UNIVERSITY OF SOUTHAMPTON

Human Development and Health Academic Unit

Faculty of Medicine

“A decade in diabetes specialist services in the UK 2000 to 2011”

by

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Thesis for the degree of Doctor of Philosophy

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ABSTRACT

FACULTY OF MEDICINE

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“A DECADE IN DIABETES SPECIALIST SERVICES IN THE UK 2000 TO 2011”

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Diabetes is one of the greatest health challenges facing the UK today. Over three million people in the UK live with diabetes, three quarters of a million have not yet been diagnosed, and prevalence is increasing. Diabetes is a complex condition requiring a wide range of healthcare professionals to support and empower patients to self manage. Increasingly complex insulin regimes and technologies require the skills, knowledge and expertise of an appropriately trained workforce. However, a decreasing workforce has significant implications for how services are organised and presents a challenge to ensure high quality services are available to all people with diabetes.

A series of quantitative surveys across the UK, aimed to obtain a complete picture of diabetes specialist services between 2006 and 2008. Questions were asked regarding core diabetes services; the roles and practices of consultant diabetologists and diabetes specialist nurses, education, retinal screening, psychological, paediatric and adolescent services. The results were analysed for regional and national variations, changes over time and progress towards meeting national targets for care.

Since then significant changes in how care is organised have occurred. In 2011, five case studies were undertaken combining quantitative and qualitative methods, exploring the views of diabetes specialist staff and their perception of the issues relating to diabetes specialist services enabling comparison from 2000 to 2011.

This research continues to provide information describing the shape and capacity of care provided. The data identifies gaps within specialist services in the context of a fast changing political health environment. It details and assesses the challenges faced by healthcare professionals providing high quality, integrated care, to people with diabetes, as they try to ensure the right care from the right person at the right time is available to minimise the risk from complications and to improve their quality of life.

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Academic Thesis: Declaration Of Authorship

I, Charlotte Anne Gosden

declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

"A decade in diabetes specialist services in the UK 2000 to 2011"

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;

2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;

3. Where I have consulted the published work of others, this is always clearly attributed;

4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;

5. I have acknowledged all main sources of help;

6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

7. Either none of this work has been published before submission, or parts of this work have been published as (Appendix L):

P. H. Winocour, C. Gosden, C. Walton, D. Nagi, B. Turner, R. Williams, J. James and R. I. G. Holt. Association of British Clinical Diabetologists (ABCD) and Diabetes-UK survey of specialist diabetes services in the UK, 2006. 1. The consultant physician perspective. Diabetic Medicine, June 2008 – Vol 25 Issue 6 pp 643-650

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ABBREVIATIONS

ABCD	Association of British Clinical Diabetologists
ACCORD	Action to Control Cardiovascular Risk in Diabetes
ACDC	Association of Children's Diabetes Clinicians
acute-GIM	acute-General Internal Medicine
APC	Annual Professional conferences
BMI	Body Mass Index
BSPED	British Society of Paediatric Endocrinologists and Diabetologists
CBT	Cognitive Behavioural Therapy
CCG	Clinical Commissioning Groups
CPD	Continuing professional development
CSII	Continuous Subcutaneous Insulin Infusion
DAFNE	Dose Adjustment For Normal Eating
DCCT	Diabetes Control and Complications Trial
DESMOND	Diabetes Education and Self Management for Ongoing and Newly Diagnosed
DISN	Diabetes Inpatient Specialist Nurse
DKA	Diabetic ketoacidosis
DNA	Do Not Attend
DOH	Department of Health
Dr	Doctor
DSN	Diabetes Specialist Nurse
EDIC	Epidemiology of Diabetes Interventions and Complications
GP	General Practitioner
GPwSI	GP with Special Interests
HbA_{1c}	Haemoglobin A1c
HCP	Healthcare Professional
HTBS	Health Technology Board for Scotland
IAPT	Improving Access to Psychological Therapies
ICD	International Classification of Diseases
IT	Information Technology
MCN	Managed Clinical Network
MDT	Multi-Disciplinary Team
MODY	Maturity-Onset Diabetes of the Young
NDA	National Diabetes Audit
NDST	National Diabetes Support Team
NHS	National Health Service
NICE	National Institute of Clinical Evidence
NSC	National Screening Committee
NSF	National Service Framework
PAG	Professional Advisory Group
PAs	Programmed Activities
PaSA	Purchasing and Supply Agency
PBC	Practice Based Commissioning
PBR	Payment By Results

PCT	Primary Care Trust
PDSN	Paediatric Diabetes Specialist Nurse
QOF	Quality and Outcome Framework
RCN	Royal College of Nursing
RCPCH	Royal College of Paediatric and Child Health
SHA	Strategic Health Authority
SHO	Senior House Officer
SIGN	Scottish Intercollegiate Guidelines Network
SpR	Specialist Registrar
SPSS	Statistical Package for Social Sciences
TREND UK	Training Research and Education for Nurses on Diabetes - UK
UK	United Kingdom
UKPDS	United Kingdom Prospective Diabetes Study
WTE	Whole Time Equivalent
SWOT	Strength Weaknesses Opportunities and Threats
YHPHO	Yorkshire and Humber Public Health Observatory

Chapter 1: Introduction

1.1 Introduction

Since the year 2000 and the introduction of the Diabetes National Service Framework (NSF) (1), the White Paper ‘Our Health, Our Care, Our Say’ (2), Quality and Outcome Framework for General Practice (QOF) and numerous other policies, guidelines and toolkits, diabetes care has undergone significant voluntary and enforced change. Whether these changes have benefitted the person with diabetes or clinicians remains to be seen.

Over the same time period, the political shifts both locally and nationally have created structural, commissioning and funding changes to diabetes services and created tension between primary, community and secondary care. Increasingly during the period of this research it has become apparent that resourcing issues are conflicting against set standards of care from the National Institute of Clinical Evidence (NICE) (3; 4). Across both geographical and clinical areas, some aspects of diabetes care are more heavily supported than others for a variety of reasons ranging from national to local politics, guidelines and patient pressure groups. Inequities are clearly demonstrated throughout the research not only between these areas but also between clinical teams and services: for example, despite being of proven benefit to those with diabetes, the provision of emotional and psychological support is lacking in many localities.

Successive surveys of diabetes specialist services since 2000 have provided data on specific diabetes service areas, workforce and clinical delivery through numerous Governmental policy changes and NHS reforms. It remains to be seen if these interventions have had any significant positive or negative impacts on the issues facing services as perceived by clinicians working in the speciality.

The thesis will begin with an overview of diabetes and diabetes specialist services and describe the rationale and aims of the research.

1.2 What is diabetes?

Diabetes is a chronic complex metabolic disorder that is defined by elevated blood glucose levels that result from a person’s inability to produce insulin and/or use insulin. Insulin is the key hormone which regulates energy supply in cells (5). The lack of or insensitivity to insulin directly affects the control, use and storage of glucose by the body which in turn affects the function of muscles, tissues and cells.

The two main types of diabetes are type 1 and type 2

- Type 1 diabetes, formerly known as insulin-dependent diabetes, is caused by a complete inability to produce insulin. It accounts for only 10% of all cases of diabetes and most are diagnosed as children or early adulthood. It is commonly caused by the auto-immune destruction of the β-cells in the islets of the pancreas (5).

- Type 2 diabetes used to be known as non-insulin dependent diabetes and results from an interaction between genetic predisposition and environmental factors which creates a combination of insulin deficiency and insulin resistance. It is the most common type of diabetes, accounting for 90% of all cases of diabetes in Western Europe. The incidence of type 2 diabetes increases with age, with most cases being diagnosed over 40 years, although this is changing and becoming more common in children and young people (5).

In addition to type 1 and type 2 diabetes, there is secondary diabetes, occurring as a result of another condition, such as pancreatic disease, endocrine disease, to drugs and chemicals, genetic abnormalities, for example, maturity-onset diabetes of the young (MODY), and infections (5).

Gestational diabetes occurs for the first time in pregnancy, resulting from the woman’s inability to produce enough insulin to support the increased insulin requirements of pregnancy (5). The condition in most cases disappears after the birth but is associated with an increase the risk of developing type 2 at a later date for the mother and offspring (6).

1.2.1 Complications

Diabetes is a lifelong condition which is associated with the development of a number of complications and premature mortality. The complications are divided into two main types: microvascular complications affecting the eye, nerves and kidney and macrovascular complications such as cardiovascular disease, stroke, cerebrovascular disease and coronary heart disease (7).

1.2.1.1 Retinopathy

Macular swelling and damage to the blood vessels within the eye causing diabetic retinopathy can lead to partial or total loss of vision in one or both eyes and in 2006 was one of the major causes of visual loss in people of working age in the Western world (8). It is estimated that up to one in three people with type 2 diabetes will develop sight-threatening diabetic retinopathy which will require laser photocoagulation at some time. Sadly retinopathy is often asymptomatic until the patient has a catastrophic intraocular sight-threatening haemorrhage, as with screening most cases of blindness are preventable but not reversible (5).

1.2.1.2 Nephropathy

This is a common cause of renal failure, although the risk of developing nephropathy is lower for those with type 2 diabetes, than for those with type 1 due to the later onset of type 2 diabetes. The development of nephropathy is associated with premature cardiovascular mortality. The initial stage of diabetic nephropathy is microalbuminuria, which is higher than normal albumin excretion and early detection with therapy can slow the progression of kidney disease (5).

1.2.1.3 Neuropathy

This affects 20% to 50% of people with type 2 diabetes and can be divided into acute and reversible neuropathy and other persistent neuropathies such as distal symmetrical and focal and multifocal neuropathies. Acute reversible, such as hyperglycaemic neuropathy, slows nerve conduction and causes uncomfortable sensory symptoms in those with poor glycaemic control. Persistent neuropathy can be classified as either symmetrical (distal symmetrical neuropathy, also known as peripheral neuropathy causing sensory or motor impairment); focal and multifocal, for example, carpal tunnel syndrome; or autonomic neuropathy which can cause distressing symptoms such as sweating and incontinence and also hypoglycaemia unawareness and even painless myocardial infarction (9). The management of diabetic neuropathy is often difficult and chronic conditions such as foot ulceration and amputation which may occur as a result can cause considerable morbidity and mortality (5).

1.2.1.4 Diabetes foot

People with diabetes have a higher incidence of microvascular complications, for example, foot disease including foot ulceration, abnormalities such as Charcot deformity, neuropathy or ischaemia, peripheral vascular disease which can cause intermittent pain in the leg and foot. Diabetes impairs wound healing and combined with loss of feeling in the feet, this could lead to wounds being undetected and becoming infected which may ultimately lead to amputation (5).

1.2.1.5 Sexual problems

Whilst not life threatening, other complications such as erectile dysfunction is a major life limiting complication and affects approximately 60% of men with diabetes over the age of 60. Erectile dysfunction in diabetes mainly results from autonomic neuropathy and endothelial dysfunction and treatment with medication can be effective in 50 to 60% of men with diabetes. Although less well described than in men, women with diabetes may have sexual problems such as vaginal dryness and impaired sexual arousal (5).

1.2.1.6 Macrovascular complications

People with diabetes have a two to four fold increased risk of myocardial infarction and stroke in men and up to a 10-fold increased risk in pre-menopausal women (5).

1.2.1.7 Acute metabolic complications of diabetes

As well as the long term complications of diabetes, people with diabetes are at risk of acute life threatening metabolic complications. Hypoglycaemia occurs when blood glucose levels fall below normal (less than 4 mmol/l) and is the commonest side effect of treatment with insulin. It results in loss of awareness, altered mental state, seizures and eventually coma and occasionally death.

Diabetic ketoacidosis (DKA) results from insulin deficiency and elevated counter-regulatory hormones and is potentially fatal (5). In type 2 diabetes, hypersmolar hyperglucaemic state is a similar complication to DKA. It is a medical emergency characterised by hyperglycaemia, dehydration and uraemia.

1.2.1.8 Cancer

Diabetes, especially type 2, is associated with an increased prevalence of certain types of cancers, such as liver, pancreas, breast, endometrium, bladder and colon and rectum. Although the underlying reason for this is unclear, there may be links to risk factors such as ageing, obesity, diet and physical inactivity (5).

1.2.1.9 Psychosocial issues

When diagnosed with diabetes, many people experience a number of emotional and psychological reactions, such as sadness and grief, while adjusting to the major lifestyle changes needed and support is required from the multidisciplinary team. The prevalence of depression is also increased two to three fold among people with diabetes. Co-morbid depression is associated with poorer glycaemic control, poorer quality of life, a higher incidence of complications and premature mortality (5).

