Relationship between pattern of diabetes care and other explanatory variables

Pattern of care is defined as GP, outpatients, neither or both depending on whether the notes record either a diabetes outpatient visit or a GP diabetes review between 1990 and 1995. All members of the survivor cohort diagnosed by 1990 (for whom pattern of care can be defined for the period 1/1/90 to 1/1/96) are included in this analysis.

Tables 8.21 shows the relationship between pattern of care and age and sex. There is little variation with sex. With increasing age the proportion attending hospital clinics decreases and the proportion reviewed within general practice increases.

Table 8.21: Pattern of care by age and sex

Sex	Male		Female		Total	
	No.	%	No.	%	No.	%
Neither	113	33.4	102	36.2	215	34.7
GP	35	10.4	38	13.5	73	11.8
Outpatient	158	46.7	123	43.6	281	45.3
Both	32	9.5	19	6.7	51	8.2
Total	338	100	282	100	620	100

Age group	16-39 yrs		40-59 yrs		60-69 yrs		70+ yrs		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
Neither	2	4.0	63	35.4	72	38.1	78	38.4	215	34.7
GP	1	2.0	12	6.7	15	7.9	45	22.2	73	11.8
Outpatient	42	84.0	88	49.4	87	46.0	64	31.5	281	45.3
Both	5	10.0	15	8.4	15	7.9	16	7.9	51	8.2
Total	50	100	178	100	189	100	203	100	620	100

Tables 8.22 to 8.25 show that pattern of care is related to ethnic group, type of diabetes treatment, duration of diabetes, Townsend score, car ownership and home ownership. These variables are interrelated: type of treatment is related to duration of diabetes and ethnic group to material deprivation. Pattern of care was not significantly related to the presence of co-morbidity or the number of non-diabetic drugs on repeat prescription.

White individuals were much more likely to be seen for review within general practice, black and Indian individuals were more likely to be seen in outpatients (Table 8.22).

Table 8.22: Pattern of care by ethnic group

	White		Indian		Black		Other		Unknown	
	No.	%	No.	%	No.	%	No.	%	No.	%
Neither	33	14.5	121	51.1	5	22.7	-	-	56	42.4
GP	60	26.3	-	-	-	-	-	-	13	9.8
Outpatient	96	42.1	115	48.5	13	59.1	1	100	56	42.4
Both	39	17.1	1	0.4	4	18.2	-	-	7	5.3
Total	228	100	237	100	22	100	1	100	132	100

87% of individuals on insulin were seen in outpatients, whilst 69% of those treated only with diet were seen neither in general practice or outpatients (Table 8.23)

Table 8.23: Pattern of care by diabetes treatment

	Insulin		Tablets only		Diet only	
	No.	%	No.	%	No.	%
Neither	21	8.2	148	49.7	46	68.7
GP	13	5.1	44	14.8	16	23.9
Outpatient	189	74.1	88	29.5	4	6.0
Both	32	12.5	18	6.0	1	1.5
Total	255	100	298	100	67	100

Increasing duration of diabetes was associated with an increasing chance of having been seen in outpatients and decreasing chance of not being seen at all (Table 8.24).

Table 8.24: Pattern of care by duration of diabetes

	0 to 10 yrs		11 to 20 yrs		21+ yrs	
	No.	%	No.	%	No.	%
Neither	97	40.4	97	35.4	21	19.8
GP	29	12.1	34	12.4	10	9.4
Outpatient	101	42.1	118	43.1	62	58.5
Both	13	5.4	25	9.1	13	12.3
Total	240	100	274	100	106	100

Those not seen at all tended to live in wards with higher Townsend indices (corresponding to greater material deprivation); those seen only in general practice lived

in areas with the least material deprivation. Although being seen in outpatients was associated with higher Townsend indices, amongst those who returned questionnaires outpatient attendance was associated with access to a car and house ownership.

Table 8.25: Pattern of care by indices of material deprivation

	Townsend index		Access to car		House owner	
	Median	IQR	No.	%	No.	%
Neither	3.54	0.21 to 5.56	60/157	38.2	94/157	59.9
GP	-0.68	-2.47 to 2.84	30/61	49.2	39/60	65.0
Outpatient	2.95	-0.45 to 5.37	169/226	74.8	169/226	74.8
Both	-1.23	-3.06 to 2.98	29/47	61.7	35/48	72.9
Total	2.74	-1.00 to 5.24	288/491	58.7	337/491	68.6

8.3.5 Secular trends in pattern of care

The pattern of diabetes care was likely to have changed over the six years of the study and also to depend on whether the general practice with which an individual is registered has an organised system for diabetes reviews. Outpatient visits and GP reviews were therefore examined by year and type of practice to look for time trends. Table 8.26 shows proportions of patients, in practices which were running CDM diabetes programmes by the end of 1995, receiving care in different settings annually and Graph 8.1 shows these as percentages. The denominator is the number of individuals in the study cohort, alive, registered with the study practices and with a diagnosis of diabetes at the start of each year.

Table 8.26: Individuals with diagnosed diabetes reviewed in hospital and primary care settings 1990 to 1995

	1990 no (%)	1991 no (%)	1992 no (%)	1993 no (%)	1994 no (%)	1995 no (%)
GP reviews only	32(11)	34(11)	62(17)	78(19)	145(32)	168(33)
Outpatients only	83(29)	102(32)	123(34)	124(30)	134(30)	143(28)
Both	16(6)	16(5)	11(3)	9(2)	9(2)	12(2)
Neither	151(54)	166(52)	162(45)	201(49)	166(37)	191(37)
Total	282	318	358	412	454	514

Graph 8.1: Percentage of individuals in CDM practices reviewed in hospital and primary care settings 1990 to 1995

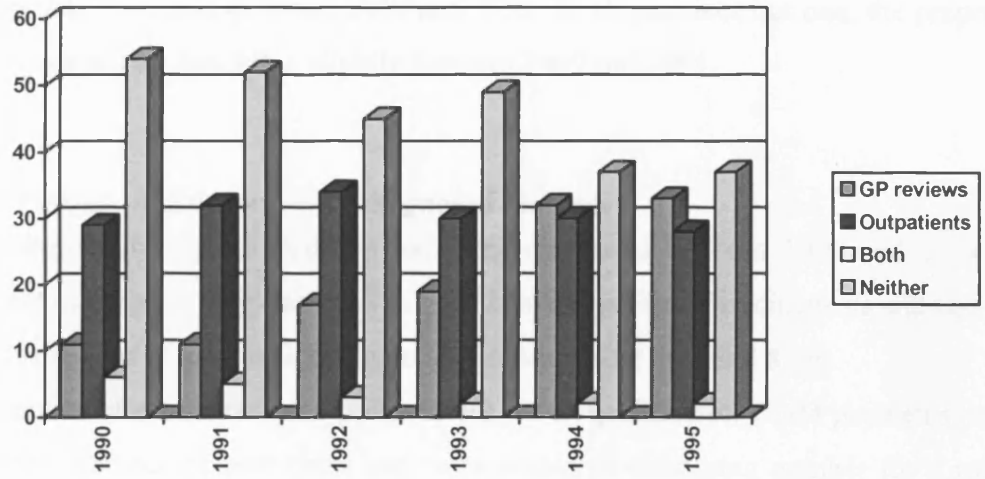


Table 8.27 shows proportions of patients, in practices which were not running CDM diabetes programmes, receiving care in different settings annually. In any one year, more than 70% were not seen in a hospital clinic and none of these patients had a routine review documented in their general practice record.

Table 8.27: Individuals in non-CDM practices reviewed in hospital and primary care settings 1990 to 1995

	1990	1991	1992	1993	1994	1995
	no (%)	no (%)	no (%)	no (%)	no (%)	no (%)
GP reviews	-	-	-	-	-	-
Outpatients	96 (28)	107 (28)	115 (28)	129 (29)	136 (28)	128 (25)
Neither	243 (72)	273 (72)	292 (72)	319 (71)	345 (72)	389 (75)
Total	339 (100)	380 (100)	407 (100)	448 (100)	481 (100)	517 (100)

Overall (including both types of practice), the proportion reviewed annually in general practice has doubled from 8% to 17% . Meanwhile the proportion seen in outpatients fell marginally from 31% to 27%. The proportion seen in both primary and secondary care in the same year fell from 3% to 1%.

In all except the practices doing no reviews at all and a practice which was already seeing 60% of patients annually in a practice clinic, the proportion reviewed in general practice has increased between 1990 and 1995. In all practices but one, the proportion seen in outpatients has fallen slightly between 1990 and 1995.

8.3.6 Pattern of care for newly diagnosed diabetes

The subgroup for whom diabetes had been diagnosed between 1990 and 1994 was analysed to see who they had seen in the 12 month period after diagnosis and how this varied with year of diagnosis and type of practice (Table 8.28 and 8.29).

Practices developing structured programmes which qualified for CDM payments had an increasing number of new cases and were seeing an increasing number for a routine review for complications within a year of diagnosis themselves. The number referred to the hospital clinic showed no consistent trend.

Table 8.28: Pattern of care in 12 months since diagnosis in practices with CDM structured programmes

	Year of diagnosis					
	1990	1991	1992	1993	1994	Total
	no (%)	no (%)	no (%)	no (%)	no (%)	no (%)
GP review only	5 (14)	2 (5)	14 (25)	12 (27)	22 (36)	55 (23)
Outpatients only	11 (30)	11 (26)	7 (12)	3 (7)	10 (16)	42 (17)
Both	2 (5)	- (-)	- (-)	- (-)	- (-)	2 (1)
Neither	19 (57)	30 (70)	36 (63)	29 (66)	29 (48)	143 (59)
Total diagnosed	37 (100)	43 (100)	57 (100)	44 (100)	61 (100)	242 (100)

In the practices which were not qualifying for CDM payments for diabetes care, there was no trend during this period in the number of new cases or in the percentage of patients referred to a hospital diabetes clinic within a year of diagnosis.

Table 8.29: Pattern of care in 12 months since diagnosis in practices without CDM structured programmes

	Year of diagnosis					
	1990	1991	1992	1993	1994	Total
	no (%)	no (%)	no (%)	no (%)	no (%)	no (%)
GP reviews	-	-	-	-	-	-
Outpatients	10 (24)	10 (38)	14 (34)	8 (24)	12 (32)	54 (30)
Neither	31 (76)	16 (61)	27 (66)	25 (76)	25 (68)	124 (70)
Total	41 (100)	26 (100)	41 (100)	33 (100)	37 (100)	178 (100)

The majority of newly diagnosed individuals (59% in CDM practices and 70% in non-CDM practices) were seen neither in a hospital clinic nor for a routine review in general practice within twelve months of diagnosis.

8.3.7 Risk factors for admission

Admissions of those survivors diagnosed before 1990 were examined to establish which variables were related to risk of admission. Characteristics of those admitted (including daycases) between 1991 and 1995 and those not admitted are compared in Tables 8.30 to 8.32.

Risk of admission is not significantly related to Townsend score, sex or to pattern of care. It is related to age, duration of diabetes, diabetes treatment and the number of non-diabetic drugs on repeat prescription.

Older patients and those who have had diabetes for longer are more likely to be admitted (Table 8.30).

Table 8.30: Comparison of individuals admitted and not admitted - continuous variables

	Admitted	Not admitted	MannWhitney:
Age in yrs	n=313	n=307	
median	65.6	61.4	p<0.0001
Townsend score	n=301	n=305	
median	2.90	2.88	p=0.8
Years since diagnosis	n=309	n=307	
median	13.0	12.0	p=0.003

Those on insulin are more likely to be admitted. Those on drugs in a number of categories (cardiovascular drugs, analgesics, nervous system drugs and those on any non-diabetes drugs) are more likely to be admitted. Risk of admission did not vary with type of practice or with socioeconomic variables.

Table 8.31: Comparison of individuals admitted and not admitted - categorical variables

	Admitted (n=313)	Not admitted (n=307)	Relative risk	Chi^2 p=
Male (%)	173/313 (55)	165/307 (54)	1.03	0.7
House owner (%)	179/259 (69)	158/232 (68)	1.01	0.8
Access to car (%)	119/254 (47)	123/234 (53)	0.89	0.2
Smoker (%)	37/260 (14)	34/235 (14)	0.98	0.9
Diabetes treatment				
Insulin (%)	144 (46)	111 (36)	1.27	
Oral only (%)	138 (44)	160 (52)	0.85	
Diet only (%)	31 (10)	36 (12)	0.84	0.04
Other drugs				
cvs drugs (%)	208 (66)	123 (40)	1.66	0.0001
analgesics (%)	129 (41)	90 (29)	1.41	0.002
cns drugs (%)	73 (23)	33 (11)	2.17	0.00003
all drugs (%)	272 (87)	198 (64)	1.35	0.00001
General practice				
CDM practices (%)	141 (45)	141 (46)		
Non CDM practices (%)	172 (55)	166 (54)	1.02	0.8

Table 8.32 shows the relationship of pattern of care to admissions for different types of admission. It was thought likely that this relationship would depend on the type of admission considered. However the proportion of individuals reviewed in different settings appears very similar whichever category of admission is considered. In general, those who attend hospital clinics are slightly more likely to be admitted and those who attend for review in general practice are slightly less likely to be admitted.

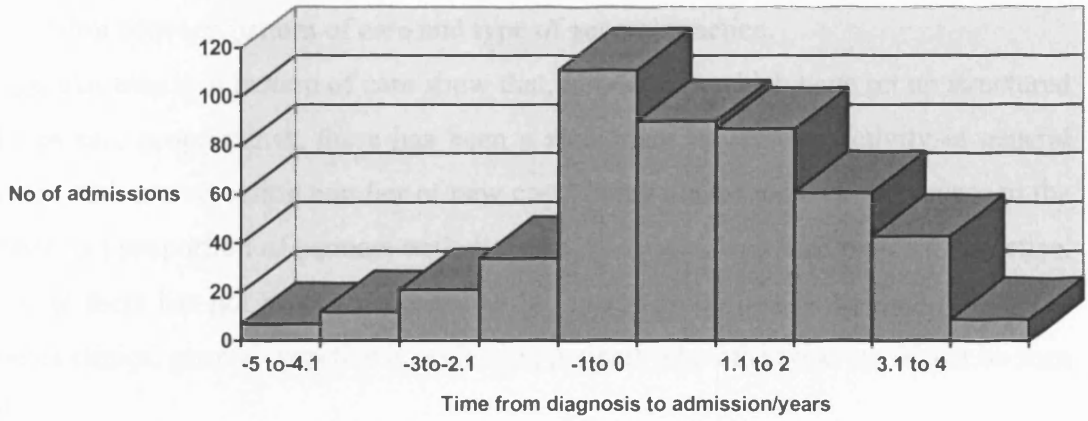
Table 8.32: Service use by primary cause of first admission:

	Admitted No (%)	Not admitted No (%)	Relative risk	chi^2 p=
Diabetes/infections				
Reviewed in general practice only	7(10.4)	66 (11.9)	0.88	
Attended hospital clinic only	37 (55.2)	244 (44.1)	1.25	
Attend both GP and hospital	3 (4.5)	48 (8.7)	0.52	
Attended neither GP or hospital	20 (29.9)	195 (35.3)	0.85	
Total	67 (100)	553 (100)		0.3
Chronic complications				
Reviewed in general practice only	12 (9.9)	61 (12.2)	0.81	
Attended hospital clinic only	59 (48.8)	222 (44.5)	1.09	
Attend both GP and hospital	9 (7.4)	42 (8.4)	0.88	
Attended neither GP or hospital	41 (33.9)	174 (34.9)	0.97	
Total	121 (100)	499 (100)		0.8
Elective eye surgery				
Reviewed in general practice only	9 (13.0)	64 (11.6)	1.12	
Attended hospital clinic only	32 (46.4)	249 (45.2)	1.03	
Attend both GP and hospital	1 (1.4)	50 (9.1)	0.15	
Attended neither GP or hospital	27 (39.1)	188 (34.1)	1.14	
Total	69 (100)	551 (100)		0.2
Other (non-diabetes related)				
Reviewed in general practice only	23 (12.4)	50 (11.5)	1.08	
Attended hospital clinic only	88 (47.6)	193 (44.4)	1.07	
Attend both GP and hospital	14 (7.6)	37 (8.5)	0.89	
Attended neither GP or hospital	60 (32.4)	155 (35.6)	0.91	
Total	185 (100)	435 (100)		0.8
All cause admissions				
Reviewed in general practice only	36 (11.5)	37 (12.1)	0.95	
Attended hospital clinic only	150 (47.9)	131 (42.7)	1.12	
Attend both GP and hospital	20 (6.4)	31 (10)	0.64	
Attended neither GP or hospital	107 (34.2)	108 (35.2)	0.97	
Total	313 (100)	307 (100)		0.3

8.3.8 Risk of admission in those diagnosed between 1991 and 1995

For individuals diagnosed between 1991 and 1995, admissions were examined to test the assumption that diagnosis is likely to be the result of (rather than a risk factor for) an admission. The distribution of times between admissions and diagnosis in this group suggests this, with very few admissions prior to diagnosis followed by a peak of admissions around the time of diagnosis.

Graph 8.2: Time from diagnosis to admission



8.4 Discussion

8.4.1 Characteristics of the survivor cohort

The cohort investigated in our study differs in several respects from diabetic cohorts recruited from clinic populations.[28,75] The cohort is relatively elderly, has a smaller proportion of insulin dependent individuals, a high rate of co-morbidity and comparatively good glycaemic control. These characteristics may be explained by the fact that they are all (except presence of co-morbidity) associated with an increased chance of not being seen in clinics.

The information on prescribing for chronic co-morbidities (defined as repeat prescribing[131] for this study) was mainly derived from computerised prescribing records. It was found that this represented a more consistent and reliable source of information on treated co-morbidity than information from general practice notes. There is likely to be a degree of diagnostic bias, in that the more frequently an individual is reviewed or admitted, the more likely any chronic condition is to be detected and treatment initiated. On the other hand, since individuals with diabetes tend to be frequent attenders, the

proportion of untreated chronic conditions is likely to be low in comparison to the general population.

8.4.2 Factors related to pattern of care

Whether an individual is seen in a hospital clinic, has a review in general practice or has neither is related, as expected, to type of diabetes treatment and duration of diabetes. The relationship between pattern of care and age may partly be explained by treatment and duration of diabetes varying with age. Similarly the relationship between pattern of care and ethnic origin and material deprivation can be explained by the strong relationship between pattern of care and type of general practice.

The secular trends in pattern of care show that, in practices which have set up structured diabetes care programmes, there has been a significant increase in activity in general practice with an increasing number of new cases being diagnosed and an increase in the number and proportion of patients with diabetes being reviewed within general practice. However there has not been a concomitant fall in the proportion being seen in hospital diabetes clinics; general practice is reviewing patients who otherwise would not be seen at all.

8.4.3 Risk factors for admission

As in the pilot study, few admissions (5%) were directly due to diabetic control. This agrees with previous findings: a similar proportion (4.6%) of admissions were directly due to diabetes in a cohort of American patients with NIDDM.[104]

Risk of hospital admission is strongly related to age. This may be explained by the evidence that co-morbidity (which increases with age) and duration of diabetes (which will also increase with age) are strongly associated with increasing risk of admission.

Our study found no association between sex and admission risk. A previous study of admissions in individuals with NIDDM found an interaction between age and sex, with women being at higher risk than men (odds ratio 1.4), but only in the age group younger than 65.[104] The inclusion of all types of diabetes and all cause admissions in our study may account for the lack of association. Associations may be present if subgroups of a population with diabetes (eg IDDM or NIDDM only) or specific admission categories (eg diabetic control or coronary heart disease) are studied.

Variables which are indicators of material deprivation are not related to admission risk at an individual level. There is some evidence at an ecological level that material deprivation is related to admission risk, since practices that did not provide routine

diabetes review have higher admission rates and higher Townsend scores.[52] However, all such ecological studies which do relate admission rates for diabetes and deprivation[88] are confounded by prevalence.[89] We found no evidence for such a relationship at the level of individuals with diabetes.

Risk of admission was related to both type of diabetes treatment and duration of diabetes. These two variables can be regarded as proxy measures of "severity" of diabetes. Type of treatment may be related to how easily controlled diabetes is and the risk of long term complications increases with duration. The strongest predictor of admission is the number of drugs on repeat prescription, reflecting the fact that most admissions are not directly due to diabetes but to related conditions such as cardiovascular disease.

Variables associated with pattern of care and with risk of admission are summarised in Table 8.33. It shows that the major confounders of the relationship of interest are likely to be age, duration of diabetes and treatment of diabetes. Treated co-morbidity (represented by the number of non-diabetic drugs on repeat prescription) is a major risk factor for admission, but is not a confounder.

Table 8.33: Variables associated with pattern of care and admission risk

Variable	Related to pattern of care	Related to admission risk
Age	√	√
Sex	**X**	**X**
Duration of diabetes	√	√
Treatment of diabetes	√	√
Treated co-morbidity	**X**	√
Ethnic origin	√	**X**
Material deprivation	√	**X**
Type of practice	√	**X**

8.5 Key Points

- **35% of individuals diagnosed before 1990 had neither attended a diabetic outpatients clinic nor had a diabetes review in general practice between 1990 and 1995.**
- **The proportion seen for review in general practice annually had increased during this time from 8% to 17% .**
- **The main factors related to pattern of care were general practice, age, ethnic origin, duration and treatment of diabetes and material deprivation.**
- **The main factors related to an increased risk of hospital admission were increasing age, increasing duration of diabetes, treatment with insulin and an increasing number of non-diabetic drugs on repeat prescription.**

9. Chapter 9: Main Study - Multivariate analysis of risk factors for hospital admission

9.1 Introduction

A major difficulty in studying the relationship between pattern of routine care and admission is that whilst the pattern of care may influence admission risk, it is also very likely that hospital admission will lead to a change in the pattern of care. We wished to examine the relationship between pattern of care prior to the admission date (rather than after admission) and admission risk. We also wished to reduce the chance that the pattern of care prior to the admission we had identified was the result of an earlier admission. A third consideration was that we needed to allow for the secular trends in pattern of care which we had identified.

9.2 Methodology

9.2.1 Design of a matched case control analysis

The three requirements described above were met by making the main analysis a matched case control analysis. It was then possible to define the "pattern of routine diabetes care" as the care received during the two years before the admission of a case, for both a case and for their matched control. This defined the relationship in time between routine care and admission and controlled for secular trends by defining the same two year period for case and control. We reduced the chance that pattern of care was the result of an earlier admission by including only individuals with no admissions during this two year "window of care" before the index admission.

This design allows comparison of the pattern of care (ie whether seen in a hospital clinic or for routine review in general practice) during the two years prior to admission of a case with the pattern of care of a matched individual from the risk set from which the individual admitted was drawn.[142] The risk set includes all individuals who had been diagnosed for at least two years, with no admissions in the previous two years, on the admission date and who would therefore be eligible as cases had they been admitted on the admission date.

Because only the five practices which received chronic disease management payments provided diabetes reviews, this analysis was initially conducted using these practices only. A secondary analysis was done using the remaining practices, in order to see

whether the findings related to review in hospital clinics could be generalised to individuals who did not have access to routine reviews in general practice.

Since preliminary analyses had shown that the explanatory variables age, treatment and duration of diabetes and number of non-diabetic drugs on repeat prescription were all related to risk of admission, for the main multivariate analyses all these variables were included.

9.2.2 Selection of cases and controls

For the case control analyses, a case was defined as any individual who has an admission between 1992 and 1995, at least two years after diagnosis and at least two years after any previous admission.

Because the principal outcome of interest was the first admission during the study period for which information on previous pattern of diabetes care over at least two years were available, this excluded admissions prior to January 1992 (since data collection started from January 1990). There were few subsequent qualifying admissions in the same individual and these were not included.

An age matched control was chosen as the individual closest in age from the appropriate risk set who had not already been selected as case or control. The age of the control had to be within 5 years of the age of the case and if no appropriate control was available, the case was excluded from the analysis. Matching on age implies that age effects cannot be examined, but since age is a powerful confounder of the relationship being examined, and cannot be modified, this was felt to be appropriate.

The identification of cases and the allocation of controls in a randomised sequence was done using SAS programmes.[143] These programmes were written by Nicola Spiers, research statistician at the Department of Public Health and Epidemiology, University of Leicester. The conditional logistic regression analysis was then done using SPSS for Windows.[128]

9.2.3 Analysis by reason for admission

"All cause" hospital admission has been selected as the principal outcome of interest in order to assess the overall impact on admission risk of the explanatory variables. As the relationship with pattern of care would theoretically be expected to vary with the reason for admission, the analysis was repeated for diabetes related and non-diabetes related admissions (as classified in Chapter 3).

9.2.4 Comparison of pattern of care before and after admission date

The extent to which admission may result in a change in the pattern of care was explored by examining how the change in pattern of care between the two years before and the two years after the admission date differed between cases and controls.

9.2.5 Influence of glycaemic control

In order to explore the relationship between glycaemic control and admission risk, the mean HbA1 result in the two years before admission was included in a matched analysis.

9.3 Results

9.3.1 Analysis for practices providing diabetes reviews

The main multivariate analyses were restricted to the subgroup of five practices which did provide diabetes reviews within general practice. Out of 579 individuals, 244 had admissions between 1992 and 1995. 160 eligible cases were identified for whom there was an admission at least two years after diagnosis and at least two years after the most recent previous admission. Two cases were excluded because there was no control available, leaving 158 pairs for analysis. The characteristics of cases and the matched controls selected for this analysis, together with the crude odds ratios are given in Table 9.1. This shows that the cases have a longer duration of diabetes, are more likely to be insulin treated and are on more non-diabetic drugs. They are also less likely to have had either a review in general practice or attended diabetic outpatients than the controls.

Both cases and controls differ from the main cohort from which they were selected, because of the restrictions applied to eligibility for the risk set. Many of those with frequent admissions have been excluded because they do not have a two year "admission free" window before an admission date. Many of those diagnosed during the study period are excluded since they have not had two years since diagnosis before the case admission date. The cases and controls represent a relatively "stable" group at least two years post diagnosis and without frequent admissions.

Table 9.1: Characteristics of cases and controls

Variable	Cases (n=158) No	%	Controls (n=158) No	%	OR (crude)
Age					
0 to 40 yrs	13	8	13	8	
41 to 60 yrs	32	20	33	21	
61 to 70 yrs	47	30	50	32	
71 to 80yrs	46	29	43	27	
81+ yrs	20	13	19	12	Matched
Sex					
Male	83	53	80	51	1.07
Female*	75	47	78	49	1.00
Treatment					
on insulin	66	42	46	29	2.39
on tablets	74	47	86	54	1.26
on diet only*	18	11	26	16	1.00
Duration of diabetes					
2 to 5 yrs	41	26	73	46	
6 to 10 yrs	54	34	37	23	
11 to 20 yrs	33	21	30	19	
21 + yrs	30	19	18	11	1.04/yr
Number of drugs					
None	22	14	48	30	
1-2	40	25	55	35	
3-5	65	41	43	27	
5+	31	20	12	8	1.35/drug
Routine care:					
None*	70	44	53	34	1.00
GP only	37	23	47	30	0.60
Hospital only	41	26	50	32	0.64
Both GP & hospital	10	6	8	5	0.88
General Practice:					
A*	54	34	50	32	1.00
B	45	28	44	28	1.26
C	41	26	41	26	1.19
D	15	9	14	9	1.24
E	3	2	9	6	0.42

* Reference category for categorical variables

The results of the main multivariate analysis are shown in Table 9.2. This analysis included all the variables which were thought for theoretical reasons to be related to admission risk (age, sex, general practice) and those which had been demonstrated to be major risk factors (number of drugs on repeat prescription) and probable confounders of the relationship between pattern of care and admission risk (duration of diabetes and treatment type). Duration of diabetes, number of drugs on repeat prescription and attendance at a hospital diabetes clinic in the previous two years all had odds ratios for which the 95% confidence interval does not include one and are therefore all apparently independently related to risk of hospital admission. Review in any setting was related to a reduced risk of admission, but this was only statistically significant for those who only attended a hospital clinic in the previous two years.

Table 9.2: Adjusted odds ratio for association with risk of admission (all cause)
(adjusted for all variables shown in Table 9.1)

Variable	Odds ratio	95% CI	
Duration of diabetes/yrs	1.07	1.03 to 1.11	p = 0.01
Number of non-diabetic drugs	1.51	1.27 to 1.79	p < 0.0001
Treatment type:			
Treatment with insulin*	2.05	0.65 to 6.44	
Treatment with tablets only*	1.56	0.59 to 4.15	
Routine care over previous 2 years:			
Review in general practice only**	0.91	0.41 to 1.99	
Outpatient visits only**	0.30	0.14 to 0.65	p = 0.003
Both GP review and outpatients**	0.77	0.19 to 3.08	

* Reference category is diet treated diabetes

** Reference category is no routine reviews in general practice or outpatient visits

9.3.2 Analysis by reason for admission

When the analysis was repeated for diabetes related admissions (Table 9.3, based on 60 matched pairs) and diabetes unrelated admissions (Table 9.4, based on 98 pairs), the same variables contributed significantly to the model (with odds ratios significantly different from one). The difference in the odds ratios associated with hospital attendance was greater for diabetes related admissions (0.24 versus 0.36). This suggests that the "protective" effect of hospital attendance, although apparent for both types of admission, may be greater for diabetes related admissions. The association with the

number of non-diabetic drugs on repeat prescription is also stronger for diabetes related admissions (2.01 versus 1.46).