1.2.2 The prevalence of diabetes

Diabetes is one of the greatest health challenges facing the UK today and the prevalence of diabetes is increasing dramatically. In the period of this research, the prevalence of diabetes increased from 2.2 million in 2006 to 2.9 million adults in 2011 in the UK (Table 1-1) and 3.1 million in 2013 (5.7% of the adult population in the UK) (10). A further 750,000 in the UK are estimated to have diabetes but have not been diagnosed (10). Despite the attempts of Government to stem the rise of diabetes, it is estimated that by 2025, the numbers people with diabetes will have reached nearly five million people in the UK since the time of the survey (11).

Table 1-1

Prevalence of diabetes in the UK 2013 (10)		
Country	**Prevalence**	**Number of people**
England	6.0%	2,703,004
Wales	6.7%	173,299
Scotland	5.6%	252,599
Northern Ireland	5.3%	79,072

In addition to this, 29,000 children and young people have diabetes in the UK, 26,500 of whom have type 1 diabetes, 500 with type 2 diabetes and 2,000 children and young people whose diagnosis is not known (12).

1.2.3 Mortality and morbidity

The life expectancy of people with diabetes is still well below that of the population average, accounting for gender and ethnicity, by approximately 20 years for type 1 and ten years for type 2 diabetes. Premature mortality and morbidity resulting from diabetes has been recorded in studies and clinical trials, such as the Diabetes Control and Complications Trial (DCCT) (13), Epidemiology of Diabetes Interventions and Complications (EDIC) (14), United Kingdom Prospective Diabetes Study (UKPDS) (15) and Action to Control Cardiovascular Risk in Diabetes (ACCORD) (16). This can be improved through high quality care, medication, maintaining blood glucose control, healthy lifestyle choices including diet and exercise.

It follows therefore that effective clinical management; supported self care, education and the monitoring of blood glucose are key elements of good quality care for all people with diabetes. A recent analysis from the National Audit Office showed that in England fewer than one in five people with diabetes are achieving the recommended standards for controlling blood pressure, blood glucose and cholesterol nor the care they should expect (17). The resultant effect of not meeting the standards is that people with diabetes are still developing avoidable complications and there are up to 24,000 deaths from avoidable causes due to diabetes (17).

1.2.4 Aims of diabetes care

As the person with diabetes spends the majority of their time managing their condition themselves and only an estimated 1% of their time in contact with healthcare professionals, it is important that the patient derives the maximum benefit from the time spent with their diabetes care team. The aims of diabetes care and management are to manage effectively and prevent life-threatening diabetes emergencies, addressing the manifestations of hyperglycaemia, the prevention of long term complications, the avoidance of iatrogenic side effects such as hypoglycaemia and the importance of psychological support and care.

1.2.4.1 Management and prevention of acute metabolic complications

Diabetic ketoacidosis is a potentially life threatening emergency that results from marked insulin deficiency and elevated counter-regulatory hormones. People with diabetes should be educated about the risk and strategies discussed on how to prevent this (5).

1.2.4.2 Management of hyperglycaemic symptoms

Likewise, hyperosmolar hyperglycaemia syndrome is also potentially life threatening and the person with diabetes should be educated about the risk of insulin omission during illness and errors and that insulin should not be discontinued even if appetite is reduced (5).

1.2.4.3 Prevention of long term complications

The management of microvascular complications requires measures to prevent; detect and treat and general measures such as optimal glycaemic control and blood pressure control are vital to reduce the incidence and progression of such complications. In particular, regular and digital screening for retinopathy, education regarding diabetic foot to alert the person with diabetes of the possibility and annual assessment and annual screening for diabetic nephropathy are essential (5). As the most common cause of death in people with diabetes is cardiovascular disease, cardiovascular risk should be assessed annually and include a family history, smoking, an examination to include weight, waist circumference, blood pressure and lipid profile and for preventative medication to be used.

1.2.4.4 Minimisation of iatrogenic side effects

Hypoglycaemia affects around 10% of people with type 1 diabetes and 2.4% of insulin-treated people with type 2 diabetes and can have a major adverse effect on quality of life. It is important that the person with diabetes is educated about the symptoms and actions to be taken to prevent this. Friends and family should also be asked to learn how to treat and manage this in case they are required to intervene and provide treatment (5).

1.2.4.5 Psychological support

Wider health and lifestyle factors such as smoking, cholesterol, obesity, high blood pressure, and lack of regular exercise can accelerate the effects of diabetes. Being newly diagnosed with diabetes can produce a range of responses and emotions and there is a lot of information, choices and changes to be made. Papers and research such as National Health Service (NHS), Emotional and Psychological support (18) and the Hertfordshire cohort study (19) confirm the links between diabetes and depression and conversely depression, mental illness and diabetes. The two conditions occur together approximately twice as frequently as would be predicted by chance alone (20). Furthermore, among individuals with diabetes, total healthcare expenditures for individuals with depression are 4.5 times higher than for individuals without depression, representing a major cost to the health service (21).

Over time, emotions, perceptions and understanding can change as help; support, guidance, professional treatment and care are received. This research shows however, that although there are lots of psychological effects on the person not all people get equal support and care either between specialist teams or geographical areas.

Coping with diabetes, both the physical, emotional and psychological aspects, relies on understanding and acceptance for the person with diabetes, the family and carers. For many people, emotional and psychological support is the greatest need however, it is very clear that this aspect is one of the worst in terms of availability and resources.

1.3 The policy context

The introduction of the diabetes service frameworks in the UK in 2000 recognised that diabetes does not affect everyone in society equally and that significant inequalities exist in the risk of developing diabetes, in access to healthcare services and the quality of those services and health outcomes. The vision of the frameworks was for diabetes services to be equitable by ensuring that services are planned to meet the needs of the population, that people with diabetes experience seamless care from services that are fully integrated by drawing on the skills and knowledge of the healthcare and social care professionals across the multidisciplinary teams, including primary, community and specialist services. One of the aims was to improve services by setting national standards to drive up quality and tackle variations in care and so the frameworks set standards, identified interventions and actions to meet those standards, and milestones were introduced against which performance could be measured. Each of the four nations developed their own version of these standards: the NSF for England, the NSF for Wales (22), the Scottish Diabetes Framework (23) and the Blueprint for Diabetes Care in Northern Ireland (24). However, whilst changes have taken place in other nations, it has been in England where the most radical political changes in the organisation of healthcare overall, not just in diabetes, have taken place.

At the same time as the introduction of the framework in England, there was a period of rapid change within the NHS which meant that the policy picture became very complex. The White Paper, Our Health, Our Care, our Say (2), on the one hand encouraged health partners to work together, yet it was set within a context of competition between providers and between primary and secondary care which was being driven by other policy changes (25).

These reforms prompted service reconfiguration, changes in the commissioning, workforce planning and the expansion of service delivery in the community. This resulted in tensions developing between primary and secondary care drawing resources away from specialist services. An objective of reconfiguration was to promote integration of services along the primary and specialist service interface with appropriate resource allocation, staffing and skill mix (1; 17-19; 21-23). The General Medical Services contract for general practitioners required the recording of process and surrogate outcome measures of diabetes care through the QOF and has improved the basic care for which all people living with diabetes should expect (26).

An NHS model striving for patient choice, provider competition and payment by results (PBR) has emerged. Funding had been put into the NHS as a whole to increase capacity but not specifically diabetes care. Unlike the NSF for coronary heart disease, the diabetes NSF and NICE guidance did not attract ring fenced budgets.

More recently the Health and Social Care Act of 2012 introduced a new commissioning framework for the NHS in England (27). Clinical Commissioning Groups (CCGs) were created replacing PCTs and all GP practices were required to be members of a CCG along with at least one hospital doctor, nurse and member of the public. Most NHS services will be commissioned services through CCGs appropriate to meet local needs.

1.4 A brief history of diabetes care

As the knowledge and understanding of diabetes as a condition has changed over time, so has the care provided by healthcare professionals. Hospital attendance was more likely if the person with diabetes required insulin and care of the patient has historically been in the hands of the secondary care physician.

Provision of diabetes care has included the direct involvement of a wide range of professionals including; general practitioners (GPs), practice and community nurses, health care assistants, podiatrists, dietitians and other professionals as well as diabetes specialist teams. In addition people with diabetes and their carers can and are now expected to provide a significant amount of care for themselves with support and education.

1.5 Key roles within diabetes specialist services

Lack of clarity about the most effective means of service delivery, has created uncertainties about the role for healthcare professionals working in the specialist environment. Consultant physicians have been affected by the provision of services to acute-general internal medicine as well as to their speciality. Whilst the development of acute physician posts has been actively supported by the Royal

Colleges of Physicians, commitment to acute medicine from consultants with special interests continues to be encouraged (28) and consultants with a special interest in diabetes and endocrinology are the highest contributors to acute medicine (29). Potential conflicts in service delivery could arise therefore with the movement of diabetes specialist services into the community, if consultants were required to work outside of acute hospital settings.

As well as consultants, diabetes specialist nurses (DSNs) play a vital role in the provision of care to people with diabetes. Their role was first introduced over 60 years ago to educate and support people with diabetes and their families at all stages of their lives (30). The role became more common in the 1980s with the advent of differing strengths of insulin and the introduction of self-monitoring of blood glucose (31; 32), and DSNs worked in primary care, acute settings or both (32). Their role has continued to change in response to the Working Time Directive (33), Government policies and strategies such as the NHS Plan (34) and NSF for diabetes. In 2000, it was predicted that DSNs would take on more direct responsibility for diabetes management and carry out prescribing (35). Owing to the increase in the numbers of people with diabetes needing the support and education offered by DSNs, there was a huge effort to establish nursing posts but with not enough consideration of their roles, entry criteria or development. This led to a profusion of job titles, a variety of pay scales and no clear role definition (36). The ABCD survey in 2000 also found a wide variation in nurse qualifications, grading of DSNs and in day to day roles suggesting a need for a nationally co-ordinated approach to training (35). In response to this lack of career structure and guidance in qualifications, An Integrated Career and Competency Framework for Diabetes Nursing was launched in 2005 to guide strategic workforce planning and career development (37). This was updated in 2010 by Training Research and Education for Nurses on Diabetes – UK (TREND UK), (38).

In an effort to provide effective and efficient care to, and respond to the high demands, of patients, diabetes specialist services have generally developed an approach to best utilise resources resulting in the multidisciplinary team approach. The multidisciplinary team provides better care than previous interactions just involving a doctor or nurse and patient.

Multidisciplinary teams are made up of a diverse group of healthcare professionals, such as physicians, nurses, pharmacists, dietitians, and podiatrists, psychologists, mental health providers and social services and others required to meet the needs of the individual patient. The most important member of the multidisciplinary team, however, is the patient who is at the centre of the team.

The multidisciplinary team approach addresses an issue or problem from all angles and aims to provide the best balance of care and individual expert advice in dedicated areas. The multidisciplinary team professionals can change from case to case depending on the patient, whilst also providing the professionals with ongoing peer support and knowledge exchange which can be invaluable as they deal with many difficult situations and cases.

Research indicates that a multidisciplinary approach in the management of type 2 diabetes can lead to an improvement of glycaemic control and quality of life (39). NICE guidelines for type 1 diabetes, 2004, state that a range of professional skills are required for the best service delivery model. Multidisciplinary teams are recommended, suggesting that a team be comprised of educators, dietitians, medical and mental health staff (4). This was supported and clarified in 2010 by a Diabetes UK Task and Finish group which led a consultation to assist managers, commissioners and healthcare professionals structure a specialist diabetes service. The resulting report aimed to help identify the roles and responsibilities of provider organisations to deliver an integrated seamless service and covered the roles of consultants, DSNs, specialist dietitians, pharmacists, local models of care, core components of a service as well as other specialist activities (40).

1.6 What is known about diabetes specialist services and the gaps in service provision?

Prior to the introduction of the NSF, the Association of British Clinical Diabetologists (ABCD) undertook an extensive survey of secondary services for diabetes in the UK (35; 41-43). Over one third of specialist services were provided by single-handed consultants; support from DSNs, podiatrists and dietitians was considerably less than recommended (44); retinal screening programmes were not operating in at least 25% of centres and access to key biochemical testing was far from comprehensive. There were clear regional variations in levels of key personnel, facilities and diabetes specialist services. Often bids for service improvements had failed, especially for dietetic and podiatry support.