Table 9.3: Adjusted odds ratio for association with risk of diabetes related admission (adjusted for all variables shown in Table 9.1)

Variable	Odds ratio	95% CI	
Duration of diabetes/yrs	1.19	1.04 to 1.37	p = 0.01
Number of non-diabetic drugs	2.01	1.24 to 3.22	p = 0.004
Routine care over previous 2 years			
Review in general practice only**	1.25	0.33 to 4.76	
Outpatient visits only**	0.24	0.07 to 0.87	p = 0.04
Both GP review and outpatients**	0.99	0.12 to 8.23	

** Reference category is no routine reviews in general practice or outpatient visits

Table 9.4: Adjusted odds ratio for association with risk of non-diabetes related admission (adjusted for all variables shown in Table 9.1)

Variable	Odds ratio	95% CI	
Duration of diabetes/yrs	1.05	1.00 to 1.10	p = 0.05
Number of non-diabetic drugs	1.46	1.18 to 1.81	p = 0.0005
Routine care over previous 2 years			
Review in general practice only**	0.86	0.32 to 2.31	
Outpatient visits only**	0.36	0.14 to 0.93	p = 0.04
Both GP review and outpatients**	0.76	0.16 to 3.65	

** Reference category is no routine reviews in general practice or outpatient visits

9.3.3 Analysis for practices not providing diabetes reviews

The analysis was repeated for the individuals registered with the practices which did not offer routine diabetes reviews. Adjusted odds ratios are shown in Table 9.5.

Table 9.5: Non-CDM practices -Adjusted odds ratio for association with risk of admission (adjusted for all variables shown in table 9.1)

Variable	Odds ratio	95% CI	
Duration of diabetes/yrs	1.02	0.98 to 1.08	
Number of non-diabetic drugs	1.34	1.19 to 1.50	p<0.0001
Routine care over previous 2 years:			
Outpatient visits **	0.99	0.50 to 1.96	

** Reference category is no outpatient visits

While number of non-diabetes drugs is again significantly positively associated to admission, duration of diabetes is no longer significantly related and the odds ratio associated with having attended outpatients is close to one.

9.3.4 Comparison of pattern of care before and after admission date

For those 65 matched pairs of cases and controls in practices providing diabetes reviews for which information was available on service use during the two years after the admission date (ie those with an admission date before 1/1/94) it was possible to compare the routine care before and after the admission date for those admitted between 1/1/92 and 1/1/94 and their matched controls (Tables 9.6 and 9.7).

Table 9.6: Setting of care in 2 years before and after admission date for cases

	After admission date				
Before admission date	Neither	GP only	Hospital only	Both	Total
Neither	15	5	10	-	30
GP only	4	8	-	-	12
Hospital only	3	-	16	1	20
Both	-	1	1	1	3
Total	22	14	27	2	65

Table 9.7: Setting of care in 2 years before and after admission date for controls

	After admission date				
Before admission date	Neither	GP only	Hospital only	Both	Total
Neither	18	6	5	-	29
GP only	2	10	-	2	14
Hospital only	5	2	9	1	17
Both	1	2	-	2	5
Total	26	20	14	5	65

Amongst the cases, ten who had not attended a hospital clinic in the two years before admission did attend a hospital clinic in the two years after admission. Only four who had attended a hospital clinic in the two years before admission did not attend a hospital clinic in the two years after admission. Amongst the controls the numbers were seven starting attending after that date and ten stopping attending, a pattern consistent with a secular trend away from hospital clinic attendance.

Conversely, the proportion attending for general practice based reviews increased more amongst controls than amongst cases. Five cases started attending after admission and five cases stopped attending; nine controls started attending and only three controls stopped attending.

9.3.5 The role of glycaemic control

In order to establish the role of glycaemic control, mean HbA1 in the two year period before the admission was calculated for 60 matched cases and controls where a value was available for both. 28 cases and 20 controls had normal mean control (HbA1<8.5). 14 cases and 23 controls had poor control (HbA1>10). Control was then included in the conditional logistic regression analysis. Inclusion had little effect on the odds ratios for other variables for these 60 pairs of cases and controls: the odds ratio associated with hospital clinic visits changed from 0.22 to 0.25 and the odds ratio associated with general practice review from 0.92 to 0.76. The adjusted odds ratio associated with poor control of 0.17 (Table 9.8), although not statistically significant, suggests a reduced risk of admission in those with poor control.

Table 9.8: Crude and adjusted odds ratio for association of glycaemic control with risk of admission

Variable	Odds ratio	95% CI	p=
Crude Odds Ratio			
Normal control	1.00		
"Reasonable" control	0.85	0.33 to 2.22	0.7
"Poor" control	0.50	0.21 to 1.11	0.08
Adjusted Odds Ratio*			
"Reasonable" control	0.80	0.19 to 3.34	0.8
"Poor" control	0.17	0.03 to 1.06	0.06

* Adjusted for all variables shown in Table 9.1

9.4 Discussion

The number of non-diabetic drugs on repeat prescription was very highly correlated with increased risk of admission. This variable was used as a proxy measure of chronic morbidity, since undiagnosed or untreated conditions could not be assessed. It is possible that contact for routine diabetes review might increase the possibility of a chronic condition, such as hypertension, being diagnosed and drug treatment started. Therefore the proportion of chronic co-morbidity diagnosed and treated may be greater in those regularly reviewed. However, in the context of our study, most conditions which lead directly to hospital admission would be likely to be symptomatic and therefore (particularly since the information was collected in 1996, after admission) both diagnosed and treated.

A longer duration of diabetes was also correlated with admission risk, for both diabetes related and non-diabetes related admissions. Duration of diabetes may therefore be a "risk marker" for an individual at high risk of admission or a contributory factor, rather than the underlying cause of admission.

9.4.1 Relationship between setting of routine review and risk of admission

The initial analyses demonstrated that the relationship between routine review and admission was likely to be confounded by clinical differences between those attending diabetes outpatients, those reviewed in general practice and those reviewed in neither setting.

Confounding by severity of disease would be expected to lead to an underestimation of any "protective" effect of hospital clinic attendance. The observed relationship cannot therefore be explained by under-adjustment for confounding factors. Over-adjustment for co-morbidity must be considered, as those attending clinics are more likely to have their chronic conditions diagnosed and treated with drugs. However even the unadjusted odds ratios suggest that outpatient attendance has a "protective" effect.

The relationship may also be influenced by the selection of those with a two year "admission free window", which will differentially exclude cases and controls who are frequently admitted. The individuals with the most severe complications are likely to be attending hospital clinics and are also likely to be frequently admitted and so will have been excluded. Therefore those both attending hospital clinics and included in the analysis are likely to be from the more problem free end of the spectrum seen by the hospital clinic. The results need to be interpreted in the light of the fact that only a selected group of hospital clinic attenders (those without frequent admissions) were eligible for the analysis.

9.4.2 General practice based diabetes review and admission risk.

This analysis did not find a significant relationship between general practice based review and admission, although the confidence interval is wide (OR 0.91, 95% CI 0.41 to 1.99). Although the crude odds ratios associated with reviews in general practice and hospital clinics are similar (0.60 and 0.64), adjustment for the more severe casemix seen in hospital clinics accounts for the difference in adjusted odds ratios.

The pilot study (Chapter 4) and a preliminary regression analysis of the survivor cohort[144] suggested that any "protective" effect of general practice based reviews was limited to the subgroup without co-morbidity. The matched analysis had insufficient power to address this, as only 23 of the cases had no co-morbidity. This highlights the fact that the group without co-morbidity is small and at a low risk of admission, so a difference in relative risk in this group would make a relatively small difference to overall admission rates.

The results provide no support for the hypothesis that those patients not reviewed at all in the previous two years are a group at higher risk of admission than those seen for a routine diabetes review within the practice.

9.4.3 Out patient diabetes review and admission risk.

The main finding was that attending a hospital diabetes clinic in the previous two years was significantly related to a reduced risk of hospital admission (OR 0.30, 95% CI 0.14 to 0.65). However this relationship was not present in individuals whose practices did not provide routine diabetes reviews (OR 0.99, 95% CI 0.50 to 1.96). This suggests that the effect seen amongst those who have the choice of general practice and hospital clinics may be related to the characteristics of individuals who are referred to (or choose to attend) hospital clinics when a general practice diabetes programme is available. It may also be possible that the characteristics of patients referred to hospital clinics in non-CDM practices (for example, Indian origin or greater material deprivation), make them less able to benefit from hospital clinic attendance in terms of reduced admissions.

It appears counter-intuitive that the population of a hospital clinic, who have been shown to be more likely to be treated with insulin and to have had diabetes for longer, should be at reduced risk of admission and this relationship does become stronger after adjustment for complications and chronic morbidity.

The population included in this study were a selected group and were not randomly allocated to patterns of care. In this context, there are three plausible explanations, all of which may play a part in explaining this result: diagnostic bias, confounding by individual characteristics of those who attend hospital clinics and the direct benefits associated with attending a hospital clinic.

1. Diagnostic bias

A cohort of individuals with diagnosed diabetes includes a group whose diabetes was asymptomatic at diagnosis. Unless these individuals are diagnosed as a result of a population screening exercise (which had not been done in this population prior to our study), a contact with health services (unrelated to diabetes and often an admission or outpatient visit) must be the reason their diabetes was incidentally diagnosed. In comparison to the general population and to individuals with undiagnosed diabetes, this group will therefore, irrespective of their diabetes, be heavier users of health services, including inpatient facilities than individuals with undiagnosed diabetes.

So the explanation of a relatively low risk of admission in the hospital clinic attenders may be that this group is less prone to the diagnostic bias which inflates admission risk in the rest of the cohort.

Previous studies provide support for this suggestion. In an earlier general practice based study,[20] 27% of patients with diabetes had been diagnosed in hospital, but 54% of those

who were asymptomatic at presentation were diagnosed in hospital. So diagnosis when asymptomatic is associated with hospital use.

Given that glycaemic control was reasonable overall in our study and better than in other studies,[145] our cohort may have included a large group of such patients whose diabetes was only diagnosed because they were already users of hospital services. Evidence that good glycaemic control is related to a higher risk of admission supports the existence of diagnostic bias. The results in Table 9.8 suggest that poor control may be associated with a decreased risk of admission and the most plausible explanation for this unexpected finding is the presence of diagnostic bias. Poorly controlled diabetes is likely to be symptomatic and be diagnosed even if an individual is an infrequent user of health services. In contrast there may be a group with mild hyperglycaemia, whose diabetes is only diagnosed because of contact with hospital services for unrelated reasons. More frequent use of health services may therefore be related to a lower HbA1 at diagnosis and explain the association of lower HbA1 and higher admission risk.

Diagnostic bias as an explanation for high admission rates in those not attending hospital clinics is also supported by the Frederica Study[66] which compared admission rates in patients aged 60 to 74, both in patients with clinically diagnosed diabetes and with diabetes detected by screening. Whilst those diagnosed clinically had an admission rate more than twice that of the general population, those with screening detected diabetes had an admission rate less than half that of the general population.

If diagnostic bias can explain the apparent "protective" effect of hospital clinic visits in this population, the lack of protective effect in the two "non-CDM" practices which had higher diagnosed prevalences and a high proportion of Indian patients may due to less diagnostic bias. This possibility is supported by evidence from the Coventry Diabetes Study that the proportion of cases undiagnosed in the population aged 65 and over was lower in South Asians (45%), than in Europeans (67%).[146]

2. Patient characteristics

Diagnostic bias cannot be the only reason for the association, because it is also seen in the subgroup with insulin dependent diabetes, a group who would present with symptoms, irrespective of their previous contact with services. It may be therefore that the type of patients who attend a hospital clinic are more concerned about their diabetes, more compliant or have other psychosocial characteristics which are difficult to capture without qualitative methods, but which relate to admission risk.

Studies of outpatient referrals have examined the different perspectives of the patient, the GP and the hospital clinician.[147] The interaction between these three in the making of referral decisions can be complex and difficult to unravel. The decision to refer an individual to the diabetes clinic may be made by the GP and the decision to review or discharge may be made by the diabetologist, but both these decisions can be influenced by the attitudes and beliefs of the individual patient. The patient also has the option of not turning up for clinic appointments, if he does not believe they are worthwhile.

3. Hospital services

In a population with onset of diabetes in childhood, attending a hospital clinic on a regular basis has been shown to be related to a reduced risk of developing nephropathy in the long term.[148] Attending a hospital clinic gives an individual access to specialist physicians and also promotes access to other hospital based services including diabetes specialist nurses and dieticians. It is therefore possible that use of these services leads to improvements in management and avoids admissions in the short term. However, this is unlikely to be the only explanation, since the reduced risk of admission applies to both diabetes related and unrelated causes. Moreover an association of the same magnitude is not observed in the population who have no access to general practice based diabetes reviews.

9.4.4 Sources of potential bias and confounding

The validation of the data sources used for this study and the implications in terms of information bias are discussed in detail in Chapter 7. The implications of using an incomplete cohort which excluded individuals with undiagnosed diabetes, most individuals who had died and all who had migrated away from the study practices are discussed in Chapter 5. The effect of selecting only those with a two year admission free period is discussed in section 9.4.1. The selection of this subgroup was done to maximise the validity of the analysis. However, the overall effect of these influences on selection are that the result apply to a relatively healthy and relatively complication free group of individuals with diabetes and need to be interpreted in that light. The results cannot be applied to those with severe complications leading to frequent admissions or a high risk of death within a few years of admission.

9.4.5 Overcoming bias due to secular trends and reverse causality

The analysis was designed to overcome the possibilities of bias and reverse causality inherent in simpler analyses. A matched design overcame these two major problems inherent in the research question. Firstly it allowed for the fact that the probability of different patterns of care (particularly the chance of receiving a general practice based review) changed over time by defining the pattern of care in terms of the care received during the same "window" of two years before the admission of the case for both case and control. Secondly it overcame, to some extent, the problem represented by reverse causality, with the pattern of care being the outcome of a previous admission, by including in the risk set only those individuals who had had a diagnosis of diabetes made at least 2 years before the admission date and who had had no admissions during the two year "window" before the admission of interest. This has the effect of excluding individuals where the admission was directly linked to diagnosis or clinic attendance is the consequence of a recent admission. It will incidentally exclude many of those individuals who have frequent admissions, as they are unlikely to achieve a two year admission free period. In this group it is impossible to untangle whether review is simply a result of previous admissions rather than an independent variable. The comparison of changes in review pattern after the admission date in cases and controls suggests that cases are more likely to be seen in hospital clinics following an admission than their matched controls, whilst those not admitted were more likely to be subsequently seen in general practice for review.

An admission more than two years prior to the first eligible admission may of course still influence the pattern of care. A patient admitted to hospital may be referred for follow up to a hospital diabetes clinic and continue attending the hospital clinic for several years. If the initial problem persists and leads to further admissions, it may appear that attending the clinic has caused the second admission. As the effect of this bias would be to reduce any "protective" effect of hospital reviews, it cannot contribute to explaining the relationship observed.

9.4.6 Analysis by reason for admission

The significant risk factors for admission remain the same, whether admission related to diabetes or admission unrelated to diabetes are considered. As "diabetes related" admissions are mainly indirectly related, for example, cardiovascular disease,

respiratory infections and cerebrovascular disease, it is plausible that the same characteristics are markers of risk for all types of admissions. Factors such as duration of diabetes and not attending a hospital clinic are markers for a vulnerability to admission in general. The observation that the association is present for "non-diabetes related" admissions undermines the suggestion that the observed relationship with outpatients attendance is directly causal - unless it is accepted that diabetes outpatient visits can influence admissions for reasons unrelated to diabetes.

9.5 Limitations of the study design

Most of the problems encountered during this study were related to it being conducted retrospectively, which meant all the study data was collected after the period studied. This led to the cohort being incomplete because patients had migrated or died and to the data collected being subject to the vagaries of routine general practice records and individual patients' recall. Although it would have been both more expensive and more time-consuming, it might be possible to conduct a similar study, but collect data prospectively to eliminate many of these difficulties. The main problem then would be avoiding changes in service use due to the practices being aware that they were being studied.

Most of the problems in interpretation of the results were due to it being an observational study. This means it could only hope to describe associations between routine care and hospital admissions and identify variables which are markers for an increased risk of admission. Only randomised controlled trials can provide wholly convincing evidence for the impact of different patterns of care on admission rates. However, it would probably not be ethical to conduct an intervention study in which the control group did not have access to regular diabetes care. So, although it might appear to offer a better answer, a randomised controlled trial is unlikely to ever be possible to directly test the hypothesis addressed by our study.

9.6 Conclusions

This analysis showed that hospital clinic attendance is related to a reduced risk of hospital admission in a population with diagnosed diabetes, in practices that organised routine diabetes reviews. In contrast, general practice based review does not appear to be related to a significantly reduced risk of hospital admission. Some of this association may be explained by diagnostic bias and by the characteristics of individuals that attend

hospital clinics. The finding that the relationship is similar for diabetes related and diabetes unrelated admissions and does not apply in the group from practices with no diabetes care programmes, suggests that the explanation may lie in the characteristics of patients who attend clinics, rather than a direct effect of hospital based care. However, given the magnitude of the association observed, a causal relationship between service use and a reduced risk of admission should not be ruled out without additional evidence: ideally, a randomised controlled intervention study, comparing routine diabetes care in different settings, with sufficient power to examine this outcome.

9.7 Key points

- **Hospital admission of individuals with diabetes is associated with clinical characteristics, particularly longer duration of diabetes and number of non-diabetic drugs on repeat prescription.**
- **The relationship between setting and occurrence of diabetes review and admission is confounded by clinical factors.**
- **If clinical factors and secular trends are adjusted for, it appears that hospital clinic attendance is related to a significant reduction in the risk of admission. This could be explained in part by diagnostic bias and the characteristics of individuals who attend hospital clinics.**
- **This analysis did not demonstrate a significant association overall between general practice based review and admission.**

10. Chapter 10: Main Study - Risk factors for use of the Accident and Emergency department

10.1 Introduction

Although previous use of the emergency department has been noted to be a marker for increased risk of hospital admission[76] and several observational studies have described the frequency of visits to emergency facilities by individuals with diabetes,[81,82] the risk factors for A&E department attendance by this group appear to have been little studied. Since the situations which precipitate a visit to the A&E department are often similar to those that precipitate a hospital admission it seemed likely that the most important explanatory variables would be the same. It also seemed possible that individuals who have more regular contact with their general practitioner through routine diabetes reviews might be more likely to use primary care resources than visit the accident and emergency department, whilst individuals seen in a hospital diabetes clinic might be more likely to choose to visit the hospital accident and emergency department. This was therefore an exploratory study to identify risk factors for A&E department attendance.

10.2 Methodology

Information on A&E department attendance was available from three different sources, all of which were known to be incomplete (for discussion see Chapter 7). Information from GP notes was available for the entire cohort, while information from questionnaires was available for 80% of the cohort and from A&E records for 64% of the cohort. The outcome of interest for the main analysis was therefore defined as a documented attendance at the A&E department between 1991 and 1995 (whether identified from general practice or A&E records or a response that an individual had visited a casualty department in the previous five years (data collected in 1996). This approach was used to minimise misclassification in the main analysis in which risk factors for having visited the A&E department (for any reason) during the period for which admissions data was available (1991-1995) were examined.

A logistic regression model was used to establish which factors were related to having visited A&E for individuals from the five practices providing diabetes reviews and the results compared to the model for risk of admission in this group.

Two additional analyses were done: the main analysis was repeated for the subgroup of patients for which data was available from all three sources and risk factors for the three

types of visit (diabetes related, other medical illnesses and injuries) were examined using the data on attendance by cause from A&E department records .

10.3 Results

Using the three data sources, 449 out of the survivor cohort of 1094 (41%) had an attendance at an A&E department between 1991 and 1995.

The potential risk factors for attendance considered are given in Table 10.1. The clinical variables which are significantly related to A&E use are duration of diabetes and diabetes treatment type. Having been seen in diabetes outpatients and having been admitted are also strongly related to A&E attendance. Being a house owner is related to a significantly reduced risk of A&E use. Results are similar when the subset of individuals for which data from all three sources is available is analysed separately to assess the possible impact of information bias due to combining of different sources.

From the information from the A&E department database, every visit was classified, from the reason given for attendance by the attending doctor on the computerised record, as due to diabetes, to other medical illness or to injury. In this analysis, younger age is related to an increased risk of attendance for all causes and longer duration of diabetes is related to an increased risk of admission for all causes except injuries. The relative risk associated with other variables are shown in Table 10.2. Type of diabetes treatment remains significantly associated with all types of visit. Diabetic outpatient visits, hospital admission and house ownership are associated with medical and diabetes related visits, but not with injury related visits. Non-diabetic drugs on repeat prescription is a significant risk factor only for medical illness related visits. GP reviews were not associated with A&E use in these univariate analyses.

Table 10.1: A&E attendance by demographic, clinical and service use variables

	Seen in A&E		Not seen in A&E		
	median	Interquartile range	median	Interquartile range	Mann-Whitney U
Age/yrs	63.5	55.0 to 73.1	64.0	54.4 to 73.1	p=0.9
Duration of diabetes/yrs	9.0	3.7 to 16.0	7.0	3.2 to 12.0	p=0.0005
	Proportion	%	Proportion	%	chi^2
Sex: % male	242/449	54	348/645	54	p=1.0
Treatment:					
Insulin	162/449	36	153/645	24	
Tablets	219/449	49	352/645	55	
Diet	68/449	15	140/645	22	p=0.00002
Drugs on repeat prescription	378/449	84	526/645	82	p=0.3
Had a GP review	108/449	24	143/645	22	p=0.5
Seen in outpatients	225/449	50	258/645	40	p=0.01
Admitted to hospital	331/449	74	265/645	41	p<0.00001
Living alone	95/383	25	107/517	21	p=0.2
Ethnic origin:					
White	184/374	49	262/512	51	
Indian	162/374	43	220/512	43	
Other	28/374	7	30/512	6	p=0.6
Car access	181/375	48	275/509	54	p=0.1
House owner	234/375	62	364/507	72	p=0.003
Smoker	53/381	14	80/515	16	p=0.5

Table 10.2: Relative risk of A&E attendance by reason for attendance

	Diabetes related		Medical illness		Injury or accident	
	Relative risk	chi^2: p=	Relative risk	chi^2: p=	Relative risk	chi^2: p=
Male sex	0.93	0.6	1.12	0.2	0.93	0.3
Treatment: Insulin	3.09		1.52		1.44	
Tablets	0.38		0.86		0.89	
Diet	0	<0.001	0.74	0.002	0.77	<0.001
Drugs on repeat prescription	0.88	0.2	1.13	0.02	1.02	0.7
Had a GP review	0.79	0.3	0.89	0.3	1.09	0.4
Seen in outpatients	1.87	<0.001	1.20	0.04	1.17	0.07
Admitted to hospital	1.33	0.03	1.49	<0.001	1.02	0.8
Living alone	0.95	0.9	1.06	0.7	0.87	0.3
Ethnic origin						
White	1.02		0.95		1.02	
Indian	1.33		1.56		1.03	
Other	0.30	0.3	0.64	0.05	0.82	0.8
Car access	0.91	0.6	1.04	0.6	1.05	0.5
House owner	0.90	0.4	0.81	0.01	0.96	0.5
Smoker	0.50	0.2	1.02	0.9	1.03	0.9

In the multivariate logistic regression analysis, the outcome was defined as use of A&E identified from any of the three data sources and only individuals who survived until 1996 from the practices which provide routine diabetes reviews are included (n=554). The explanatory variables included were identical to those included in the model for risk of admission (Chapter 9): age and sex, general practice, duration of diabetes and type of treatment, number of drugs on repeat prescription (to adjust for severity and co-morbidity respectively) and setting of diabetes care. The odds ratios derived from this model are shown in Table 10.3. Only insulin treatment, an increasing number of drugs on repeat prescription and routine review in general practice are significantly related to an increased risk of A&E attendance. Younger age and increasing duration of diabetes were associated with odds of attendance greater than one, but these associations were not statistically significant.

Table 10.3: Adjusted odds ratio for association with risk of A&E attendance

Variable	Odds ratio	95% CI	
Age/years	0.89	0.74 to 1.06	
Duration of diabetes/years	1.22	0.99 to 1.49	p = 0.06
Number of non-diabetic drugs	1.26	1.15 to 1.37	p < 0.0001
Treatment type:			
Treatment with insulin*	2.37	1.18 to 4.73	p = 0.01
Treatment with tablets only*	1.41	0.85 to 2.33	
Routine care over five years:			
Review in general practice only**	1.73	1.01 to 2.98	p=0.05
Outpatient visits only**	1.21	0.65 to 2.23	
Both GP review and outpatients**	1.59	0.78 to 3.26	

* Reference category is diet treated diabetes

** Reference category is no routine reviews in general practice or outpatient visits

10.4 Discussion

The descriptive analyses show that the clinical variables significantly related to A&E attendance are duration of diabetes and diabetes treatment. Home ownership is related to a decreased risk of attendance. However car ownership (which might affect access to A&E) and smoking habit (which might be related to morbidity) were not significantly related to risk of attendance. It may be that differences in social or material circumstances which influence A&E use generally, are outweighed by clinical factors in a population with diabetes. A&E attendance is closely related to hospital admission. The most plausible explanation for this is that the two outcomes share the same predictors and may be part of the same process: an individual who attends A&E with his medical problem then has a chance of being admitted for the same problem.

This suggestion is supported by the multivariate model, in which the main risk factors for A&E attendance are similar to the main risk factors for admission: namely duration of diabetes and number of non-diabetic drugs on repeat prescription. Whilst routine care in any setting is associated with an odds ratio greater than one, only for general practice review does it reach statistical significance. Thus, while hospital clinic attendance is related to a reduced risk of admission in a subgroup of the population (Chapter 9), routine review in general practice is associated with an increased risk of attending A&E. There is therefore no support for the original hypothesis that attendance

for routine diabetes care in general practice could be related to a reduced risk of A&E attendance.

10.5 Key points

- **In a multivariate model, A&E use by an individual is associated with duration of diabetes, treatment with insulin, the number of non-diabetes related drugs on repeat prescription and attending for general practice based diabetes review.**
- **This study provides no support for the hypothesis that individuals with diabetes who attend their general practices for routine reviews are less likely to use A&E facilities, or that individuals with diabetes who attend hospital diabetes outpatient clinics are more likely to use A&E facilities, after adjusting for confounders.**

11. Chapter 11: Main Study - Comparative use of Accident & Emergency facilities by individuals with diabetes

11.1 Introduction

A review of the published literature revealed that there was little information on how the pattern of use of the accident and emergency (A&E) department differed between the diabetic population and others. A previous study in East Anglia[81] had raised the intriguing possibility that despite being heavy users of other services and bearing a heavy burden of excess morbidity, individuals with diabetes seemed not to use A&E facilities any more than the general population. Therefore the data collection was extended to include a matched cohort of non-diabetic individuals for a study which could compare the pattern of use by the cohort with diabetes with a matched cohort of the general population.

The pilot study highlighted the problem of collecting accurate data retrospectively on visits to the accident and emergency (A&E) department. Neither general practice notes nor patient questionnaires could contributed sufficiently complete or detailed data. The possibilities of using the data collected in the A&E department was therefore explored and a pilot search suggested that this was a more complete source. The comparative analysis is therefore based on information from the A&E department database.

The aim of the present study was to compare the frequency and pattern of use of an inner-city accident and emergency department by a cohort of individuals with diabetes with a matched nondiabetic cohort. We sought to answer the questions: do individuals with diabetes have a different pattern of A&E use and, if so, what are the likely explanations for any observed differences? Our initial hypothesis was that the diabetic cohort would have a higher threshold for attendance, and therefore fewer attendances, for problems unrelated to diabetes.

11.2 Methods

The seven practices involved in the admissions study all agreed to be involved in this additional study. All practices were in the catchment area of the Leicester Royal Infirmary NHS Trust, which is the only A&E department in the city. One practice was excluded because it did not have an up to date computerised age-sex register for matching. From the remaining six practices 696 individuals, all over the age of 16 when the cohort was identified in 1996, all currently registered with the practice and all receiving repeat prescriptions for insulin, oral hypoglycamics or diabetes testing

equipment were identified. Each individual was matched with the non-diabetic patient closest in age and of the same sex from the same practice. For each individual date of birth, sex, postcode and medication on repeat prescriptions were recorded. Postcodes were linked to wards, using a computerised postcode directory, in order to calculate Townsend scores using 1991 census data. The Townsend score is an indicator of material deprivation which combines four variables: unemployment, car ownership, house ownership and overcrowding.[129] Since previous work has shown that A&E use is related to age, sex, deprivation, registration with a GP[149] and distance from the department,[150] the matching was designed to achieve similarity in all these characteristics to reduce the possibility that differences would be due to confounding by these variables.

Records of all A&E visits from November 1984 to June 1996 were extracted by manual searches on the A&E computerised database which has been in use for recording all new registrations (which will not include follow up or clinic visits) since November 1984. To minimise the chance of information bias, the data extractor was blind to the diabetic status of individuals and a standardised search procedure was employed. Every visit was classified, from the reason given for attendance by the attending doctor on the computerised record, as due to diabetes, to other medical illness or to injury. Self-harm was classified as injury because there was insufficient clinical information to confidently distinguish accidental injury from self-harm. This classification was done independently by two doctors (using previously agreed criteria) who achieved 100% agreement. Information on whether the patient had been referred by a GP or had arrived via the "999" emergency ambulance service and whether the patient was admitted to hospital was recorded.

The number of visits by individuals for different causes and admission rates were calculated. The proportions of visits arising from general practitioner referral, from a 999 call and resulting in hospital admission were compared, using the sign test, for all three categories of visit described above. For these comparisons only those pairs where both individuals had had at least one visit to the department could be included.

The data were analysed using SPSS for Windows[128] and all significance tests were based on a matched analysis.

11.3 Results

Each cohort of 696 individuals included 368 men (53%). The mean age of both cohorts at the start of the period studied was 53.0 years. The mean age difference between

matched pairs was only 19 days. The matching on general practice resulted in the distribution of postcode areas (and therefore distance from the A&E department) being similar for the two cohorts. Median Townsend scores were 0.7 and 0.3 for the diabetic and nondiabetic cohorts respectively (sign test: p=0.04). The range of scores was from -5.3 (least deprived) to 10.9 (most deprived).