In 2004 to 2005, 89 consultant diabetologists in England were interviewed in a review of their roles and responsibilities, working practices and job satisfaction (45). This was before the impact of the White Paper on ‘Shifting the balance of power’ to the community and the financial shortfall in the acute sector in 2006 (46). Challenges, whilst recognised, did not detract from a general high level of job satisfaction, and there was a clear understanding of the multifaceted role of consultant diabetologists. Most consultants were keen to take part in the process of reconfiguration, but were frustrated by organisational structures and the introduction of plurality of providers into healthcare.

In 2006, Diabetes UK carried out a survey of people with diabetes who were members of the charity and a progress survey of primary care commissioning organisations (47). Most patients were highly satisfied with the care they received, but noted deficiencies in specialist psychological support, inadequate retinal screening services and poor transition from paediatric to adult services for young people with diabetes. There seemed to be concern that a ‘post-code lottery’ operated in accessing new therapies and services. The findings from the Primary Care Trust (PCT), progress survey in 2006 confirmed the issues identified regarding psychological support and care and also a shortfall in resources available for patient education.

Gaps have been identified in the provision of psychological support and care for people with diabetes although psychiatric disorders and psychological problems are common in diabetes (48) and diabetes is common amongst those with psychiatric disorders. People with diabetes are twice as likely to have depression (49-51) and eating problems (52) and these are associated with suboptimal glycaemic control (53; 54) and increased mortality (55). Cost-effective treatments exist for depression in diabetes (56) and psychotherapeutic approaches to improve glycaemic control (57-60) but, despite this, the majority of psychological and psychiatric problems go undetected and untreated (49; 61). At the time the study commenced, there were no formal clinical pathways for delivering expert psychological care in diabetes. The NSF had set standards to provide counselling (standard 3) and management of depression (standard 12) and the National Institute for Health and Clinical Excellence (NICE) has also made explicit recommendations (4).

Since 1988, the four surveys of paediatric and children's diabetes services in the UK have shown an overall improvement in service provision. However, the last survey in 2002 highlighted serious deficiencies in dedicated paediatric staff numbers, difficulties in transitional care and as with adult services poor access to psychology support (62) which is concerning as the incidence of type 1 diabetes has doubled in the last decade especially in younger children (63). The management of these individuals has become more complex to avoid the long term complications of diabetes yet maintain good quality of life. National Diabetes Audit data at the time suggested that diabetes control is consistently poor within this age group throughout the UK (64). It is possible that deficiencies in clinical service provision may have an adverse impact. Since the survey in 2002, the NICE (4) and the Scottish Intercollegiate Guidelines Network (SIGN) (65) published guidelines for standards of diabetes care for children which is addressed within this research.

Diabetic retinopathy is often asymptomatic until it reaches an advanced stage and therefore regular screening is recommended to allow timely diagnosis and treatment (66). It is now well established that early detection through screening and effective treatment in the form of photocoagulation prevents visual impairment (67; 68). In addition, strategies including the optimal management of blood pressure and blood glucose slow down the progression of retinopathy in type 1 and type 2 diabetes (13; 15; 69). The UK National Screening Committee (NSC) launched a national programme to facilitate the reduction of diabetic retinopathy in 2003 (70) as part of the delivery of the NSF for diabetes (1; 71). The programme set out national targets to offer comprehensive retinal screening to all people with diabetes in England, Scotland, Wales and Northern Ireland. The aspiration was to offer 100% of people with diabetes access to retinal screening by December 2007, however, there were criteria on which patients could be excluded. Primary care trusts demonstrated wide variations in the actual numbers of people with diabetes being excluded from screening indicating that this was an area in which there was a lack of clarity and formal quality control and that some people with diabetes had been inappropriately excluded from screening (72).

1.7 Research questions

In 2005, Diabetes UK collaborated with the Association of British Clinical Diabetologists (ABCD), the Association of Children’s Diabetes Clinicians (ACDC), British Society of Paediatric Endocrinologists and Diabetologists (BSPED), Leeds partnership NHS Foundation and the Institute of Psychiatry, Kings College London, to review the provision of diabetes specialist services, to identify national and regional differences and to compare findings to previous research.

The aims of the surveys were; to assess core diabetes specialist services, the introduction and activity of retinal screening programmes, the provision of psychological services for people with diabetes, education provision and content, paediatric and adolescent diabetes services, the working practices consultant diabetologists and the roles and responsibilities of diabetes specialist nurses throughout the UK. Following the quantitative survey work, a qualitative case study analysis of the views and perceptions of consultant diabetologists and diabetes specialist nurses in 2011 was undertaken at a time of dramatic NHS reform to compare and contrast these views to those expressed in the 2006 and 2000 surveys to provide a longitudinal perspective.

During the course of this research programme I aimed to examine:

- What can be learnt from the surveys about the provision of diabetes specialist services in the UK in 2006 to 2009?
- Halfway through the NSF were services delivering to standards set out?
- What provision was there of psychological services for adults with diabetes and to what extent had national guidance been met?
- What progress had been made in the implementation of retinal screening services? What barriers or difficulties were faced by programmes implementing this service?
- To what extent are there variations or inequalities in access to diabetes service provision across the UK?

- What were the views and perceptions of consultant diabetologists and DSNs in 2011 of the issues facing diabetes specialist services, how did these differ between professional groups and how had these issues changed from 2000 to 2011?

- What lessons can be learnt from combining a mixed methods approach and their future suitability for reviewing diabetes healthcare services?

This thesis aimed to answer these questions and further develop the themes raised from each of the individual chapters published in papers and reports. The following chapters present the findings from each of the surveys; the Consultant, Diabetes Specialist Nurse (DSN), Retinal screening, Psychological, Paediatric and Professional perspectives and each chapter contains a discussion of the findings. The last chapter presents the conclusions and recommendations for clinicians, diabetes service, commissioners and Government and my own personal reflections on the learning process undertaken.

Consultant survey

2.1 Introduction

The aim of this study was to examine core diabetes specialist services and to focus on the views and working practices of consultant diabetologists across the four nations of the United Kingdom. It also sought to assess the impact of acute medicine on the ability of consultants to carry out their diabetes specialist clinics, develop their diabetes service and train future diabetologists. In England, questions were asked about consultants' input to and engagement with commissioning and tariff structures at the time.

2.2 Method

2.2.1 Outline

The following describes; who was responsible for the development of the research methodology, why the different research methods were selected, where the research was to be carried out, who the research participants were to be and how they were selected, how the research was to be carried out, the data collection processes and data analysis techniques. As the methodology for each of the surveys was similar, the detail will be described in this chapter. In the following chapters differences will be highlighted.

2.2.2 Role of the working group

In 2005, a committee comprising members of Diabetes UK and the Association of British Clinical Diabetologists (ABCD) collaborated to develop a survey to would cover all aspects of diabetes specialist services. The working group consisted of members from the following areas and their roles in 2005:

2.2.2.1 Diabetes UK Policy team

- Bridget Turner – Head of Policy Care & Improvement Team.
- Charlotte Gosden – Information Analyst, Policy Care & Improvement Team.

2.2.2.2 Diabetes UK Professional Advisory Council

- Richard Holt – Professor in Diabetes and Endocrinology, University of Southampton, Honorary Consultant Physician, University Hospitals Southampton and Chair of Professional Advisory Council Diabetes UK.
- June James – Nurse Consultant, Leicester University Hospitals and Vice-Chair Professional Advisory Council, Diabetes UK.
- Rhys Williams – Professor of Clinical Epidemiology, University of Swansea, Chair Diabetes UK Wales Professional Advisory Council.

2.2.2.3 ABCD

- Peter Winocour – Secretary and Consultant Physician at Queen Elizabeth II Hospital, England.
- Chris Walton – Treasurer and Consultant Physician at Hull Royal Infirmary, England.
- Dinesh Nagi – Committee Member, Consultant Physician, Pinderfields Hospital, England.

2.2.2.4 My role to manage the programme of research was to:

- Develop the research questions, questionnaires, respondent lists, data analysis protocols, reporting mechanisms and quality control procedures such as requirements for ethical approval and data protection.
- Manage the process of creating, formatting, writing questions and designing forms suitable for each target group in the form of questionnaires.
- Distribute questionnaires, data collection, data analysis, report writing, assisting and writing journal articles.
- Hold and manage the contacts databases and overall timeline for each survey
- Manage outputs including reports, articles, website updates, presentations and conference presentations.
- Co-ordinate meetings with the working groups, take minutes, distribute minutes, set agendas for meetings, organise meeting rooms and follow up on actions raised during meetings.
- Present the findings at national and international conferences.
- Distribute results of the research through Diabetes UK and partner agencies to support policy work and provide detailed information to support the

lobbying function at Diabetes UK. Act as the representative and information expert for Diabetes UK to partners working groups such as NHS Diabetes, Department of Health, Royal Colleges, and Kings Fund to disseminate findings.

- Inform the results of the research to Diabetes UK membership via newsletters, website and magazines, to other teams for press releases, parliamentary questions and lobbying.

2.2.3 Why was this methodology selected?

The first task of the working group was to decide the aims and objectives of the research area and to choose methods which would address the research questions.

The main purpose of the research was to:

- Understand current diabetes specialist service provision.
- Identify inequalities within diabetes specialist service provision.
- Inform and direct the planning of future diabetes specialist services.

As the purpose was primarily to drive policy change, rather than to build or generate theoretical knowledge in the field, cross-sectional questionnaires and semi-structured interviews which would produce descriptive findings, were selected. It might be considered that descriptive findings are more restrictive than those providing explanations of the data which might then help make predictions. However, this study did not seek to explain why certain situations existed, but to describe them so that comparisons could be made to previous years and for recommendations to be made and used in future service improvement programmes. Following this, it was hoped to discuss if the methods applied were successful in delivering the aims of the research.

2.2.4 Setting

The research was carried out in adult and paediatric diabetes specialist services within the National Health Service (NHS) of the United Kingdom (UK), and was funded by Diabetes UK and the ABCD.

2.2.5 Study participants

To gain as complete a picture as possible, all identifiable diabetes centres across the four nations of the UK were invited to take part in the research.

It was important to capture as many diabetes centres as possible rather than sampling services because the aim was not to compare groups, as in a typical experimental design, but rather to identify where there were differences in the quality of service provision geographically. This was achieved through the cross-tabulation of selected variables between regions and nations.

For this survey, consultants were identified from the membership of ABCD, Diabetes UK and the Royal College of Physicians Diabetes Manpower survey. I sent surveys to all identifiable consultant diabetologists (n=693). Questionnaires were sent to the individuals within the service to respond on behalf of their service. Where there were multiple responses from one service, the responses were compared and if differences were found, I contacted each of the consultants and asked them to reach a consensus for the service. However, where consultants were asked for their individual perspective on their diabetes specialist service, these view points were retained.

2.2.6 Research instruments

Questionnaires were used for data collection and their development are described next.

2.2.7 Survey development

Traditionally data collection of this type is often empirical in nature, asking questions of healthcare professionals working in the field via audits to obtain information about services.

The first task was to describe the aspects of diabetes specialist care that could be assessed by questionnaire. This provided a framework of topics and questions which then became the focus of a literature search.

The literature search was carried out focussing on surveys and publications from the UK from 1995 onwards. The geographical limitation was applied as it was felt that the purpose of the review was to enhance and build upon previous survey findings relevant to UK services. As the NHS was undergoing significant structural changes it was hoped that a review would highlight areas of change and key questions that could be answered in the next set of surveys. Only surveys and audits carried out in the last ten years were included as these were deemed to be comparable in nature and format.

The starting point was to assess previous questionnaires used in the ABCD 2000 survey of the UK (29; 35-37). Other national and local audits of diabetes specialist services were also included in the review.

The topics covered within the literature review included:

- diabetes relevant staffing
- manpower levels and
- sub-specialities such as
    - dietetics
    - podiatry
    - ophthalmology
    - paediatrics
    - psychology
    - renal
- care processes

At the time of the literature review, services provided varying levels of education to patients. Although evidence existed and literature supporting education and particularly structured education was available, education was not included within the literature review as a separate speciality or sub-speciality of diabetes care as it was seen as an integral part of the clinical role rather than a commissioned activity. The substance of the literature review was focused onto clinical delivery and activities. Where questions on education had been asked in previous surveys and were identified by the working group as important for inclusion in the current survey, these were addressed within the DSN survey.

Staff education competency was also excluded from the literature review as this was not seen at the time as a separate component in the delivery of diabetes services.

However, as with education for patients, aspects of clinical competency were addressed within the DSN and DSN workforce survey.

The literature search was led by Dr Peter Winocour who reported findings to the working group. The results of the review were read by the working group who compared and contrasted the topics and questions within a framework into areas of importance. After the comparisons were made between the framework and the literature review, it was found that overall, all the sections of the survey carried out in 2000 were still considered relevant, but where applicable could be modified to reflect changes to the commissioning and provision of services. Despite the diversity of the working group, a framework of topics and questions was identified and a consensus reached.

Peter Winocour and I led the process of developing the framework and analysis of the questions. During the process, due to the scale and complexity of the topics to be included in the questionnaire, myself and Peter Winocour, with the agreement of the working group, broke the questionnaire down into five key aspects to gain the depth of information that was felt to be important:

- Consultants and core diabetes services including podiatry and dietetic support.
- Diabetes specialist nurses including a focus on education.
- Retinal screening.
- Psychological provision.
- Paediatric and adolescent services.

The rationale used to define the individual surveys reflected the composition of multidisciplinary teams, where the consultant, DSN, podiatrist and dietitian in the main work together to provide holistic diabetes care to the person with diabetes. Separate surveys were considered necessary for psychological care, which was largely absent in many services, and retinal screening, which was mainly linked to ophthalmology services separate to diabetes and was undergoing major service reform at the time.

Education was linked to the DSN questionnaire as in recent years NICE guidance has recommended that this activity should be led by DSNs shifting the emphasis from the medical team to the nursing team. A separate survey for DSNs was also considered important because of the expanding and changing role undertaken by DSNs since the 2000 ABCD survey.

For paediatric and adolescent services, it has long been recognised that services are geographically inequitable. They operate as separate services to adult care with a cross over at the point of transition to adulthood, at different ages for each service. This survey was also intended to build on the experience of four previous surveys to provide comparison and continuity.

Initially there was to be a separate survey on demographics, which would contain questions on medical staffing levels; however, after discussion this was included in the 'consultants and core diabetes services' survey. Also a sixth survey to explore primary and community services was planned to gain an understanding of specialist and intermediate services provided in the community and of the structures that support these models in community care. This was to take into account the emergence of new posts such as community matrons. Owing to a lack of funding, this survey was not undertaken.

The previous 2000 ABCD questionnaire and the paediatric and adolescent questionnaire in 2002 were used as a basis for discussion. I wrote the questionnaire using questions either taken directly from the previous questionnaire, modified based on the working group's decision or excluded altogether. I also added new questions to reflect changes to the commissioning of services and political changes.

It was important to establish a link between the surveys to enable information to be collated across surveys by myself in the analysis and to provide an in-depth understanding of specialist diabetes care at each location. To achieve this and ensure that information was not being duplicated, I asked in each survey, which primary care organisations were served by the hospital trust, the name of each hospital within the trust and the name of the diabetes network, if one existed. This would provide information to describe the diversity of hospital trusts across the nations.

We discussed whether an emphasis on the hospital trust or primary care organisation would allow inequalities in service provision to be highlighted by those who commissioned services; if, for example, one hospital trust serves three primary care organisations, there may be inequalities if the trust provides different services to each primary care organisation depending on what the primary care organisation has commissioned. However, we decided to focus on the hospital trust as the key provider of diabetes specialist care both historically and currently.

I paid particular attention to ensure that the surveys were relevant to each of the four nations of the UK as each nation had modified healthcare systems and organisational structures both for commissioning and provision following devolution of authority and budgetary control.

We agreed to use whole time equivalents to define staffing levels throughout the questionnaires and to change diabetes specialist nurse to hospital diabetes specialist nurse (DSN) (as opposed to Community DSNs) for clarity to reflect changing roles and service changes.

The use of open ended questions was discussed. In the 2000 ABCD survey, the qualitative data collected were not used because of insufficient time and resource to analyse the large amount of data collected. Given this previous experience, it was felt that the number of qualitative questions included in the questionnaires should be limited to take account of the capacity of myself to code, analyse and report on this data.

It is important to recognise that the composition of a questionnaire and how questions are phrased may influence responses and the type of information this will generate. Topics and questions were drafted and measuring techniques selected (for example numbers, yes/no responses or responses to a scale such as a numerical range). The items for response (such as yes/no) were generated by discussion with the group, prior knowledge, previous questionnaires and through reading by myself and the working group. I structured the questionnaires with easy and basic questions at the start and open questions towards the end of the questionnaires. I worded the questions to ensure that the language used would be familiar to the healthcare professionals responding and were not leading or double barrelled (that is where two questions are asked within one sentence) to reduce the risk of bias or confusion.

I presented each draft of the questionnaires to the working groups for discussion. I then amended the questionnaires and sent revisions to each member for comment. These comments were discussed with the working groups until a consensus was reached and I incorporated their comments accordingly. Following the pilots, the comments from the respondents were discussed with the working groups until a consensus reached and the members felt the questionnaire to be complete.

Where possible, questions from the year 2000 questionnaire were used again to allow direct comparison between the surveys. However, some former questions were considered to be no longer relevant or applicable, as some practices may have been superseded as a result of the guidance from NICE, Scottish Intercollegiate Guidelines Network (SIGN) and the NSF.

2.2.7.1 Aim of the consultant survey

The aim was to identify the views and working practices of consultant diabetologists in the United Kingdom in 2006 to 2007. The survey aimed to examine current provision of specialist services, where there were gaps in the service and to examine changes since 2000.

2.2.7.2 Special issues: brief background

Since the introduction of the NSF for diabetes in England and Wales (1), Scottish Diabetes Framework in Scotland (23) and the blueprint for diabetes care in Northern Ireland (24), the NHS has seen substantial changes in the commissioning and design of diabetes specialist services. Between 2000 and 2006 the prevalence of diabetes had increased creating a growing demand on specialist services. It was important to ascertain current staffing levels (consultants, DSNs, dietitians and podiatrists) as the effectiveness and quality of a service requires an adequate number of specialist staff to provide specific diabetes specialist services, training to junior doctors and primary care staff and education to people with diabetes.

Furthermore with the development and changes to the acute physician post, the survey was designed to assess the impact of acute medicine on the ability of consultants to carry out their specialist diabetes duties, develop the service and train specialist registrars. Surveys were sent to centres for a response per centre; however, the opinion of individual consultants was also sought about issues including the strengths and weaknesses of services and job satisfaction which were analysed individually.

2.2.7.3 Topics

These included:

- the provision of acute-general internal medicine and diabetes services
- provision of specific diabetes services
- current staffing levels
- strengths and weaknesses of their specialist service
- perceived threats to the specialist service

2.2.7.4 Structure of the survey

The questionnaire included 71 questions (open and closed) to gather both qualitative and qualitative information about the provision of core diabetes services and the perceptions of consultant diabetologists (Appendix A).

2.2.8 Pilots

The questionnaires were piloted before mailing to ensure both question and answer comprehensibility with relevant healthcare professionals. The consultant survey was piloted with 32 consultant diabetologists identified from the ABCD and Diabetes UK membership.

I distributed initial drafts and respondents were asked to complete the questionnaire to:

- Test if the wording of the questions was interpreted as intended.
- If the instructions supplied were readily understood.
- For closed (pre-coded) questions, if an appropriate response was available.

Once completed, questionnaires were returned to me and I entered the data from the questionnaires into excel spreadsheets and summarised the results in word documents.

Attention was paid to frequently missed questions and if unintentional responses were generated. The pilots were used to make sure all relevant issues had been covered and no pertinent areas were missing. Respondents were asked to give their views on the questions and response codes. This feedback was vital as many of the questions were new and untested. I wrote this feedback up with a summary of the results and circulated to the working group for review.

Following the pilots, I amended questions that were confusing or poorly answered. At this stage I carried out an initial analysis of the data to test if the responses provided would generate valid data.

2.2.9 Distribution of the questionnaires

I constructed most questionnaires using an online survey website called Opiniontaker (www.opiniontaker.com) which was used to host the questionnaires (except the psychological and DSN workforce questionnaires which were created in Word). I uploaded the mailing lists to the website using a Microsoft Excel spreadsheet that was linked to each of the questionnaires. Once the draft questionnaires had been finalised, I wrote a covering email which contained a link to the questionnaire with instructions on how to complete the questionnaire. When I had emailed the questionnaires to the participants, they could then complete the questionnaires online using the link in the email. I was able to track who had taken part in the survey, who had started the questionnaire and saved their results but not completed the questionnaire, and those who had completed and submitted their results. For those who received a paper copy, the questionnaire enclosed was given a unique ID to allow me to track responses and I had personalised the cover letter which was printed on Diabetes UK headed paper. The consultant, DSN, retinal screening and paediatric survey were all hosted on Opiniontaker for the first contact.

For the reminders, I posted paper copies; where email addresses were either not available or not recognised, I also sent paper copies. If it had not been possible to arrange a contact via email or post, then I contacted participants via telephone for their responses.

The covering email explained the aims of the survey, the importance of their response and why as many responses as possible were required in order to obtain complete coverage of the four nations, and how responses would be used. All participants were assured of the confidentiality and anonymity of all responses. The questionnaire included the logos of both Diabetes UK and ABCD, and BSPED and ACDC for the paediatric questionnaire. This partnership approach was hoped to increase response rates.

As a further measure to increase response rates, the surveys were publicised via the ABCD and Diabetes UK websites, journal editorials, at conferences and through telephone calls. This approach raised awareness in advance of the survey which increased credibility and explained the value. The aim of this publicity drive was also to increase the number of potential participants and to increase confidence in the validity of the research amongst service providers.

For the consultant survey when the initial contact sought was not the intended person to complete the questionnaire, I asked this person to forward the questionnaire, as an email attachment, to the appropriate person. I asked for the first contact to confirm by email that this had been done. Where I received notification of undelivered emails, I sent a paper copy of the questionnaire in the post.

As responses were received, I prepared a map of the UK to identify geographically at a glance where respondents were located. Where there were localities with few respondents, I targeted these for action to increase the response rate using the Diabetes UK regional offices for support as well as sending letters with a duplicate questionnaire. I also contacted consultants' secretaries by email and telephone to ask for help in gaining responses and completed surveys.

2.2.10 Data collection and reminders

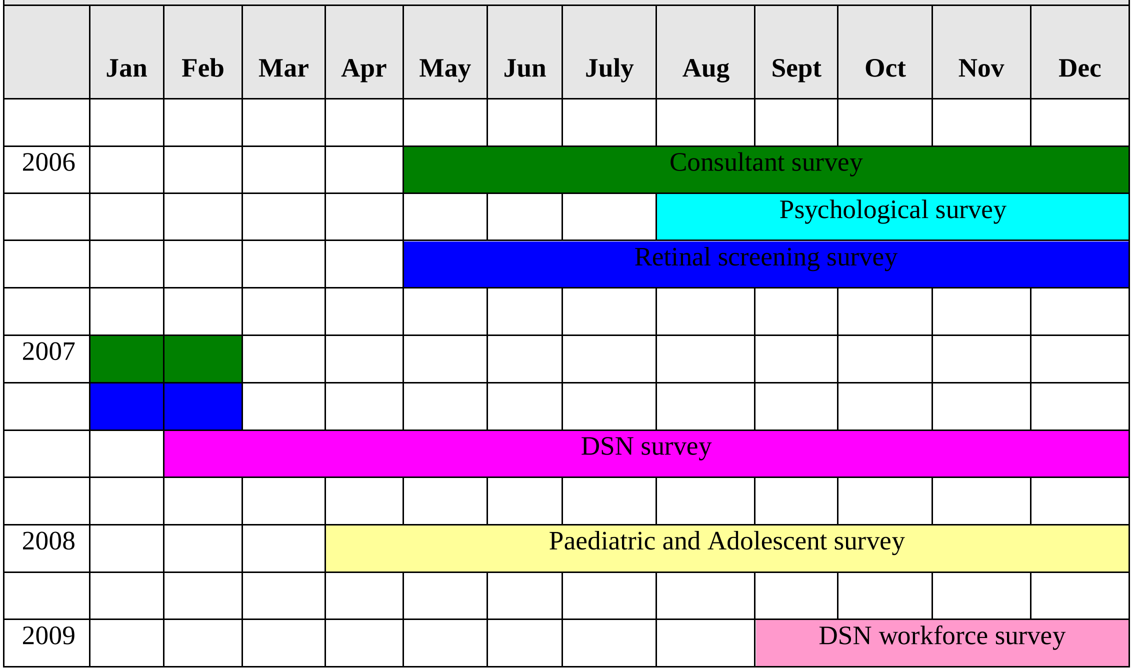
I designed a database in Microsoft Excel format to log and track all responses to the questionnaires. This detailed when reminders were sent, how centres were contacted and when responses were received. All the details of my telephone conversations were logged to support the monitoring of responses. I kept records of those services where the contacts had retired or were not involved in diabetes services to ensure that an accurate base number could be recorded from which to derive the response rate.