The proportion of individuals with repeat drug prescriptions, after excluding diabetes related drugs, are compared in Table 11.1. The proportion of individuals receiving any drugs, and also cardiovascular and analgesic drugs, was higher in the diabetic cohort.

Table 11.1: Number of individuals receiving repeat prescriptions (excluding diabetes related medications)

	Diabetic cohort (n=696)	**Non-diabetic cohort (n=696)**	McNemar test
Any repeat prescriptions	504 (72%)	369 (53%)	p<0.001
Cardiovascular drugs	347 (50%)	208 (30%)	p<0.001
Analgesics	220 (32%)	148 (21%)	p<0.001

11.3.1 A&E attendances

There were 1002 visits recorded for the diabetic cohort and 706 for the comparison cohort. 45 members of the diabetic cohort made 121 visits for diabetes related conditions and these are summarised in Table 11.2.

Table 11.2: Diabetes related visits to A&E

	Number of visits
Hypoglycaemia	52
Hyperglycaemia/ketoacidosis	2
Diabetic collapse/coma	7
Diabetes other/not specified	60
Total	121

The numbers of visits, over the 12 year period, by individual patients are shown in Table 11.3. The Wilcoxon signed rank test compares the number of visits for each matched pair and tests the hypothesis that the pattern of visit frequency is the same for both cohorts. Overall the proportion who had ever attended the A&E was also significantly higher for the diabetic cohort (McNemar's test: p=0.0007). The number of

visits for medical illness excluding diabetes was significantly higher in the diabetic group. The number of attendances for injuries was similar in the two groups.

Table 11.3 : Number of visits by individuals between November 1984 and June 1996

Type of visit		Diabetic cohort (n=696)	Non-diabetic cohort (n=696)	Wilcoxon signed rank test
diabetes	0	651(94%)	-	
related	1	29(4%)	-	
	2-10	13(2%)	-	
	>10	3(0.4%)	-	
other	0	505(73%)	574(82%)	
medical	1	130(19%)	89(13%)	
	2-10	56(8%)	31(4%)	
	>10	5(1%)	2(0.3%)	p=0.0001
injuries	0	425 (61%)	433 (62%)	
	1	157 (23%)	163 (23%)	
	2-10	111 (16%)	98(14%)	
	>10	3 (0.3%)	2 (0.3%)	p=0.3
total visits	0	322 (46%)	385 (55%)	
	1	180 (26%)	165 (24%)	
	2-10	186 (27%)	143 (21%)	
	>10	8 (1%)	3 (0%)	p=0.0001

Table 11.4 shows the attendance rates for the two cohorts and shows that for both cohorts the commonest reason for attendance was injury.

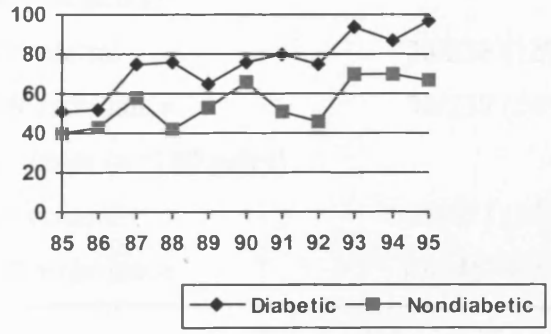
Table 11.4: Attendance rates for diabetic and non-diabetic cohorts

	Diabetic cohort		Non-diabetic cohort	
Reason for visit	rate per 100 per year	95% CI	rate per 100 per year	95% CI
diabetes related	1.49	1.25 to 1.78	-	-
other medical	4.40	3.96 to 4.88	2.84	2.50 to 3.24
injuries	6.45	5.92 to 7.03	5.84	5.33 to 6.39
total visits	12.34	11.60 to 13.13	8.69	8.08 to 9.36

11.3.2 Time trends

Trends in the number of visits recorded between 1985 and 1995 are shown in Graph 11.1. The rate ratio for attendance by the diabetic cohort relative to the non-diabetic cohort did not change significantly between the first and second half of the period studied. The average rate ratio for attendance by those with diabetes was 1.42 (95%CI: 1.30-1.56).

Graph 11.1: Number of visits annually 1985-1995



11.3.3 Source and outcome of attendances

Only the first 10 visits to the department by any one individual were included to avoid the proportions calculated being dominated by the few more frequent attenders, when the total number of visits were small. Similar results to those shown are obtained for the sign tests when recalculated to include all visits and the conclusions are unchanged.

The source of attenders (proportion of individuals who had been referred by a GP and proportion who arrived by "999" ambulance) and outcome (proportion who were admitted) are shown in Tables 11.5 and 11.6. Only matched pairs for which both members had at least one visit are included in this analysis and the denominator is the total number of visits recorded for these pairs.

Individuals with diabetes were no more likely to have been referred to A&E by a GP or to be admitted from A&E. They were more likely to have used a 999 ambulance. If visits for injuries only are analysed, it is more likely that an individual with diabetes will have used an ambulance, whilst for medical visits no significant difference was found.

Table 11.5: Source for A&E visits by reason for visit

	Diabetic cohort Proportion of visits (%)	**Non-diabetic cohort Proportion of visits (%)**	**Sign Test**
Diabetes related visits (n=82 individuals)			
GP referral	5/82 (6%)	-	
999 ambulance	69/82 (84%)	-	
Non-diabetes medical visits only (n=38 pairs)			
GP referral	14/68 (21%)	13/64 (20%)	p=0.6
999 ambulance	29/68 (43%)	34/64 (53%)	p=0.5
Injury related visits only (n=121 pairs)			
GP referral	28/238 (12%)	29/224 (13%)	p=0.5
999 ambulance	58/238 (24%)	34/224 (15%)	p=0.05
All visits (n=180 pairs)			
GP referral	65/457 (14%)	65/399 (16%)	p=1
999 ambulance	164/457 (36%)	103/399 (26%)	p=0.02

Table 11.6: Proportion of individuals admitted by reason for visit

	Diabetic cohort Proportion admitted	**Non-diabetic cohort Proportion admitted**	**Sign Test**
Diabetes related visits	24/82 (29%)	-	
Medical visits	32/68 (47%)	29/64 (45%)	p=0.6
Injury related visits	9/238 (4%)	11/224 (5%)	p=1
All visits	93/457 (20%)	67/399 (17%)	p=0.07

11.4 Discussion

We found that individuals with diabetes were more likely to visit the A&E department, and attended more often than their matched controls. The magnitude of the difference was very similar to the relative risk of 1.4 reported by a Swedish study.[83] Where differences are found in the pattern of A&E use, there are four possible types of explanation for such differences. First the difference may be a spurious finding due to biases in the data collected. Secondly, a real difference may be due not to the presence of diabetes but to confounding by a variable associated with both diabetes and A&E department use. Finally if the difference in service use is really due to diabetes, it may reflect either a difference in incidence of health problems or a difference in response to such problems.

11.4.1 Potential sources of bias

Studies relying on A&E records may fail to identify diabetes in those with a presenting problem unrelated to diabetes and underestimate overall use by this group. The cohort design eliminated this, but some misclassification will occur due to identification of the cohorts being retrospective. Comparison of the first and second halves of the study period suggests that change within the cohorts has not influenced the study conclusions significantly.

A degree of under-identification of attendances due to changes or mistakes in recorded names, addresses and birth dates is inevitable. However there is no reason to suggest this source of bias would differ between the two cohorts and so it would not influence relative differences between the cohorts.

11.4.2 Potential confounders

The design of this study allowed for matching of several of the known potential confounders. Confounding by registration with a GP was controlled for by restricting the study to individuals registered with GPs. It was assumed that matching on general practice would to some extent match for material and geographical circumstances. Although matched on general practice, individuals with diabetes lived in statistically significantly more deprived postcodes. This is consistent with the observed association

of non-insulin dependent diabetes and deprivation.[89] If the analysis is limited to those pairs for which the diabetic individual was assigned to a Townsend score equal to or less than that of their matched pair (316 pairs), similar differences in visit frequency still are observed, so confounding by deprivation does not explain the differences.

11.4.3 Explanations for the differences observed

The significant difference in attendance for medical problems reflects an increased incidence of medical problems (particularly ischaemic heart disease) in the diabetic population. The greater underlying chronic morbidity is confirmed by the greater number of drugs on repeat prescription in this cohort. The pattern of attendance for injuries is not influenced by a diagnosis of diabetes, being very similar in the two cohorts. The proportion of visits arising from a GP referral and the proportion resulting in admission are similar, suggesting the casemix of conditions presented is similar.

It must be realised that an increase in A&E use by a population with diagnosed diabetes may in part (like the relative increase in admissions in individuals with diabetes who do not attend hospital clinics discussed in Chapter 9), be due to diabetes being diagnosed sooner in regular users of health services. It is not possible therefore to extrapolate from the A&E use by individuals with diagnosed diabetes to predict use by individuals with undiagnosed diabetes.

Our findings do not support the hypothesis that this population, which will make heavy use of other health services, has a different threshold for A&E attendance. Diabetic individuals are more likely to arrive in A&E as a result of a "999" ambulance call. This difference is also present when the reason for attendance is an injury and may reflect the fact that individuals with diabetes, or those around them, are more ready to call an ambulance.

11.5 Conclusions

In an urban population, the use of an A&E department was greater by those with diabetes, both for diabetes and other medical reasons but not for injuries. It is likely that these differences in service use are due to differences in morbidity.

One reason for a population with diagnosed diabetes having greater service use (as discussed at length in Chapter 9) is diagnostic bias. This may explain in part both the increased co-morbidity (as reflected in the number of drugs on repeat prescription) and the increased use of health services (as reflected in the increased use of A&E).

This study provides no evidence that A&E use by individuals with diabetes is significantly more or less "appropriate" than that of the population registered with GPs as a whole, despite more frequent contact with their GPs. Further evidence might come either from a population based study of the management of injuries and medical emergencies in the community or from more qualitative studies of the way the experience of chronic disease influences use of emergency services.

11.6 Key points

- **In an urban population, the use of an A&E department was greater by those with diagnosed diabetes, both for diabetes and other medical reasons but not for injuries.**
- **It is likely that these differences in service use are due to differences in morbidity, which may partly be the result of diagnostic bias.**
- **This study provides no evidence that A&E use by individuals with diabetes is significantly more or less "appropriate" than that of the population registered with GPs as a whole, despite more frequent contact with their GPs.**

12. Chapter 12: Implications for health policy and future research

12.1 Introduction

The collection and analysis of detailed information on the health service use of a cohort of individuals with diabetes, despite its limitations, yields a number of insights and challenges some current assumptions about diabetes care. The study has provided a detailed description of a cohort of individuals with diabetes in the UK, including their demographic and social characteristics, clinical characteristics, and use of health services. The UK general practice record, since it is essentially composed of contemporary records of all health service contacts, offers a unique opportunity to study service use and clinical characteristics retrospectively in a well defined population.

12.2 Insights from descriptive analysis

Even within the survivor cohort, the prevalence of treated co-morbidity was high (73%), with 50% on drugs for chronic cardiovascular disease. This provides an explanation for the high proportion of admissions which were only indirectly related to the diagnosis of diabetes. Although overall control was better than in some other studied populations,[145] 42% of those diagnosed before 1990 had poor mean control over a six year period. Although the proportion seen annually in general practice doubled, from 8% in 1990 to 17% in 1995, there was still a sizeable minority (35% of those diagnosed before 1990) who did not have a documented review in general practice or attend a hospital clinic at all over a six year period.

We found that individuals who did attend hospital clinics or for routine reviews in general practice differ systematically from individuals who did not. Many studies of service use investigate subgroups of the diabetic population (for example, hospital inpatients,[151] clinic populations,[75] institutionalised populations).[152] Although it may be difficult to identify individuals with diabetes who are not in regular contact with services, it is worth studying the characteristics of these individuals. It may not be possible to directly extrapolate findings in populations who are already in contact with services to individuals who are not currently in contact with services, who will have different social and clinical characteristics.

We found major differences between practices, particularly in prevalence of diabetes and diabetes care provision. It may not be possible to interpret associations at the level

of general practice, such as the association observed between facilities for diabetes care and admission rates,[110] because of the many systematic differences that exist between practices in terms of factors such as practice staffing and facilities, diabetes prevalence and casemix, material deprivation, ethnicity and patient expectations.

It is important to bear in mind that although our study is based on a population cohort, the results discussed below do refer to analyses in a selected group of individuals who did not have very frequent hospital admissions.

12.3 Insights into the relationship between diabetes, diagnosed diabetes, co-morbidity and hospital use.

We found that, after adjusting for demographic and clinical differences, individuals who have attended a hospital clinic in the previous two years, have a reduced risk of admission, in comparison to those who have had no routine care. This finding applies to a specific subgroup of patients: those who attend practices which have organised diabetes care programmes, who have had at least two years since diagnosis and two years without a hospital admission and few of whom have died or migrated since their admission. This is likely to be a relatively fit subgroup of clinic attenders, particularly because it excludes those with frequent admissions and it is possible that this striking finding may, at least in part, be due to diagnostic bias (discussed in Chapter 9). The presence of significant diagnostic bias has at least two important implications.

Firstly, this source of bias will influence estimates of co-morbidity in a population with diabetes.[153] The presence of another condition will increase the chance that a diagnosis of diabetes is made either opportunistically (for example, from glycosuria on routine urinalysis) or because diabetes has a recognised association with the co-morbid condition (for example, cardiovascular disease or endocrine disorders).

Secondly, there are implications for studies which link diagnosed diabetes to service use in order to estimate diabetes related hospital use. The matched study of A&E use (Chapter 11) demonstrated that a population with diagnosed diabetes have a greater burden of co-morbidity than a matched non-diabetic population. If presence of co-morbidity and health service use increases the likelihood that diabetes is diagnosed, use of diagnosed diabetes to estimate hospital use due to diabetes could result in an over estimate of the impact of diabetes. Only a study of hospital use by a screened population would be able to accurately assess the proportion of admissions due either to diabetes or to conditions truly associated with diabetes.

12.4 Implications for strategies to reduce use of A&E departments and hospital admission rates

Attending for at least one general practice based review was associated with an increased chance of having visited the A&E department, while we found no significant association between hospital clinic visits and use of the department. This suggests that increased preventative primary care activity may not lead to reduced use of A&E services. We also found no significant association between general practice based reviews and admissions. A major impact of increased diabetes review in general practice in reducing admission rates or use of the A&E department, in the short-term at least, is unlikely. This is not surprising, since the vast majority of visits to A&E and admissions in this population are not directly related to diabetes. Although the population is one at high risk of admission, the risk is often present before the diagnosis of diabetes is made and is related to co-morbidity such as cardiovascular disease which is unlikely to have its prognosis significantly altered by general practice based surveillance, without intensive interventions.[154,155]

In contrast, for hospital clinic attendance there was a significant association with reduced admission risk. If the association is due to individual characteristics of clinic attenders, outpatient attenders would maintain their relatively low risk of admission if they were discharged from the clinic. However, it is possible that a proportion of their lower risk could be causally associated with use of hospital services. Policies which encourage a shift to general practice based review, should therefore be considered in the light of these findings. Improved access to routine diabetes care in general practice should not be at the expense of poorer access to the resources of the hospital clinic or diabetes centre. It would be worthwhile ensuring that access to specialist facilities for those who might benefit from such access, including access to specialist nurses and dieticians, is not adversely affected by such policies. Equally, it should not be assumed, particularly in the short term, that increasing surveillance in general practice will reduce admission rates or A&E department visits.