2.2.11 Timeline of data collection

The Gantt chart below (Table 2-1) shows the timeline of when all the questionnaires were sent out.

Table 2-1

Timeline to show distribution dates and data collection period of questionnaires



	Jan	Feb	Mar	Apr	May	Jun	July	Aug	Sept	Oct	Nov	Dec
2006					Consultant survey							
								Psychological survey				
					Retinal screening survey							
2007	🟩	🟩										
	🟦	🟦										
		DSN survey										
2008				Paediatric and Adolescent survey								
2009									DSN workforce survey			

For the consultant survey, I sent the questionnaires on the 5th May 2006 and replies were collected until 28th February 2007. I sent the first reminder on the 5th June and the second on the 21st July. The third reminder was sent on the 14th September 2006. From the 5th June 2006 until February 2007 I called individuals by telephone to encourage responses. The survey was advertised through ABCD and Diabetes UK websites and through mailshots to service providers.

2.2.12 Data management and data cleaning

Once completed questionnaires were returned, I entered them either onto a package called SNAP, survey software designed for data input, or into a Microsoft Excel database. I later transferred the data into the Statistical Package for Social Sciences (SPSS version 16) for analysis. I checked the data for missing values and to ensure that recorded values fell within a pre-specified range. If an out-of-range value had been entered, I contacted the diabetes centres for clarification.

2.2.12.1 Data analysis

I analysed the results using Microsoft Excel and SPSS (version 16) using both parametric and non-parametric tests depending on the distribution of the data. Association and correlation between variables were measured using Pearson's *r* or

Spearman's rho and chi-square test. I analysed categorical data using chi-squared tests where appropriate.

ANOVA was used to assess differences between means and online statistical calculators (http://survey.pearsonncs.com/significant-calc.htm and http://www.langerresearch.com/moe.php) tested significant differences between survey results in the year 2000 to the year 2006. A p value of <0.05 was considered statistically significant.

I have presented data as percentages, medians and ranges. I undertook an analysis of regional and national differences and where these were statistically significantly different, these are reported. Not all respondents answered each and every question. To present accurate representation of the findings, missing values have been removed from the analysis (e.g., where the number of possible respondents for a question was 68 and only 66 responded, then there were two missing responses for that question and the percentage would be taken from 66).

Descriptive statistics were produced to gain an understanding of the data and to check for skewness. The data were analysed for patterns using tables, pie charts and graphs.

As qualitative findings may provide valuable insights and explanations into health systems, which can be widely used by policy makers to understand health systems, open questions were used to explore the nature of healthcare professionals' experiences, including strengths, weaknesses and threats facing diabetes services and how services can be improved. The findings provide depth to the quantitative findings, as well as providing possible explanations for the quantitative findings. Ultimately, the analysis can aid policy makers understand the issues, which can influence policy or decision making.

Open questions were systematically coded by myself using an approach based on the framework method (73). I read all responses to gain familiarity with the data. I assigned each response a code and grouped them into themes as they emerged from the data. These were entered in a separate column in an Excel spreadsheet or written alongside the text in a word document. As several concepts could be contained within each response, there may have been several columns utilised by each response. For the open questions in the consultant survey, to validate my interpretation, two consultant physicians re-read the data and the interpretations and a consensus was reached to ensure that the codes remained as close to the original intentions portrayed by the initial responses as possible.

I counted and ranked both codes and themes in order of frequency to represent the strength of the views of the respondents when analysing the strengths, weaknesses and threats as perceived by the consultants to the diabetes specialist services. In this way the key elements voiced by the respondents were summarised and an overview was achieved.

2.2.12.1.1 Well-resourced score

As in the ABCD year 2000 survey, a ‘well-resourced service score’ was used to describe variability in specialist service provision. This was based on levels of staffing, diabetes care services, and other core measures. The weightings assigned to the components of the well-resourced score are described in Table 2-2. The same methodology was employed in the current survey as in 2000 with the exclusion of coding for retinal screening as this was the focus of another survey, also without a variable for DSN from the 2000 survey which was not used in the year 2006 survey. The final difference between the scores in the two surveys was the inclusion of a variable for education for people with diabetes. This was felt to be important to include as this had become a clinical priority and a key policy driver by 2006, although the scores would no longer be directly comparable to 2000. With a possible maximum score of 25 points, responses were graded A* (24-25), A (21-23), B (18-20), C (15-17), D (12-14) or E (<12 points), (Table 2-3).

Table 2-2

Weightings and components of the well-resourced score

Score component	Weighting	Score	Maximum score
The number of WTE consultants per 100,000 catchment population	>0.76	=4	4
	0.51-0.75	=3	
	0.26-0.5	=2	
	0.1-0.25	=1	
	0	=0	
The number of WTE DSNs per 100,000 catchment population	>1.5	=3	3
	1.1-1.5	=2	
	0.1-1.0	=1	
	0	=0	
WTE dietitian for service	0.6 and >	=2	2
	0.1-0.5	=1	
	0	=0	
WTE podiatrist availability for diabetes service	1 and >	=2	2
	0.1-0.5	=1	
	0	=0	
Diabetes Register	Yes	=2	2
	No	=0	
Joint ante-natal diabetes service	Yes	=1	1
	No	=0	
Joint diabetes ophthalmology clinic	Yes	=1	1
	No	=0	
Separate diabetes clinic for elderly	Yes	=1	1
	No	=0	
Local vascular surgeon	Yes	=1	1
	No	=0	
Lipids measured	Yes	=1	1
	No	=0	
Microalbuminuria	Yes	=1	1
	No	=0	
HDL measured	Yes	=1	1
	No	=0	
Erectile dysfunction service	Yes	=1	1
	No	=0	
Joint paediatric and adult diabetes specialist service	Yes	=1	1
	No	=0	
Guidelines	Yes	=1	1
	No	=0	
Structured education for people with diabetes	Yes	=1	1
	No	=0	
Access to a psychologist	Yes	=1	1
	No	=0	

Table 2-3

Grades achieved by each score	
Grade	**Score**
A*	24-25
A	21-23
B	18-20
C	15-17
D	12 to 14
E	<12

2.2.12.1.2 Pre-specified sub-group analysis

I identified hospitals that responded to both the 2000 and 2006 surveys in order to examine any differences in how this sub-group responded compared to the overall findings. There were 123 hospitals that responded to both surveys. By analysing these findings, the aim was to check for any possible bias, as the response rate for the 2007 survey was lower than the response rate to the 2000 survey. The findings from the sub-group are presented with the findings where appropriate.

2.2.13 Limitations of the survey

Whilst dietetics and podiatry were included in the core diabetes services, further work is needed to assess these specialist areas fully. Furthermore only specialist services were approached. Originally it was envisaged that a community based survey would be completed but this was unfeasible due to a lack of resources. In future it would be useful to take a more holistic approach to include primary and intermediate services to provide a more rounded view of services operating in the current political and economic climate. The resources available to the study consisted of the time of the working group members and organisational resources used for printing, postage and telephone calls. No other sources of funding were sought.

2.3 Results

2.3.1 Response rate

The response rate to the survey was 49% (289 out of 580 consultants identified). The original number of consultants identified for the survey was 692, however, 112 consultants were excluded for reasons including:

- no longer involved in diabetes care (38)
- practising endocrinology only (35)
- retired or died (27)
- moved on (9)
- unknown (2)
- duplicate (1)

Geographically, 82% of respondents were from England, 8% from Scotland, 5% from Wales and 4% from Northern Ireland. Table 2-4 shows how many consultants responded from each nation.

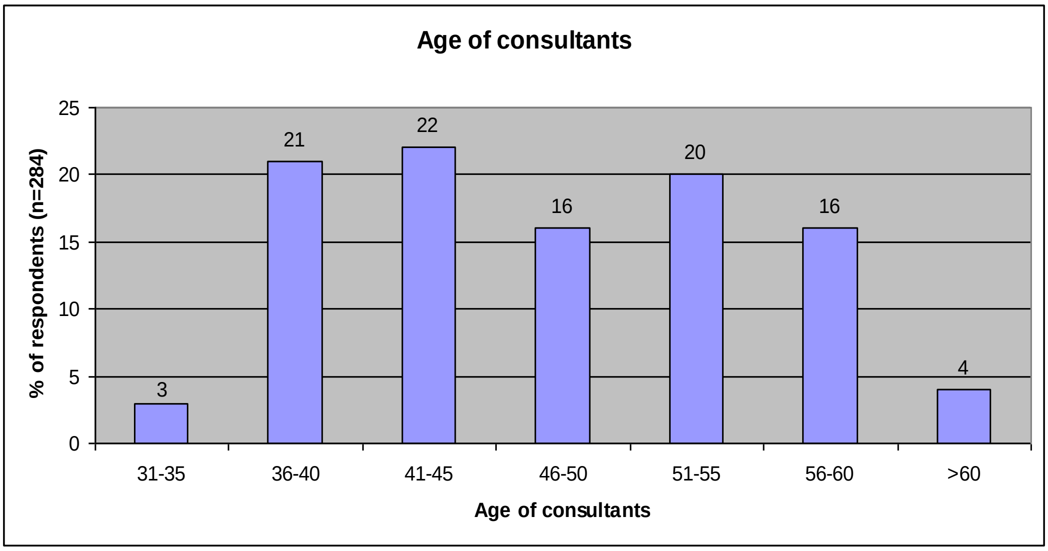
Table 2-4

Number of consultants who responded per nation			
	Number of respondents	**Total number surveyed by nation**	**Percentage of respondents**
England	236	465	51
Wales	15	46	33
Northern Ireland	12	24	50
Scotland	24	55	44
Guernsey	1	1	100
Isle of Man	1	1	100
Total	289	592	

Of the 195 trusts and 295 hospitals surveyed, a consultant response was received from 48% of these. Within each Strategic Health Authority (SHA) region in England, the response rate from consultants varied (33% to 100%).

The majority of consultants were male (80%) and 55% were aged over 46 years (Figure 1). On average they had spent 11.4 years in a consultant post (range 0.6 to 35 years) with 25% having previously been a consultant in a different trust. This demonstrated that overall the demographics of consultants are of an age and have been in post for a considerable number of years which could have implications for succession planning, fulfilling training requirements and service development.

Figure 1 Age of responding consultants



As approximately half of consultants did not respond, differences between responders and non-responders were examined to provide further validation of the survey. This examination was undertaken by nation (Table 2-5), SHA (Table 2-6) and gender (Table 2-7); no statistically significant differences between the two groups were evident, which substantiated our view that the survey results were credible.

Table 2-5

Difference between non responders and responders by nation		
	Percentage of non-respondents (n=302)	**Percentage of respondents (n=289)**
England	76	82
Wales	10	5
Northern Ireland	4	4
Scotland	10	8
Isle of Man		0.35
Guernsey		0.35

Table 2-6

Difference between non responders and responders by SHA		
	Percentage of non-respondents (n=222)	**Percentage of respondents (n=-236)**
East Midlands	7	7
East of England	10	11
London	24	12
North East	3	8
North West	14	16
South Central	7	9
South East Coast	7	7
South West	8	11
West Midlands	11	8
Yorkshire and the Humber	10	10

Table 2-7

Difference between non responders and responders by gender		
	Percentage of non-respondents (n=300)	**Percentage of respondents (n=278)**
Men	83	80
Women	17	21

To validate the reliability of the results further, three key questions were analysed by date of survey completion; no differences were found showing there was no response bias in these important questions as a result of any delayed response. The questions used for analysis were; the provision of guidelines (Table 2-8), access to a psychologist (Table 2-9) and the well-resourced score (Table 2-10).