12.5 Assumptions challenged

12.5.1 Assumption 1: A major risk factor for admission in a cohort with diagnosed diabetes is the level of glycaemic control

Only 5% of admissions in the cohort were directly related to diabetes control and the vast majority of admissions were related to associated chronic medical problems. Although measuring treated co-morbidity will lead to overestimation of relative co-morbidity in individuals with diabetes (because other conditions are more likely to be recognised and treated in an individual who already has one chronic disorder), the absolute level of co-morbidity is undeniably high. For this reason, in our cohort the main risk factor associated with admission was the number of non-diabetes drugs on repeat prescription. Duration and treatment of diabetes may be related to admission risk through their association with a greater chance of complications, however good current glycaemic control appears not to be related to a reduced risk of admission. Once complications or chronic co-morbidity is established, it is effectively too late for improved control to have much impact on overall admission rates.

The finding that poor control was apparently related to a reduced risk of admission in the matched analysis may well be explained by the presence of diagnostic bias in this group of individuals and by the exclusion of individuals with a high frequency of admission.

12.5.2 Assumption 2: Scope to reduce admission rates by increasing routine surveillance is greatest in high risk groups

Cohort and case-control studies of admission risk have mainly focused on identifying individual clinical characteristics associated with an increased risk of admission.[75,76] This has been justified by the assumption that high risk individuals can then be effectively targeted with interventions which will reduce admissions.[156] However trials of interventions which increase surveillance of high risk individuals have been disappointing,[28] and have actually been found to increase readmission rates in the intervention group in one study.[29]

Our study suggests that such "high-risk" individuals are likely to already have established chronic co-morbidity and so it may not be easy to avert their admission. The pilot study finding that admission risk was only related to routine review in the subgroup without co-morbidity supports a suggestion that, if routine reviews can make a

difference, it is unlikely to be in the high risk group with co-morbidity. An early preliminary analysis of the main study data set, which did not consider the relationship in time between routine care and admission, also supported this contention.[144] Interventions involving better access to routine surveillance may actually be more effective if targeted towards those who do not yet have chronic co-morbidity or diabetic complications, particularly individuals who are not already in regular contact with health services.

12.5.3 Assumption 3: Increasing diabetes care activity in primary care will reduce the workload of the hospital diabetes services

Our analysis of secular trends confirms that there has been a significant increase in activity in general practice with an increasing number of new cases being diagnosed and an increase in the number and proportion of patients with diabetes being reviewed within general practice. However there has been no concomitant fall in the numbers being seen in hospital diabetes clinics, since general practice is often reviewing patients who otherwise would not be seen at all.

The introduction of new services, even if they are intended to "shift" activity away from more expensive facilities, invariably seem to result in increased activity overall. Other recent examples include the introduction of minor injury units[157] and general practice minor surgery.[158] There seems to be much more potential for meeting new demand (which arises from previously unmet "need") than for any shifting of care from secondary to primary care. In the case of diabetes this is particularly likely because of the high level of unmet need in terms of undiagnosed cases and individuals not receiving regular comprehensive reviews. Increasing activity in general practice is probably resulting in more cases being diagnosed and more complications being detected. As has been argued by those in the hospital sector, increases in primary care activity may increase, rather than decrease, the need for properly resourced hospital services.[27]

We conclude from our study results that there is still plenty of scope for increasing activity in general practice to provide annual reviews for all, but it seems unlikely that this can be funded in the short term by shifting resources from secondary care.

12.6 Implications for purchasers of diabetes services

Hospital admission is only one possible outcome of a routine diabetes care programme which merits examination. Policy should ideally be based on knowledge of all

significant outcomes, including quality of life and patient satisfaction measures as well as morbidity and mortality.[6] However, hospital admission has been highlighted as an important outcome of diabetes care because it has large opportunity costs and because the development of health services in the primary care sector needs to take into account the likely impact on other health service providers.

There has been discussion of the possibility of "shifting" resources to support general practices' increasing activity in chronic disease management and it has been pointed out that there is a lack of research evidence for this increasing activity.[159] Our study suggests that it will be even harder to find any evidence for decreasing activity in terms of hospital admissions or hospital clinic workloads, to justify moving resources away from secondary care. Purchasers need to critically examine the expected long and short term impacts of policy changes. There is no doubt that there is room for improvement in the provision of routine care for diabetes. Decisions about the best way to provide such care need to be informed by the audit of a range of service outcomes, rather than assumptions about the merits of increasing activity within the general practice setting.

12.7 Scope for further research

Our study attempted to quantify the relationship between routine diabetes care and hospital admission at the level of the individual patient. It has shown that in a selected group of individuals, after adjusting for the severity of diabetes and for co-morbidity, hospital clinic visits are associated with a significantly reduced risk of admission, whilst general practice reviews are not associated with a reduced risk of admission of the same magnitude. We were able to look retrospectively at admission rates over a five year period and further, prospective, follow up of the cohort is possible. It may be feasible to continue to follow up this cohort by using record linkage to study their future pattern of hospital use and mortality and ethical approval to do so will be sought.

The study was too small to look in detail at specific types of admission. It also relied on the main diagnosis given on a hospital discharge letter to establish the cause of admission. Since the risk factors for admission and the relationship with routine review may vary with the cause of admission, prospective studies, which could collect more precise and verifiable information about the clinical reasons for admission, could further unravel these differences.

The pattern of diabetes care of an individual is influenced by a complex web of personal and organisational characteristics which influence whether an individual is seen in a hospital clinic and whether reviewed in general practice. Research in the field of

outpatient referrals has not only included studies which quantified variations in referral patterns and suggested explanations,[160] but also qualitative exploration of the roles, attitudes and beliefs and interactions of general practitioners, hospital doctors and patients.[147] Similar exploration of factors influencing patterns of care could be developed in the field of diabetes, where ideally structured programmes integrate primary and secondary resources in ways which are responsive to patients' needs. There is therefore much scope for qualitative studies in diabetes care to unravel these relationships.

Our study suggests that increased primary care activity cannot be justified by a resultant decrease in hospital activity. A cost-effectiveness study, which includes possible effects on admission rates as well as other relevant outcomes, is needed to compare different patterns of diabetes care. These outcomes should include patient satisfaction with care as well as quality of life, morbidity and mortality. Since it seems unlikely that putting more resources into general practice based diabetes care will have much impact on reducing overall hospital admission rates or in reducing the activity of outpatient clinics, evidence in terms of benefits for patients are needed to justify the opportunity costs.

12.8 Conclusion

This study represents an attempt to predict the impact of changes in routine diabetes care provision. In general, the impact of changes in provision of health services is difficult to predict and often the impact is different from that intended. The assumption that better preventive care in general practice can reduce demand for hospital care may be just as naive as the hope, expressed at the inception of the NHS, that the introduction of a service with universal access would eventually lead to a reduction in demand for health care. There remains unlimited scope for increasing activity and providing better services. This study suggests that we should be cautious in assuming that encouraging the provision of diabetes care programmes in general practice will be keeping patients out of hospital, particularly in the short term.

Appendices

13. Appendix 1: Pilot Data Forms and Questionnaires

13.1 Pilot form for general practice records data

Demographic Data:

Patient Code No:_ _ _ _ GP code No _ _ _

1.Surname..... 2. First name.....

3. Address.....

4. Postcode..... 5. NHS no: .....

6.Date of birth:_ _/ _ _/ _ _ _ _ 7. Sex M _ F_

8. Hospital nos:.....

.....

.....

Prescribing data:

9.Diabetes treatment: Insulin ❑$_1$ Oral hypoglycaemics ❑$_2$ Both ❑$_3$

Neither ❑$_4$

Testing supplies: Blood testing ❑$_5$ Urine testing ❑$_6$

10.No. of other drugs on repeat: CVS __ CNS __ Ophthalmic__ Other__

Service Use in past 4 years (from GP notes):

No. visits GP diabetes clinic/routine diabetes appt _ _

Total other GP attendances or home visits _ _ _ _

Hospital Visits (from GP notes):

Diabetes out-patients _ _ _

Other out-patients _ _ _ Reasons.....

In-patient :Dates..... - ..... Diagnosis.....

" ..... - ..... " .....

" ..... - ..... " .....

" ..... - ..... " .....

Clinical details:

Date of diagnosis _ _/_ _/_ _ Date started on insulin (if applicable) _ _ / _ _ /_ _

Wt..... Ht.....BMI.....

HbA1c (most recent).....Date.....

Lipids: Normal ❑$_1$ Abnormal ❑$_2$ Not recorded ❑$_0$

Date (when first diagnosed) _ _/_ _/ _ _

Proteinuria: No ❑$_1$ Yes ❑$_2$ Not recorded ❑$_0$

Date (when first diagnosed) _ _/_ _/ _ _

Creatinine:Normal ❑$_1$ Abnormal ❑$_2$ Not recorded ❑$_0$

Date (when first diagnosed) _ _/_ _/ _ _

Hypertension: No ❑$_1$ Yes ❑$_2$ Not recorded ❑$_0$

Date (when first diagnosed) _ _/_ _/ _ _

Foot pulses Present ❑$_1$ Absent ❑$_2$ Not recorded ❑$_0$

Date (when first diagnosed) _ _/_ _/ _ _

Fundi: Normal ❑$_1$ Abnormal ❑$_2$ Not recorded ❑$_0$

Date (when first diagnosed) _ _/_ _/ _ _

Other medical problems.....

Dates (when first diagnosed) _ _/_ _/ _ _

Information from hospital sources:

Hospital admission recorded by hospital:

1. Dates.....Diagnosis.....
2. " ..... " .....
3. " ..... " .....
4. " ..... " .....

Contact with Diabetes Specialist Nurses in last 4 years Yes ❑$_1$ No ❑$_0$

Whether patient questionnaire returned Yes ☐$_1$ No ❑$_0$

13.2 Pilot postal questionnaire

Questionnaire No: Date:

We are interested in your experience of diabetes care and any treatment you have had recently. Please tick one box for each question you answer. Please return the questionnaire as soon as possible in the stamped addressed envelope provided.

About diabetes:

1.Do you have diabetes? Yes ❑ No ❑$_0$

If yes, how long have you had diabetes for?
- Less than 1 year ❑$_1$
- Between 1 and 5 years ❑$_2$
- Between 5 and 10 years ❑$_3$
- More than 10 years ❑$_4$

2.Are you on any treatment for diabetes? Yes ❑ No ❑$_0$

If yes, what treatment are you on?
- Insulin ❑$_1$
- Tablets ❑$_2$
- Diet ❑$_3$
- Other (please specify)

.....

About your contact with health services

3.Have you ever seen your GP about diabetes? Yes ❑$_1$ No ❑$_0$

4.Do you see your GP regularly for diabetes checks? Yes ❑$_1$ No ❑$_0$

If yes, how often do you see him/her?
- Less than once a year ❑$_1$
- Once a year ❑$_2$
- Every 6 months ❑$_3$
- More often than every 6 months ❑$_4$
- Don't know ❑$_5$

5.Have you ever attended a hospital diabetes clinic? Yes ❑$_1$ No ❑$_0$

6.Do you go to a hospital diabetes clinic regularly? Yes ❑$_1$ No ❑$_0$

If yes, how often do you attend?
- Less than once a year ❑$_1$
- Once a year ❑$_2$
- Every 6 months ❑$_3$
- More often than every 6 months ❑$_4$
- Don't know ❑$_5$

7.Have you ever seen a diabetes specialist nurse (a nurse with special training in diabetes who may have given advice about diabetes)? Yes ❑$_1$ No ❑$_0$

If yes, where did you see her:
- hospital ❑$_1$
- health centre/surgery ❑$_2$
- in your home ❑$_3$

8.Have you ever seen a dietician? Yes ❑$_1$ No ❑$_0$

9.Have you ever seen a chiropodist? Yes ❑$_1$ No ❑$_0$

10.Have you seen any other health professionals about diabetes (for example, private consultation)? Yes ❑$_1$ No ❑$_0$
If yes, please give details.....

11.In the last 4 years, have you been seen as a patient in Casualty (Accident & Emergency)?

Yes ❑$_1$ No ❑$_0$

If yes, how many times have you been to Casualty .....

If yes, what were the reasons?
- Accident or injury ❑$_1$
- Diabetes ❑$_2$
- Illness not due to diabetes ❑$_3$
- Other(please explain)

.....

12. In the last 4 years, have you been admitted to hospital?

Yes ❑$_1$ No ❑$_0$

If yes, how many times have you been in hospital? .....

If yes, what were the reasons?
- Operation ❑$_1$
- Diabetes ❑$_2$
- Illness not due to diabetes ❑$_3$
- Other(please explain).....

.....

13. Please indicate if you have had treatment for any of the following:
(if yes, please give details)

Eye problems Yes ❑$_1$ ..... No ❑$_0$
.....

Foot problems Yes ❑$_1$ ..... No ❑$_0$
.....

High blood pressure Yes ❑$_1$ ..... No ❑$_0$
.....

Kidney problems Yes ❑$_1$ ..... No ❑$_0$
.....

Other medical problems(please explain).....
.....

About you (all information is entirely confidential):

14. Are you male or female? Male ❑$_1$ Female ❑$_2$

15. What is your date of birth? _____

16.How many other people live in your home (not including yourself)

Adults..... Children (under 16 years).....

17.How would you describe your ethnic group?

White British ❑$_1$ White other ❑$_2$ Indian ❑$_3$ Pakistani ❑$_4$ Chinese ❑$_5$

Bangladeshi ❑$_6$ Black African ❑$_7$ Black Caribbean ❑$_8$ Black other ❑$_9$

Other (please specify).....

18.Were you born in Britain Yes ❑$_1$ No ❑

If no, at what age did you first come to Britain ? Younger than 16 years ❑$_2$
16years or older ❑$_3$

19.Do you currently smoke? Yes ❑$_1$ No ❑$_0$

If no, have you given up in the last 4 years? Yes ❑$_1$ No ❑$_0$

If yes, do you smoke: More than 20 cigarettes a day ❑$_2$
Between 10 and 20 cigarettes a day ❑$_3$
Less than 10 cigarettes a day ❑$_4$
Pipe or cigars only ❑$_5$

20.Do you have the use of a car? Yes ❑$_1$ No ❑$_0$

21.Do you own your home (or have a mortgage)? Yes ❑$_1$ No ❑$_0$

22. Are you working:

Full-time ❑$_1$ Part-time ❑$_2$ Retired ❑$_3$ Unemployed ❑$_4$ Student ❑$_5$

What is your job (your last job if retired or unemployed)? .....

23. Does your husband/wife/partner work:

Full-time ❑$_1$ Part-time ❑$_2$ Retired ❑$_3$ Unemployed ❑$_4$ Not Applicable ❑$_5$

What is your husband/wife/partner's job.....