Table 2-8

Response to question on provision of guidelines by date of response			
	Date of survey response		
Provision of guidelines	**May-July 2006 Percentage**	**August-October 2006 Percentage**	**November 2006 - February 2007 Percentage**
Yes	82	85	81
No	18	15	19

Table 2-9

Response to question on access to a psychologist by date of response			
	Date of survey response		
Access to a psychologist	**May-July 2006 Percentage**	**August-October 2006 Percentage**	**November 2006 - February 2007 Percentage**
Yes	39	36	45
No	61	64	55

Table 2-10

Response to analysis of well-resourced score by date of response			
	Date of survey response		
Well-resourced score	**May-July 2006 Percentage**	**August-October 2006 Percentage**	**November 2006 - February 2007 Percentage**
A*A	21	26	19
BC	58	56	62
DE	21	19	19

A sub analysis found 123 hospitals from which consultant responses were received in both 2000 and the 2006 surveys. The findings are presented where appropriate to strengthen the validity of the findings. These hospitals are referred to as the comparable hospitals.

2.3.2 Status of diabetes services

A key objective of the survey was to establish current staffing levels within services and multidisciplinary teams (consultants, diabetes specialist nurses, dietitians and podiatrists) and overall services seem to be expanding, perhaps as a result of greater investment following the NSF leading to the development of multidisciplinary teams and service redesign.

2.3.2.1 Key personnel

2.3.2.1.1 Consultant diabetologists

The actual number of consultant physicians providing diabetes specialist services had increased from 456 in 2000 to 592 in 2006 (the diagnosed prevalence of diabetes increased from 2.5% in 2000 (74) to 3.54% in 2006(75)). Therefore whilst diagnosed prevalence increased by approximately 40% the increase in whole time equivalent (WTE), of consultants increased by only 30%. Whilst in 2000 and 2006 most services were provided by less than 1 WTE in 2006 there were a greater proportion of services being provided by 1.1 to 1.5 WTE consultants compared to 2000; this was also reflected in the sub-analysis of comparable hospitals (Table 2-11).

Table 2-11

WTE consultants per 100,000 of the catchment population				
	All respondents	**All respondents**	**Comparable hospitals**	**Comparable hospitals**
	2006 Percentage (n=272)	**2000 Percentage (n=178)**	**2006 Percentage (n=117)**	**2000 Percentage (n=119)**
Greater than 1.5	9	6	11	8
1.1 to 1.5	27	6	29	7
1.0 and under	65	88	60	86

It is important to note that previously in 2000, the survey asked for the number of consultants per site; in this report, this number was divided by 100,000 head of population to become numerically comparable to the question asked in the 2006 survey.

The number of single-handed diabetes specialist consultants had decreased from 36% in 2000 to 10% of services in 2006. This was also shown in the sub-analysis of the 123 hospitals included in both 2000 and 2006, which found there were 31 single handed consultants in the year 2000 and only nine in the year 2006. Geographically, single-handed consultants were more frequently reported in Northern Ireland (50%) than in other nations (England 8%, Wales 14%, and Scotland 4%, $p<0.001$). The reason for this variation may have reflected the low response rate from Northern Ireland or other factors not revealed by the survey findings.

2.3.2.1.2 Diabetes specialist nurses

The provision diabetes specialist nurses (DSNs) had increased so that nearly 60% of services had at least 1 WTE per 100,000 of the catchment population, compared to 60% having less than 1WTE in 2000 (Table 2-12). Direct comparison between the two surveys is difficult as a different unit of measurement was used in the year 2000 survey.

Table 2-12

Provision of DSNs			
What is the number of WTE hospital DSNs per 100,000 of the catchment population?	**2006 Percentage**	**How many full-time DSNs do you have working in your unit per 250,000 effective population case-load?**	**2000 Percentage**
Greater than 1.5	21	5-5.9	5
1.26-1.5	16	4-4.9	8
1.1-1.25	20	3-3.9	27
0.76-1.0	22	2-2.9	40
0.51-0.75	12	1-1.9	16
Less than 0.50	8	Less than 1	4

2.3.2.1.3 Dietitians

Dietitian availability appeared to have increased, the average WTE dietitian availability was 1 per 100,000 (median 1, range 0 to 24) and over 58% of services had access to at least 1 WTE of dietetic support compared to 18% in 2000. In 2000 there was a recommended level of support of 1.5 WTE per 250,000 of the catchment population (equivalent to 22 hours per 100,000 of the population) yet in 2006 many services were still falling short of this target despite the overall rise in staff numbers (Table 2-13). In 2000, dedicated dietitians spent 4.7 hours (median) per 100,000 population on diabetes care (43).

Table 2-13

WTE dietitian support		
	WTE Dietitian 2006 Percentage	**WTE Dietitian 2000 Percentage**
0	3	24
0.1-0.9	39	58
1.0-1.9	43	15
2 or more	15	3

2.3.2.1.4 Podiatrists

The provision of podiatry staff also appeared to have increased since 2000. The median WTE podiatry availability was 1 per specialist service (mean 1.36, range 0 to 12). 61% of services had access to at least 1 WTE of podiatry support compared to just 9% in 2000 (Table 2-14).

Again direct comparison of the two surveys was difficult because a different unit of measurement was used in year 2000 survey; the median number of weekly podiatry sessions was 3 with almost 97% of responses stating that the WTE availability of podiatry services was less than 1 WTE. In the year 2000, the unit of measurement was the number of sessions (each last four hours). These were divided by 35 hours to calculate the WTE.

Table 2-14

WTE podiatry support		
WTE	**WTE Podiatrist 2006 Percentage**	**WTE Podiatrist 2000 Percentage**
0	0.8	2
0.1-0.9	38	89
1.0-1.9	33	7
2 or more WTE	28	2

2.3.2.2 Specialist services and resources

Diabetes care requires a range of specific diabetes services to provide holistic care. Since 2000, there have been improvements in the provision of joint ante-natal diabetes services, joint paediatric and adult diabetes clinics and joint ophthalmology clinics, laboratory access to serum cholesterol including high-density lipoprotein cholesterol and microalbuminuria measurements and education for people with diabetes. By contrast, there was no change in the provision of services for erectile dysfunction. Several aspects of service provision had deteriorated since 2000 such as the maintenance of a diabetes register, access to separate diabetes clinics for the elderly and psychologists, the presence of a local vascular surgeon and guidelines to ensure comprehensive care in all settings (Table 2-15).

Table 2-15

The characteristics of diabetes specialist services					
	All respondents	**All respondents**	**Comparable hospitals**	**Comparable hospitals**	**P value**
Characteristics of specialist service	**2006 Percentage**	**2000 Percentage**	**2006 Percentage**	**2000 Percentage**	
Joint ante-natal diabetes service	93	85	92	86	
Lipids measured in diabetes service	100	99	100	99	
HDL measured in diabetes service *	967*	85*	97	85	0.000
Microalbuminuria available *	99*	93*	98	91	0.001
Specific service for Erectile Dysfunction	61	60	63	62	
Structured education for people with diabetes	87 offer structured education to people with diabetes	81 of staff have been trained to educate people with diabetes	85	76	
Guidelines to ensure comprehensive care in all settings	82	85	82	84	
Joint diabetes-ophthalmology clinic in the diabetes service	21	15	18	17	
Register for service	66	73	65	76	
Separate diabetes clinics for elderly	9	13	11	16	
Local vascular surgeon in the hospital	86	88	83	91	
Access to a psychologist for the patient	41	45	36	47	
Joint paediatric and adult diabetes specialist service	75	60	73	64	
Education offered to medical staff	94	N/A	N/A	N/A	

*indicates where the difference is statistically different when compared to 2000.

Diabetes consultants were involved in a wide range of clinics reflecting their various sub-specialist interests (Table 2-16). This highlights the diverse nature of the condition and the difficulties faced by clinicians and commissioners in providing a service fit for purpose and meeting standards within available resources.

Table 2-16

Sub-specialist interests of consultant diabetologists	
Sub-specialist interest	**Percentage (n=289)**
General diabetes	99
Ante-natal	48
Transitional adolescent-adult clinic	42
Joint foot	38
Pump-intensive management	26
Diabetes renal	22
Joint adolescent	21
Other specialist clinics	16
Community diabetes clinics	13
Joint paediatric	9
Joint ophthalmology	5
Liaison psychiatry diabetes	2
Joint men’s health	1
HIV-diabetes	1
Sport and diabetes	0.7

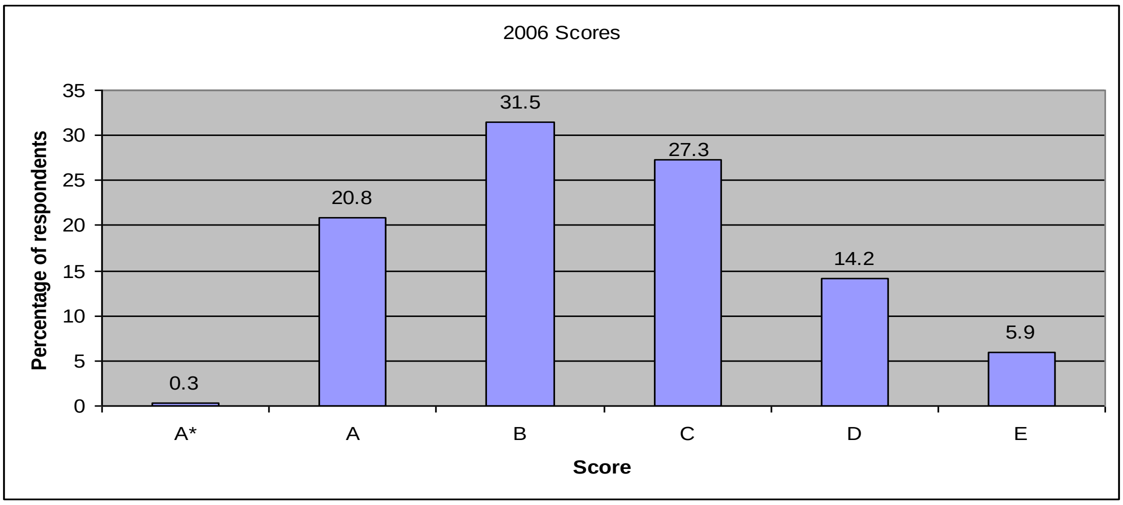
2.3.2.3 Well-resourced service score and perceptions of service

Overall the average well-resourced service score was 17.3, (Grade C) which was lower than the mean score in 2000, 18.1 (p=0.06) indicating that the quality of diabetes specialist service provision may have declined over the six years (Table 2-17). Only one Trust achieved the maximum score A*, just over 20% were awarded an A, and 16% of responses were scored D or E (Figure 2).

Table 2-17

Comparison of the average well-resourced score from 2006 to 2000				
	All respondents	**All respondents**	**Comparable hospitals**	**Comparable hospitals**
	2006 Score	**2000 Score**	**2006 Score**	**2000 Score**
Mean	17	18	17	19
Median	18	18	18	19
Range	9 to 24	10 to 25	9 to 23	12 to 25

Figure 2 Figure to show scores achieved by trusts



Service quality varied nationally and within regions in England. The highest scores were found in England and Scotland compared to Wales and Northern Ireland (p=0.007). Within the Strategic Health Authority of England, the highest scores were in the North of England and lowest scores in the East Midlands and Eastern regions (p=0.029) (Table 2-18). Varying the weighting of the scores did not appreciably alter these findings or comparisons.

Table 2-18

Variation in well-resourced score by nation			
	A*A	**BC**	**DE**
Nations	**Percentage**	**Percentage**	**Percentage**
England (n=236)	23	58	20=101
Wales (n=15)	7	73	20
Scotland (n=24)	21	75	4
Northern Ireland (n=12)	8	33	58=99
English Regions			
Regions			
North (n=81)	32	52	16
Midlands and South (n=155)	18	61	21

Those services with a greater number of consultants in post achieved a higher score (Table 2-19) than those with fewer WTE consultants (p<0.001).

Table 2-19

Well-resourced score by WTE of consultants			
	A*A	**BC**	**DE**
WTE of consultants	**Percentage**	**Percentage**	**Percentage**
0.1-0.25 (n=5)	0	40	60
0.26-0.50 (n=38)	3	63	34
0.51-0.75 (n=45)	9	56	36
0.76->1.5 (n=184)	30	63	7

Most consultants perceived their service to be reasonably well-resourced (56%), 36% thought their service was not well-resourced while only 8% thought their service was well-resourced.

There was good agreement between the perceived and calculated well-resourced score (p=0.001) (Table 2-20).

Table 2-20

Perception of service and well-resourced score (n=285)			
Perception of service	**A*A Percentage**	**BC Percentage**	**DE Percentage**
Well-resourced	58	38	4
Reasonably well-resourced	26	62	12
Not well-resourced	6	61	33

Consultants were less likely to say that their services were well-resourced compared to 2000 which indicates that consultants have felt there had been a decline in service quality (Table 2-21).

Table 2-21

Consultant perception between 2006 and 2000				
Consultant perception of their diabetes specialist service	**2006 Percentage (n=285)**	**2000 Percentage (n=176)**	**Comparable hospitals 2006 Percentage (n=121)**	**Comparable hospitals 2000 Percentage (n=118)**
Well-resourced	8* (p=0.001)	23	9* (p=0.00)	26
Reasonably well-resourced	56* (p=0.5)	60	55* (p=0.00)	59
Not well-resourced	36* (p=0.00)	17	36* (p=0.00)	15

* indicates if the difference between the surveys in the years 2000 and 2006 is statistically different

Interestingly, well-resourced score was positively associated with job satisfaction (p=0.001) (Table 2-22). This could demonstrate the impact that well motivated and supported consultants as leaders of the multidisciplinary team, have on driving up standards of care in local areas.

Table 2-22

Level of job satisfaction				
	Job satisfaction (n=285)			
Well-resourced score	**Poor Percentage**	**Moderate Percentage**	**Good Percentage**	**Excellent Percentage**
A*A	3	36	39	22
BC	8	44	39	9
DE	13	54	26	7

2.3.2.4 Consultant perceptions of diabetes specialist service

The majority of the open response comments made by consultants about their diabetes specialist services were negative. In particular, consultants felt that specific diabetes services, such as access to psychologists, were poorly supported and they were concerned about job losses. On a positive note, some consultants felt they worked within an excellent diabetes service and some described good integration with primary care. Others comments were coded as ‘mixed’ where services were in the process of change (Table 2-23).

Table 2-23

Themes identified concerning the diabetes specialist service	
Negative theme	**Count**
Specific diabetes services are poorly supported	112
Job losses	66
Increased workload, increasing prevalence of diabetes and lack of resources to meet demand	27
Restructuring and move to primary care diminishing specialist services	15
Poor work environment, IT support and facilities for patients	9
Pressure from acute and general internal medicine reduces time for speciality	3
Positive theme	**Count**
Excellent diabetes specific services	9
Good collaborative links and integrated service with primary care	6
Service reasonably well-resourced	5
Excellent staff	2
Raised own funds	1
Mixed theme	**Count**
Services are being developed therefore neither well-resource nor poorly resourced	6
Some aspects of the service are better than others	2
Good service but under threat due to changes e.g. commissioning	1

2.3.2.4.1 Strengths, weaknesses and threats to the specialist service

Where services were working well, consultants believed this to be due to expert, committed and motivated specialist staff. If staff were lacking this was seen as a weakness to the service. Once again, perceptions described in the previous section were identified as weaknesses such as under-resourced specific diabetes services including psychological services, dietetics and access to education. Many of the perceived threats related to the negative impact of central government policy on diabetes specialist services and ineffective commissioning with the feeling that commissioners did not sufficiently understand the complexity of diabetes. Consultants believed these threats were leading to funding cuts for resources, staff and training and service reconfiguration and fragmentation. It was felt that diabetes was seen as a low priority by commissioners and acute trust management in many cases (Table 2-24).

Table 2-24

Strengths, weaknesses and threats to the specialist service		
Strengths	**Main themes**	**Count**
1	Expert, committed and motivated specialist staff	166
2	Excellent team work and multidisciplinary team working	118
3	Good links with primary care, effective networks and integrated community focused services	88
4	Good range of speciality and sub-specialist clinics	86
5	Patient focused, innovative and high-quality service	78
6	Comprehensive, well organised service and well-resourced service	68
7	Excellent education for patient s and healthcare professionals	28
8	Good systems in place for achieving targets	22
9	Good facilities in place	19
10	Good IT systems in place	18
11	Research	12
12	Enough staff	9
13	Good laboratory support	5
14	Tertiary support	2
15	The patients	2
16	Good telephone support	1
17	Supported by charity	1
18	Enjoy general medicine	1

Weaknesses	**Main themes (count)**	**Count**
1	Under-resourced specialist services, in particular psychology (33), dietetics (35), education (23)	169
2	Lack of staff	99
3	Organisation of service, including no prospect for development, lack of a register and too much work	73
4	Poor facilities, also includes split site working	42
5	Funding and finance cuts and higher prevalence	41
6	Lack of strategy and leadership	32
7	Poor links with community and/or primary care	32
8	Poor IT	29
9	Poorly organised commissioning, including shift to primary care, expensive or undervalued service and threats from PBR	19
10	Poor inpatient care	11
11	Too generalised service	11
12	Poor multidisciplinary and team working	10
13	Access to the service	7
14	Case mix and do not attends	6
15	Impact of general internal medicine	6
16	Targets and guidelines	6
17	Diabetes not prioritised	5
18	Low morale and stress	5
19	Poor community diabetes	5
20	Poor awareness or promotion of service	4
21	Poor training	4
22	Research	2
23	Not enough prevention	1
24	Size of service	1

Threats	Main themes	Count
1	Commissioning and negative impact of central government policy on diabetes care	176
2	Lack of understanding of complexity of diabetes and shift to primary care	106
3	Staffing and training cuts	93
4	NHS funding/ finance/ deficits	88
5	Service reconfiguration and fragmentation of care provision	51
6	Diabetes not prioritised, poorly valued and reduced investment to specific services	46
7	Pressures from acute medicine or general medicine	19
8	Poor communication and collaboration primary care, Primary Care Trusts and specialist services	16
9	None	3
10	Lack of IT support	2

2.3.3 Working methods in hospital

Nearly all consultants were involved in the delivery of general medicine (94%) while 95% had involvement within a medical admissions unit.

38% of consultants operated together with junior doctors but only sometimes with junior members of their own team when on-call. For those who do work within a ‘firm’ or rota structure, the frequency of the on-call is shown in Figure 3.

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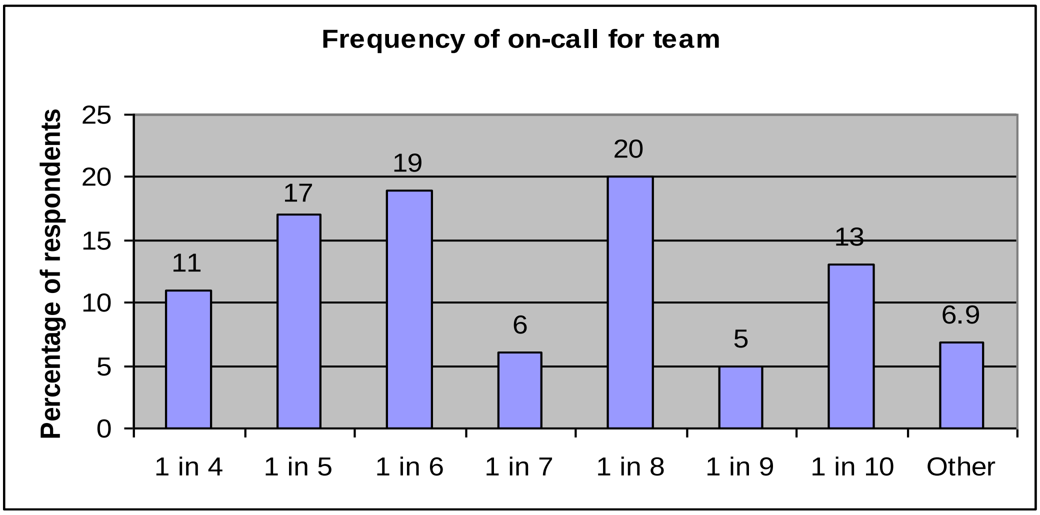
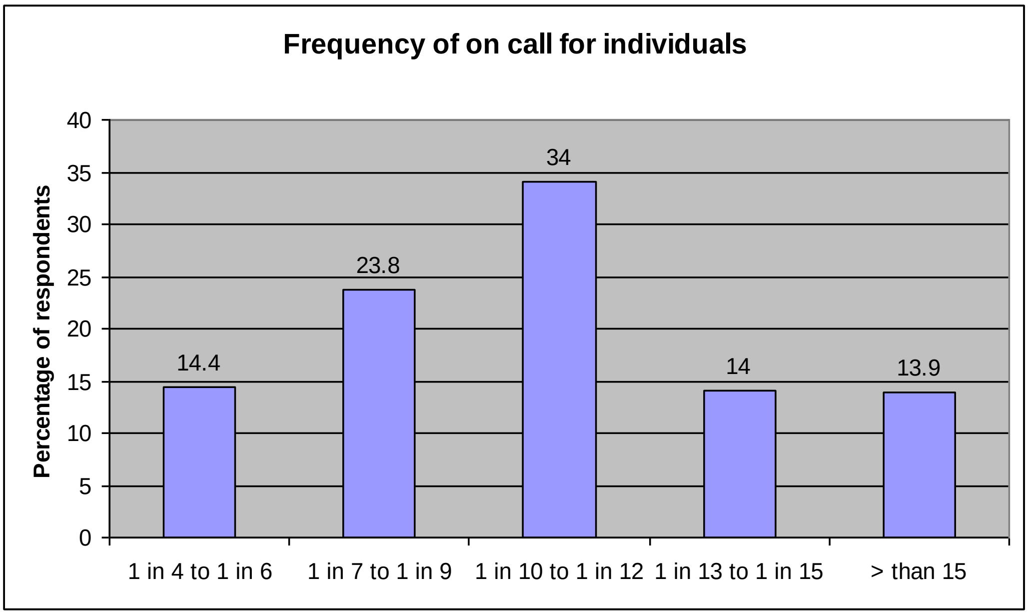
Figure 3 Frequency of on-call for the team



Consultants, who do not work with their team when on call, tend to have less onerous rotas than those who work on-call with their team. Working patterns differed between consultants and other team members and this was reported by 80% of consultants. The median frequency of on-call duties for individual consultants was 1 in 10 weeks and the frequencies are shown in Figure 4.

Figure 4 Frequency of on call for individual consultants



When on-call, 24% of consultants took part in a physician of the week system, where they were the named consultant responsible for general medical admissions. 54% of such systems separated weekdays and weekends, 30% covered the whole seven day week and 16% covered a block of days, rather than a fixed calendar.

The working patterns and operational conditions also varied quite considerably between hospitals and between nations. Whilst nearly all consultants (81%) worked a ward-based system, this varied by nation (Scotland 87%, England 83%, Northern Ireland 67% and Wales 54%; p=0.03). Consultants reported that 52% of hospitals integrated general medicine with care of the elderly (Wales 85%, England 53%, Northern Ireland 42% and Scotland 26%; p=0.006). Overall 67% of consultants had a designated ward for diabetes in-patients (Scotland 78%, England 69%, Wales 62% and Northern Ireland 25%; p=0.01).

2.3.3.1 General and specialist duties

Consultants reported that 69% of their physician colleagues had opted out of acute medical on-call rotas and this varied by nation (England 71%, Scotland 67%, Wales 29% and Northern Ireland 67%; p=0.01). Respondents reported that some specialties were more likely to opt out than others (Table 2-25).

Table 2-25

Medical specialties opting out of on call rotas	
Speciality	**Percentage (n=194)**
Cardiology	77
Neurology	56
Rheumatology	56
Renal medicine	42
Gastroenterology	23
Elderly care	13
Thoracic	11
Respiratory	11
Diabetes and endocrinology	9
Other *	6

* Other specialties included dermatology, haematology, oncology and pharmacology.

Most consultants (including both diabetes and other specialities) opting out were aged between 40 to 49 years of age:

up to 39 years	14%
40 to 49	58%
50 and over	28%

Consultants from designated teaching hospitals (42%) were more likely to opt out of general medicine than those from associated teaching (23%) or district general hospitals (34%) ($p<0.001$).