Your views on services:

24.What do you think is the best thing about the services provided for people with diabetes?

.....
.....
.....
.....

25. What do you think is the worst thing about the services provided for people with diabetes?

.....
.....
.....
.....

26.What is the one thing that you think should be changed about the services provided for people with diabetes?

.....
.....
.....

27. Do you have any comments on how this questionnaire could be improved for future use?

.....
.....
.....
.....

Thank you very much for your help.

Now please post this questionnaire in the envelope provided to:
Dr Elizabeth Goyder
Department of Public Health and Epidemiology
22-28 Princess Road West
Leicester
LE1 6TP

13.3 Pilot letter sent with questionnaire

Dr Elizabeth Goyder
Department of Public Health and Epidemiology
22-28 Princess Road West
Leicester
LE1 6TP
Tel: (0116) 252 5419

1st November 1995

Dear Sir/Madam

We are writing to ask you to help with a study of the use people with diabetes make of health services. We are interested in your experience of services provided by the hospital and by your GP. Your GP is involved in this study and has given us permission to ask if you would help by completing the enclosed questionnaire. It should only take a few minutes of your time. The information you provide will be completely confidential and used only by the researchers. It will help us to see how services are used at present and if this could be improved.

Simply complete the questionnaire enclosed and return it in the stamped addressed envelope provided.

If you have any questions about this study or how to complete the questionnaire you can contact me on Leicester (0116) 252 5419 between 8:30am and 1:00pm, Monday to Friday.

Yours Sincerely,

Dr Elizabeth Goyder

14. Appendix 2: Variable definitions and coding

14.1 Prescribing information

Recording of repeat prescriptions issued is automatic with a computerised system, and at all surgeries repeat prescriptions could be issued without an appointment, so accurate recording of current repeat prescriptions is likely. Where computerised records were not available or no recent prescriptions had been issued (which may indicate a housebound patient getting regular repeat prescriptions hand-written during home visits, for example) drug information was taken from the notes.

Completeness of recording of chronic disease was found to be highly variable between practices and in all practices many more patients were on repeat prescriptions than had chronic diseases recorded. Repeat prescriptions were therefore used as a proxy measure of the presence of co-morbidity. Although misclassification will still occur, it is unlikely to show significant and consistent differences between practices.

14.1.1 Coding of prescribing information

Drugs commonly prescribed for patients without chronic systemic illness were excluded. These were hormonal treatments given to healthy women (hormone replacement therapy for post-menopausal or peri-menopausal women and oral contraception) and topical treatments for acute complaints and skin conditions. These are often put on repeat prescription so a patient can obtain them when required without an appointment. These were further defined as topical treatment for the nose, ear and oropharynx (including cough medicines) and topical treatments which do not have systemic mechanisms of action (which excludes topical non-steroidal anti-inflammatory drugs).

Drugs were classified according to the British National Formulary section in which they appear, except for analgesics which were classified separately as shown below. Where a drug appears in more than one section, it was coded to the most likely indication in the individual patient, after examination of medical records. The number of different drugs in each category was recorded.

Category of drug	Variable (no of drugs)	BNF Section Number
Gastrointestinal System	gidrugs	1
Cardiovascular System	cvsdrugs	2
Respiratory System	respdrug	3
Central Nervous System	cnsdrugs	4 excluding 4.7 (analgesics)
Infections	infdrugs	5
Endocrine System	endodrug	6 excluding 6.1 (drugs used in diabetes), 6.4.1.1.(HRT)
Genitourinary System	gudrugs	7 excluding 7.3 (contraceptives)
Nutrition/Cancer	nutrdrug	8 and 9
Musculoskeletal	muscdrug	10 excluding 10.1.1 (analgesics), 10.3.2 (topical drugs)
Eye	ophdrugs	11
Analgesics	paindrug	4.7 and 10.1.1
Other	othdrugs	Not otherwise classified

Information on diabetes treatment and testing equipment was derived in the same way. Treatment and prescribed testing equipment was coded as follows:

	Variable	Coding
Diabetes treatment	treat	1=insulin
		2=tablets (oral hypoglycaemics)
		3=both insulin and tablets
		4=diet only
Testing equipment	testing	1=blood testing
		2=urine testing
		3=blood and urine testing
		4=no testing equipment

14.2 Medical record information

Patient information obtained from computer records was checked against the written records (available in all practices). This include name, address, postcode, sex and date of birth. Date of registration (joining the practice) or migration (leaving the practice), if since 1/1/90, and date of death if applicable, were available either from computerised or written records.

NHS number and hospital numbers for the four main Leicester hospitals were recorded from computerised or written records to facilitate linkage of the cohort with routine hospital admission information collected by the health authority.

Date of diagnosis of diabetes (year of diagnosis if pre 1990) and date of starting insulin (if applicable) were obtained from the notes. An individual was defined as having insulin dependent diabetes mellitus (IDDM) if insulin had been prescribed within a year of diagnosis.

Service use was derived from written notes, hospital letters within the notes and from specific diabetes record cards in the three practices where they were used.

General Practice reviews:

A general practice diabetes review was recorded if at least three of the following were recorded as having been done: examination of fundi, blood pressure check, foot examination, injection site examination, weighing and urinalysis. Other diabetes related visits were excluded because the hypothesis related to whether routine regular checks within general practice made a difference to inpatient care for the individual, and visits

simply for management of current problems are unlikely to involve routine checks unless these are specifically recorded in the notes.

Outpatient visits:

Every visit to a diabetes outpatient clinic which generated a letter to the general practitioner, which was found in the patient's records was included. It was not possible to distinguish "routine review" visits from visits specifically for management of a specific problem, related to diabetic control or complications. It was assumed that any patient seen in the clinic who had not had a recent review for complications would have these. Weight, blood pressure and urinalysis are routinely recorded at every clinic visit. Visits to the UK Prospective Diabetes Study (UKPDS) research clinic were included. Visits to a general medical, endocrine, cardiology or other outpatient clinics were excluded as although aspects of diabetes management may be undertaken within these clinics, routine examination for complications is not generally expected or done.

If a mention is found of referral, in either primary or secondary care, to a dietician, chiropodist or diabetes specialist nurse (DSN) or attendance at a foot clinic is recorded this was also coded.

Accident and emergency visits and inpatient visits, including day cases, were usually identified from hospital discharge letters filed in the records. Occasionally visits were recorded only in the general practice notes. Where only the discharge date was recorded this was used as an approximation for the admission date for analysis.

Glycaemic control measures were mainly glycosylated haemoglobin A1 (HbA1) results from the laboratory of Leicester Royal Infirmary which came from samples taken either in general practice or from hospital clinics which reported the result in a letter to the GP. The main exception was patients attending a UKPDS clinic who had fasting blood glucose (FBG) measured at each attendance. A few patients also had HbA1c measurements performed at the Leicester General Hospital, but these results were not included in the analysis because it was not possible to ascertain a comparable normal range and distribution for this particular measurement, which was rarely the only available measure of glycaemic control.

The specific complications of retinopathy, renal failure and peripheral vascular disease were only recorded if they had required treatment. This definition aimed to exclude the range of less severe cases where recording was likely to be variable and closely related to intensity of surveillance. Hypertension and hyperlipidaemia were similarly only recorded if they were severe enough to require treatment. Up to five other chronic medical conditions, including congenital conditions, were recorded.

14.2.1 Coding of medical record information

Item recorded	Variable name	Codes
Patient unique identifier	id_no	
GP identifier	gpid	1 to 7
Dates of GP routine reviews	d1 to d15, m1 to m15, y1 to y15	date as day/month/year
Dates of outpatient visits	d16 to d40, m16 to m40, y15 to y40	date as day/month/year
Location of outpatients	op16 to op40	1=NHS 2=private
Referral to dietician	diet	yes=1
chiropodist	chiro	yes=1
dsn	dsn	yes=1
foot clinic	foot	yes=1
Date of A&E visit	d41 to d50, m41 to m50, y41 to y50	date as day/month/year
A&E diagnosis	cas41 to cas50	1=injury 2=medical 3=not in Leicester 4=overdose 5=hypoglycaemia 6=ketoacidosis/hyperglycaemia 7=diabetic collapse 8=diabetic other 9=eye casualty

Item recorded	Variable name	Codes
Date of hospital admission	d51 to d60, m51 to m60, y51 to y60	date as day/month/year
Date of hospital discharge	d51 to d70, m61 to m70, y61 to y70	date as day/month/year
Primary discharge diagnosis	inpt51 to inpt60	Code for admission diagnosis
Place of admission	a51 to a60	1=Leicester NHS 2=other NHS 3=abroad 4=private UK 5-unknown
Test for glycaemic control	t71 to t90	1=HbA1 2=HbA1c 3=FBG
Value of test result	v71 to v90	numerical result in conventional units
Date of test	d71 to d90, m71 to m90, y71 to y90	date as day/month/year
Hyperlipidaemia (treated)	hl	1=yes 0=no
Hypertension (treated)	ht	1=yes 0=no
Renal failure (treated)	crf	1=yes 0=no
Peripheral vascular disease (treated)	pvd	1=yes 0=no
Retinopathy (laser treated)	laser	1=yes 0=no
Date treatment started	d91 to d95, m91 to m95, y91 to y95	date as day/month/year
Chronic diagnoses	diag1 to diag5	Code for chronic diagnosis
Date diagnosis made	d96 to d100, m96 to m100, y96 to y100	date as day/month/year

14.3 Postal questionnaire information

Each questionnaire sent was marked with a unique identifying number so that the returned questionnaires could be assigned to the individual it had been sent to. Where cohort members in the same household had completed each other's copies of the questionnaire this was recognised from the sex and date of birth information.

Some respondents completed both an Asian language and English questionnaire. All returned questionnaires were coded from the English version if this was completed and from the Gujarati or Punjabi version only if the English version was not completed.

14.3.1 Coding of postal questionnaires

Item recorded	Variable name	Codes
Unique questionnaire identifier	questid	1-1100
Duration of diabetes	duratioq	0=no diabetes 1=less than 1 yr 2=1to5yrs 3=6to10yrs 4=more than 10 yrs 5=not stated
Diabetes treatment	treatq	0=none 1=insulin 2=tablets 3=diet only 4=exercise 5=ayurvedic
See GP regularly	gp	1=yes 0=no
See practice nurse regularly	nurse	1=yes 0=no
Visit outpatients regularly	hosp	1=yes 0=no
Ever seen a nurse at home	home	1=yes 0=no
at hospital	dsnq	1=yes 0=no
at surgery	pracnurs	1=yes 0=no
Seen dietician	dietq	1=yes 0=no
Seen chiropodist	chiroq	1=yes 0=no

Item recorded	Variable name	Codes
Seen others	private	1=yes,unspecified 2=private diabetologist 3=other NHS dr. 4=nurse 5=occupational health 6=optician 7=alternative practitioner 8=chemist
Been to A&E	casulty	1=yes 0=no
Been to hospital	admiss	1=yes 0=no
Sex	sex	1=male 2=female
No of adults in home	adults	number
No of children	kids	number
Residential home	group	1=yes
Ethnic group	ethnic	1=white British 2=white other 3=Indian 4=Pakistani 5=Chinese 6=Bangladeshi 7=black African 8=black Caribbean 9=black other
Born in Britain	born	1=yes 2=came as child 3=came as adult
Smoking	smoke	1=yes 0=no
Smoking history	amount	0=never smoked 1=exsmoker 2=20+/day 3=10-20/day 4=less than 10/day 5=pipe/cigars
Use of a car	car	1=yes 0=no
Home owner	hholder	1=yes 0=no
Current employment	job	1=full-time 2-part-time 3=retired 4=unemployed 5=student 6=health benefit 7=housework
Manual job	manual	1=yes 0=no
Partner's employment	jobpart	1=full-time 2-part-time 3=retired 4=unemployed 5=student 6=not applicable 7=housework
Partner's job manual	partman	1=yes 0=no

Item recorded	Variable name	Codes
Main change/comment	change	1=More advice or information (for public and patients) 2=More regular check ups 3=Better access to clinics/ other services 4=Financial help for diet/equipment/glasses/cold weather etc 5=fewer restrictions in activities 6=continuity of care 7=Changes to doctors' attitudes 8=Better co-ordination of services

15. Appendix 3: Pilot study results

Table 15.1: Comparison of those with and those without an admission between 1991 and 1994 - demographic and clinical characteristics

	All admissions				Diabetes related admissions			
	Admitted		Not admitted		Admitted		Not admitted	
		%		%		%		%
Proportion male	32/44	73	33/52	63	13/19	68	52/77	68
Age group								
0 to 40 years	4/44	9	7/52	13	3/19	16	8/77	10
41 to 60 years	15/44	34	17/52	33	7/19	37	25/77	32
61 to 70 years	14/44	32	19/52	37	5/19	26	28/77	36
71 to 80 years	9/44	20	7/52	13	4/19	21	12/77	16
81+ years	2/44	5	2/52	4	-		4/77	5
Duration of diabetes								
0 to 5 years	15/44	34	20/51	39	5/19	26	30/76	39
5 to 10 years	15/44	34	17/51	33	7/19	37	25/76	33
11+ years	14/44	32	14/51	27	7/19	37	21/76	28
General Practice								
GP 1	20/44	46	25/52	48	8/19	42	37/77	48
GP 2	16/44	36	10/52	19	7/19	37	19/77	25
GP 3	8/44	18	17/52	33	4/19	21	21/77	27
Treatment								
On insulin	15/44	34	20/52	39	9/19	47	26/77	34
On tablets only	22/44	50	22/52	42	7/19	37	37/77	48
On diet only	7/44	16	10/52	19	3/19	16	14/77	18
Testing								
Blood+/- urine	17/44	39	18/52	35	9/19	47	26/77	34
Urine only	18/44	41	28/52	54	6/19	32	40/77	52
Neither	9/44	21	6/52	12	4/19	21	11/77	14
No of drugs on repeat								
None	11/44	25	20/52	38	4/19	21	27/77	35
1 -2	8/44	18	16/52	31	1/19	5	23/77	30
3-5	16/44	36	14/52	27	8/19	42	22/77	29
6+	9/44	20	2/52	4	6/19	32	5/77	6
Complications								
Hyperlipidaemia	12/22	55	17/36	47	5/9	56	24/49	49
Hypertension	20/41	49	20/49	41	8/19	42	32/71	45
Absent pulses	4/31	13	4/39	10	4/13	31	4/57	7
Retinopathy	11/34	32	10/46	22	4/14	29	17/66	26
Proteinuria	2/27	7	2/39	5	2/10	20	2/56	4
Raised creatinine	4/33	12	7/35	20	2/13	15	9/55	16
Glycaemic control								
Normal (HbA1<8.5)	18/42	43	14/49	29	8/18	44	24/73	33
Acceptable (8.5-10.0)	11/42	26	20/49	41	2/18	11	29/73	40
Poor (HbA1 >10.0)	13/42	31	15/49	31	8/18	44	20/73	27

Table 15.2: Comparison of those with and those without an admission between 1991 and 1994 - social variables from questionnaires

	All admissions				Diabetes related admissions			
Socioeconomic variables	Admitted	%	Not admitted	%	Admitted	%	Not admitted	%
Household size								
Live alone	6/25	24	3/33	9	3/10	30	6/48	13
Live with 1-2 others	17/25	68	25/33	33	7/10	70	35/48	73
Live with 3+ others	2/25	8	5/33	15	-	-	7/48	15
Smoker	3/28	11	5/36	14	2/11	16	6/53	11
Access to car	10/28	36	24/35	69	4/11	36	30/52	58
House owner	19/28	68	28/35	80	6/11	55	41/52	79
Employment								
Full-time	8/28	29	9/36	25	2/11	18	15/53	28
Part-time	-	-	4/36	11	-	-	4/53	8
Retired	18/28	64	22/36	61	7/11	64	33/53	62
Unemployed	2/28	7	1/36	3	2/11	18	1/53	2

Table 15.3 Comparison of those with and those without an admission between 1991 and 1994 - number of service contacts from GP notes

	All admissions		Diabetes related admissions	
Service Contacts (mean number)	Admitted	Not admitted	Admitted	Not admitted
GP contacts	20.8 (n=42)	14.4 (n=52)	21.0 (n=17)	16.4 (n=77)
Outpatients visits	7.6 (n=44)	2.1 (n=52)	10.3 (n=19)	3.2 (n=77)
Casualty visits	1.1 (n=44)	0.4 (n=52)	1.5 (n=19)	0.6 (n=77)
GP diabetes reviews	3.1 (n=43)	2.9 (n=52)	2.6 (n=18)	3.1 (n=77)
Diabetes outpatient visits	1.4 (n=44)	1.7 (n=52)	2.2 (n=19)	1.4 (n=77)

Table 15.4: Comparison of those with and those without an admission between 1991 and 1994 - service contacts from questionnaires

	All admissions				Diabetes related admissions			
Service Contacts	Admitted	%	Not admitted	%	Admitted	%	Not admitted	%
Seen Nurse	16/27	59	22/34	65	7/10	70	31/51	61
at hospital	8/27	30	6/34	18	5/7	71	9/32	28
at GP surgery	8/27	30	15/34	44	2/7	29	21/32	66
at home	2/27	7	2/34	6	1/7	14	3/32	9
Seen chiropodist	21/28	75	16/34	47	7/11	64	30/51	59
Seen dietician	19/27	70	26/33	79	7/11	64	38/49	78
Seen private diabetologist	1/27	4	0/33	-	1/11	9	0/49	-

16. Appendix 4 : Estimating deaths and admissions within a cohort of individuals with diabetes

Information from 26 sets of general practice records of cohort members who had died was available. Of these 26 individuals, 20 had a total of 63 admissions and then died at home. 6 (23%) had 16 admissions which they survived and subsequently died in hospital.

We used published mortality rates[161] for a population cohort with diabetes to estimate the total number of individuals who would have died, between the start of 1991 and the end of 1995, from the age and sex distribution of the survivor cohort (Table 16.1). An estimated 210 individuals with diabetes in the study practices (16% of the diabetic population) would have died between 1991 and 1995.

Table 16.1: Calculation of expected deaths by age and sex

Sex	Age (mean)	Survivors (S)	Mortality rate in 5yrs (MR)	Expected no of deaths (E) (S*(MR/1-MR)
Males	15-44	74	0.008	0.5846
	45-64	311	0.130	46.4323
	65-75	155	0.269	57.0958
	75+	51	0.465	44.3445
	Total	591		148.4572
Females	15-44	75	0.018	1.3575
	45-64	214	0.102	24.3104
	65-75	126	0.283	49.8330
	75+	88	0.380	54.0056
	Total	503		129.5065
	Total			**278 in entire cohort**

The expected pattern of admissions for these 278 individuals was then explored in order to estimate the number of admissions by this group.

The proportion of admissions which result in death is strongly related to age and sex and whether an admission is elective or not. Less than 7% of hospital deaths are related to elective admissions, although these represent 59% of admissions (Leicestershire Health Information Department, routine unpublished data provided by D Jackson).

The routine data was initially examined to see whether coding for diabetes (either as a primary or secondary coding) influenced the proportion of admissions resulting in death. The SMR (Standardised Mortality Ratio) for admissions coded for diabetes in Leicestershire from 1992 to 1994, standardised by age, sex and whether elective, was 1.08 (95% CI: 1.01-1.15). Since this result suggests that the proportion of admissions resulting in death was similar whether or not an admission is coded for diabetes and a large proportion of admissions by a cohort with diabetes may not be coded as such,[55] further analyses used data based on all admissions.

From the admission histories of the 26 known deaths, it was assumed that the individuals who died in hospital contributed 3.67 admissions and individuals who died at home contributed 2.86 admissions each. Since 67 out of 87 (77%) admissions by this group were non-elective, and virtually all deaths would be in non-elective admissions, the admissions of individuals who died were ascribed to the non-elective category.

The total number of admissions could then by estimated by calculating for each age sex strata the number of predicted deaths in hospital:

If A = emergency admissions by survivor cohort, D= deaths in hospital, E=total deaths

Total admissions = $A + 3.67D + 2.86(E-D) = A + 2.86E + 0.81D$

Also:

Total admissions = D/dr where dr= proportion of admissions resulting in death

Solving these simultaneous equations: $D=(A+ 2.86E)*(dr/(1- 0.81dr))$

The values for each strata are given in Table 16.2.

Table 16.2: Estimated deaths in hospital by age and sex strata

Male	A	E	dr	D
0-44	43	0.5846	0.007204	0.332
45-64	271	46.4323	0.046641	19.333
65-75	142	57.0958	0.104257	31.809
75+	63	44.3445	0.153756	21.650
Female				
0-44	40	1.3575	0.00497	0.199
45-64	132	24.3104	0.051996	11.639
65-75	118	49.8330	0.056937	13.634
75+	77	54.0056	0.137287	28.510
Total				**127**

If 127 died in hospital and 151 died outside hospital, they would contribute a total of:
(127 * 3.67) + (151 * 2.86) = 898 admissions

Overall these estimates suggest that if the cohort could have included all individuals with diabetes who died between 1991 and 1995, there would have been 278 additional cohort members who died, of which about 127 would die in hospital. There would be a total of 898 admissions by this group before they died.

17. Appendix 5: Main Study Data Forms and Questionnaires

17.1 General practice information form

Name..... Code no.....

Size of pop.....No.partners.....

Pilot only:
Summary of No. of diabetics identified: (to be calculated from computer lists)

Treatment	Repeat	All scripts	Register	Reg/No R*	R/Not reg**
Insulin					
Tablets only					
Diet only					

*On register, no scripts issued ** Scripts issued, not on register

No cases gestational diabetes(excluded from table above).....

Practice Interview: Facilities for diabetes (code yes=1, no=0) :

	Yes	No
Provides diabetic care	❑	❑
Practice nurse	❑	❑
" " with diabetes training	❑	❑
Blood glucose meter	❑	❑
Chiropody	❑	❑
Dietician	❑	❑
Diabetic register	❑	❑
Recall system	❑	❑
GP run clinic	❑	❑
Nurse run clinic	❑	❑
Receives CDM Diabetes payments	❑	❑

17.2 Main study form for general practice records data

Demographic Data:

Patient Code No:_ _ _ _ GP code No _ _ _

1.Surname..... 2. First names .....

3. Title:Mr/Mrs/Miss/Ms 4. Maiden name.....

5. Address.....

6. Postcode..... 7. Telephone.....

8. NHS no: .....

9.Date of birth:_ _/ _ _/ _ _ 10. Sex M _ F_

11. Hospital nos: .....

12.Date diagnosis ..... 13.Date died/left practice .....

14.Date started insulin .....

Prescribing data:

15.Diabetes treatment: Insulin ❑$_1$ Oral hypoglycaemics ❑$_2$ Both ❑$_3$
Neither ❑$_4$

16.Testing supplies: Blood testing ❑$_1$ Urine testing ❑$_2$ Both ❑$_3$
Neither ❑$_4$

17.Other drugs (on repeat):

.....

.....

.....

.....

Service Use 1991-1995 (from GP notes):

No. visits GP diabetes clinic/routine diabetes appt _ _

Dates ....

....

Diabetes out-patients _ _

Dates ....

....

A&E : Date..... Diagnosis .....

Date..... Diagnosis .....

Date..... Diagnosis .....

Date..... Diagnosis .....

Date..... Diagnosis .....

In-patient :Dates..... - ..... Diagnosis.....

" ..... - ..... " .....

" ..... - ..... " .....

" ..... - ..... " .....

" ..... - ..... " .....

" ..... - ..... " .....

Clinical details:

HbA1c ..... Date.....

....

....

. ...Average.....

Hyperlipidaemia ❑1 Date _ _/_ _/ _ _

Renal failure ❑1 Date _ _/_ _/ _ _

Hypertension ❑1 Date _ _/_ _/ _ _

PVD ❑1 Date _ _/_ _/ _ _

Retinopathy ❑1 Date _ _/_ _/ _ _

Other medical problems:

Diagnosis 1..... Date1.....

Diagnosis 2..... Date2.....

Diagnosis 3..... Date3.....

Diagnosis 4..... Date4.....

Diagnosis 5..... Date5.....

17.3 Main study postal questionnaire

We are interested in your experience of diabetes care and any treatment you have had recently. Please tick one box for each question and return the questionnaire as soon as possible in the freepost envelope provided.

About diabetes:

1.Do you have diabetes? Yes ❑ No ❑$_0$

If yes, how long have you had diabetes for?
- Less than 1 year ❑$_1$
- Between 1 and 5 years ❑$_2$
- Between 6 and 10 years ❑$_3$
- More than 10 years ❑$_4$

2.Are you on any treatment for diabetes? Yes ❑ No ❑$_0$

If yes, what treatment are you on?
- Insulin ❑$_1$
- Tablets ❑$_2$
- Diet only ❑$_3$
- Other (please specify) .....

About your contact with health services

3.Do you see your GP regularly for diabetes checks? Yes ❑$_1$ No ❑$_0$

4.Do you see a practice nurse regularly for diabetes checks? Yes ❑$_1$ No ❑$_0$

5.Do you go to a hospital diabetes clinic regularly? Yes ❑$_1$ No ❑$_0$

6.Have you ever seen a nurse for advice about diabetes or for diabetes treatment?

at home	Yes ❑$_1$	No ❑$_0$
at the hospital	Yes ❑$_1$	No ❑$_0$
at the surgery/health centre	Yes ❑$_1$	No ❑$_0$

7.Have you ever seen a dietician? Yes ❑$_1$ No ❑$_0$
(Someone who gives advice on diet)

8.Have you ever seen a chiropodist? Yes ❑$_1$ No ❑$_0$
(Someone who treats feet)

9.Have you seen any other health professionals about diabetes (for example, private consultation)? Yes ❑$_1$ No ❑$_0$

If yes, please give details.....

10.In the last 5 years, have you been seen as a patient in Casualty (Accident & Emergency)?

Yes ❑$_1$ No ❑$_0$

11. In the last 5 years, have you been admitted to hospital?

Yes ❑$_1$ No ❑$_0$

About you (all information is entirely confidential):

12. Are you male or female? Male ❑$_1$ Female ❑$_2$

13. What is your date of birth? _____

14.How many other people live in your home (not including yourself)

Adults..... Children (under 16 years).....

(if a residential or group home please tick ❑)

15.How would you describe your ethnic group?

White British ❑$_1$ White other ❑$_2$ Indian ❑$_3$ Pakistani ❑$_4$ Chinese ❑$_5$

Bangladeshi ❑$_6$ Black African ❑$_7$ Black Caribbean ❑$_8$ Black other ❑$_9$

Other (please specify).....

16.Were you born in Britain Yes ❑$_1$ No ❑

If no, at what age did you first come to Britain ? Younger than 16 years ❑$_2$
16years or older ❑$_3$

17.Do you currently smoke? Yes ❑$_1$ No ❑$_0$

If no, have you given up in the last 4 years? Yes ❑$_1$ No ❑$_0$

If yes, do you smoke:
More than 20 cigarettes a day ❑$_2$
Between 10 and 20 cigarettes a day ❑$_3$
Less than 10 cigarettes a day ❑$_4$
Pipe or cigars only ❑$_5$

18.Do you have the use of a car? Yes ❑$_1$ No ❑$_0$

19.Do you own your home (or have a mortgage)? Yes ❑$_1$ No ❑$_0$

20. Are you working:

Full-time ❑$_1$ Part-time ❑$_2$ Retired ❑$_3$ Unemployed ❑$_4$ Student ❑$_5$

On disability or sickness benefit❑$_6$

What is your job (your last job if retired or unemployed)? .....

21. Does your husband/wife/partner work:

Full-time ❑$_1$ Part-time ❑$_2$ Retired ❑$_3$ Unemployed ❑$_4$ Not Applicable ❑$_5$

What is your husband/wife/partner's job.....

Your views on services:

22.What the main thing that you think should be changed about the services provided for people with diabetes?

.....
.....
.....
.....

27. Do you have any comments on this questionnaire?

.....
.....

Thank you very much for your help.

Now please post this questionnaire in the freepost envelope provided to:
Dr Elizabeth Goyder
Department of Public Health and Epidemiology
22-28 Princess Road West
Leicester
LE1 7ZE

17.4 Main study letter sent with questionnaire

The Surgery
Leicester

18 April 1996

Dear Mrs Smith

I am writing to ask for your help with a study of the use people with diabetes make of health services, both services provided in the hospital and by your GP. You can help by completing the enclosed questionnaire. It should only take a few minutes of your time and will be of very great help in seeing how services are used at present and how this could be improved. The information you provide will be completely confidential and used only by the researchers.

Simply complete the questionnaire enclosed and return it in the freepost envelope provided (no stamp needed). If you have difficulty you can ask someone else to help complete it.

If you have any questions about this study or how to complete the questionnaire you can contact Dr Elizabeth Goyder on Leicester (0116) 252 5419 between 8:30am and 1:00pm, Monday to Friday. At any other time you can leave a message at the same number and she will ring you back.

Yours Sincerely,

Dr X

17.5 Main study reminder letter

The Surgery
Leicester

12 July, 1996

Dear Mrs Smith,

A few weeks ago I sent you a questionnaire about diabetes and your use of health services. Since the questionnaire has not yet been returned, I am writing again in the hope that you can help.

Your response is very important for the success of this study. It will help us to learn whether people are benefiting from diabetic services. Even if you do not have diabetes or do not use services, it would be very helpful if you could return the questionnaire so we do not bother you again. **All information will be anonymised and will not be disclosed by the researchers to anyone else, including hospitals and GPs, in a form in which individuals could be identified.**

I enclose a copy of the questionnaire in case the original has been mislaid and I hope that you will be able to spare a few minutes to complete it and send it back. A freepost envelope (no stamp required) is also enclosed for its return. If you have returned the questionnaire in the last few days please ignore this reminder.

If you have any questions or problems with filling in the questionnaire, please call Elizabeth Goyder on Leicester 252 5419.

Many thanks for your help.

Yours Sincerely,

Dr X

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