2.3.4 Contracts, programmed activities and clinics

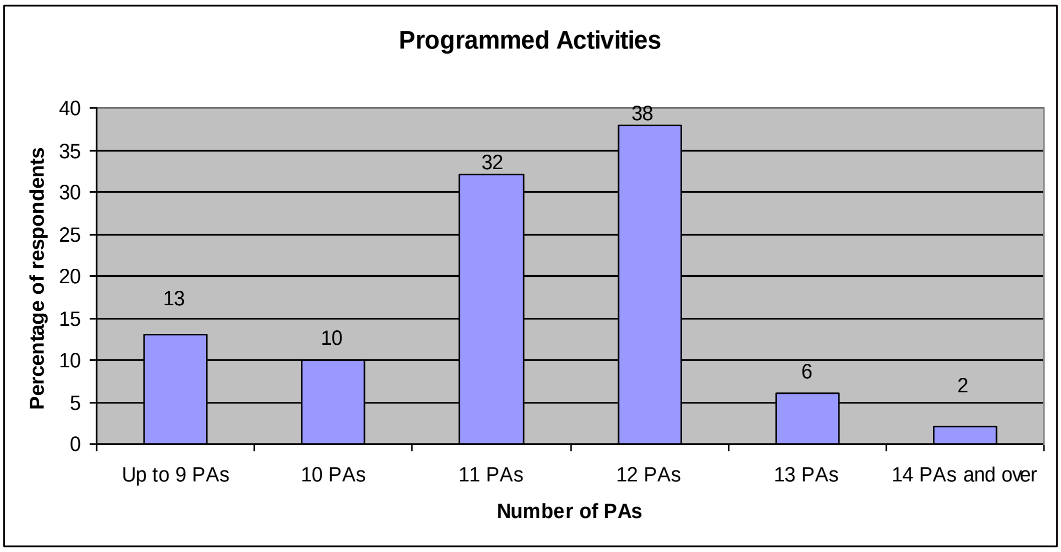
2.3.4.1 Contracts

92% of respondents were employed on the new NHS consultant’s contract, 5% were on university contracts, 1% on old NHS consultant contracts and 2% other.

2.3.4.2 Programmed activities

A programmed activity is a scheduled session of work time, such as an afternoon or morning consisting of a block of four hours. Most consultants worked full-time as on average consultants carried out an average of 11 programmed activities (PAs) (median 12, range 1 to 15) a week. Only 13% of respondents were part time consultants (up to 9 PAs) (Figure 5).

Figure 5 Average programmed activities for diabetes



When comparing full-time to part-time consultants by nation, there were proportionally more full time consultants (i.e. 10 programmed activities or more) in England compared to other nations (p=0.05) (Table 2-26).

Table 2-26

National comparison of part-time to full-time consultants		
Nation	**Part-time consultants (1 to 9 PAs) Percentage**	**Full-time consultants (10 PAs and over) Percentage**
England (n=221)	10	90
Wales (n=12)	33	67
Scotland (n=22)	23	77
Northern Ireland (n=12)	17	83

2.3.4.2.1 Programme activities for diabetes specialist services:

On average 3.4 programmed activities of consultant time were devoted purely to diabetes out-patient activity (range 0 to 8) while an average of 2.1 programmed activities was dedicated to diabetes in-patient activity (range 0 to 10). The average time devoted to endocrine activity was 1.2 programmed activities (range 0 to 7).

Some services operated within a different delivery model with consultants working within a community setting. The average number of programmed activities for this was 0.2 (range 0 to 6) reflecting this was still a small proportion of overall specialist service activity.

The number of programmed activities devoted to diabetes services was not affected by the well-resourced score; that is, those services which were better resourced did not have more PAs devoted purely to diabetes services than those which were identified as being not well-resourced.

2.3.4.2.2 Programme activities for acute-general internal medicine

The role of consultants, although specialists, still requires input into the running of the hospital general medical services. As a result, a number of programmed activities are dedicated to acute medicine. Respondents reported devoting an average of 2.8 programmed activities to acute medicine (range 0 to 10.5). This number varied depending on whether the consultant was full or part time. Part-time consultants worked proportionately more programmed activities in acute medicine compared to full-time consultants (p=0.03) (Table 2-27).

Table 2-27

Proportion of consultants time working in acute medicine			
	Percentage of time working in acute medicine		
Consultant	**0-30%**	**31-60%**	**61-100%**
Part-time consultants (1 to 9 PAs) (n=33)	52	39	9
Full-time consultants (10 or more PAs) (n=216)	72	24	4

2.3.4.3 Endocrine clinics

Most diabetes consultants (79%) also provide endocrine services as well as diabetes. These specialist endocrine activities included thyroid (78%), obesity (24%), lipid clinics (21%), metabolic bone-osteoporosis (16%), reproductive (14%) and paediatric-adolescent endocrine clinics (12%).

2.3.4.4 Comments on the impact of acute general internal medicine on speciality workload

192 consultants commented on the impact of acute medicine on speciality workload. These were divided broadly into positive (n=52, Table 2-28) and negative themes (n=210, Table 2-29).

Table 2-28

Positive themes reported on impact of acute medicine on speciality workload		
	Positive themes	**Number of counts**
1	Acute medicine is central to role and provides leverage with the Trust	20
2	Low or no impact from acute medicine	15
3	Efficient when system not overloaded, well managed and sufficient consultant numbers	15
4	Diabetes is a common accompaniment of the acute medical problem and diabetologists are best placed to manage both	2

Table 2-29

Negative themes reported on impact of acute medicine on speciality workload		
	Negative themes	**Number of counts**
1	Less time for speciality and to develop service	46
2	Increased acute and overall workload and difficulty balancing both roles	45
3	Cancelled and reduced sessions	42
4	Reduced junior doctor input into service due to rotas increasingly consultant led and juniors deskilled	38
5	Quality of care has reduced	23
6	Case mix (increase in chronic elderly care, need social care rather an acute)	10
7	Problems with poor rota system poor organisation and split sites	6

Often consultants commented that there was both '*less time for speciality and to develop service*' and '*increased acute and overall workload and difficulty balancing both roles*'. Despite this, consultants reported that their presence within acute medicine increased their visibility with Trust management.

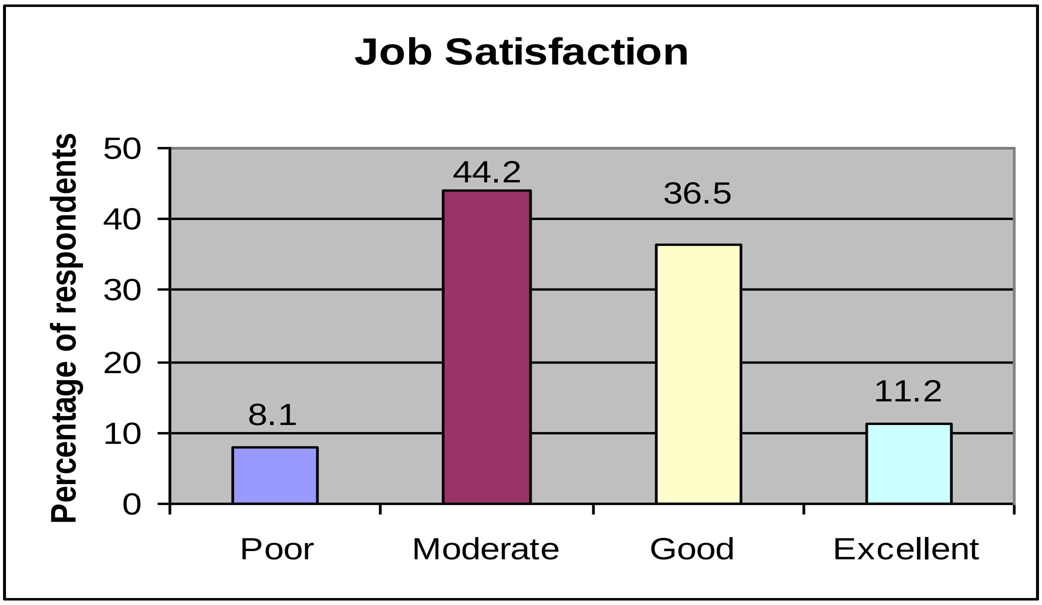
2.3.4.5 Cancelled clinics

As a result of commitments to acute medicine, 66% of consultants, 88% registrars and 44% of SHOs had to cancel diabetes clinics.

2.3.4.6 Job satisfaction

Nearly half of consultants expressed that they experienced good or excellent job satisfaction (Figure 6). Job satisfaction was not affected by having previously occupied a consultant post in another trust.

Figure 6 Job satisfaction amongst consultants



2.3.5 NHS System reform

At the time of the 2006 survey, new NHS bodies and funding mechanisms, such as practice based commissioning (PBC) and payment by results (PBR), were being introduced but not all organisations and partners were equally engaged in the new process. In England, over 99% of respondents were aware of practice based commissioning and 99% were aware of payment by results, yet only 17% of respondents were involved in discussions regarding the tariffs with commissioners and hospital business units.

63% of consultants were aware of the proposed tariffs for diabetes specialist services, but when asked specifically about the recommended tariff for a new diabetes consultation (which was at the time £247), none were able to provide the correct monetary value. 51% came within £10 (mean £215.18; median £241; range £80 to £388). Similarly when asked the recommended tariff for a follow up consultation only 4% gave the correct monetary value of £90 although 66% were within £10 (mean £80.53; median £86; range £30 to £180). This lack of information regarding new pricing structures corresponds with the figure of only 17% of respondents being involved in the discussions regarding tariff.

2.3.6 Best and worst issues of consultant post and/or most pressing concerns

Consultants provided their opinions on the best and worst issues of the consultant post and most pressing concerns for acute medicine and diabetes.

2.3.6.1 Acute medicine

Most comments were negative and concerned the high pressure through-put, lack of beds, poor ward facilities and ineffective discharge policies (Table 2-30). These issues when grouped together indicated fragmented services and organisational deficiencies. Positive comments included the diagnostically challenging aspects of acute medicine and the broad case mix encountered (Table 2-31) reflecting consultants’ interest in providing quality care.

Table 2-30

Worst aspects of acute medicine	
Worst themes	**Number**
High pressure through-put, lack of beds, poor ward facilities and ineffective discharge policy	59
Increasing workload and intensive	51
Less availability of junior doctors	37
Team fragmentation	32
Lack of continuity of care	29
Increased dependency of inexperienced juniors requiring an increasingly consultant lead service	28
Pressure of targets reducing quality of care	26
Poor morale, stress, quality of life and low job satisfaction	22
Less time for diabetes speciality	21
Impact of opt out of other specialties on ward case mix	14
Financial cuts, staff shortages and job losses	12
Harder to keep up to date and maintain skills in acute medicine	7

'Expectations of general medicine are rising- whenever anything comes up, it is always a specialty clinic that is cancelled' (quote from consultant).

Table 2-31

Best aspects of acute medicine	
Best themes	**Number of counts**
Diagnostically challenging and broad case mix	36
Robust integrated team approach to on-call	22
Enjoyable	20
Opportunities for teaching and training and recruitment into diabetes and endocrinology	15
Maintaining skills	7
The patients	5
Provides important role as perceived by Trust Executives	3

'I enjoy working on Acute Medical Unit where I can make a real difference to people early in their hospital admission' (quote from consultant).

2.3.6.2 Diabetes services

Once again most comments were negative (Table 2-32) reflecting the uncertainty of the political situation of the time. Changes to commissioning of specialist services, the shift away from secondary to community care with a fear of job losses was often reported. Positive comments centred on strong multidisciplinary teams, good team working and the challenging and satisfying nature of working within diabetes (Table 2-33).

Table 2-32

Worst aspects of diabetes care	
Worst themes	**Number of counts**
Commissioning, negative impact of central government policy on diabetes care and uncertainty over future e.g. Payment By Results/ Practice Based Commissioning, perverse incentives, policy intervention and creating divisions between primary and specialist services	94
NHS Funding/Finances/Deficits and no prospect of service development	47
Shift to primary care with limited capacity, lack of knowledge and experience and quality of care is variable	40
Lack of staff, downgrading of posts and job losses e.g. Downgraded, lack of DSNs, threats and job losses	32
Lack of understanding of complexity of diabetes, diabetes not considered a priority and poor management support	24
Specific diabetes services not adequately supported, e.g. education, psychology and retinal screening	24
Poor communication and collaboration primary care, PCT and specialist services	23
High workload and increasing prevalence	22
Loss of specialist skills, difficulty recruiting and training staff	20
Lack of time	10
Low morale	8
Service reconfiguration and fragmentation	8
Poor admin, facilities and Information Technology (IT)	8
Poor inpatient care	6
Acute medicine reduces time for speciality	2
Unrealistic patient expectations	1
Poor knowledge of hospital staff (not diabetes specialists)	1
Difficulty mixing community and acute work	1
Change in case mix	1

‘Uncertainty of practice based commissioning plus acute financial constraints of trust is putting morale at all time low. Almost certain that services will be cut further’ (quote from consultant).

‘There is a huge impact on morale of diabetes specialist teams from the threat of decimation of the service that we have worked so hard to develop’ (quote from consultant).

‘Inability to get funding for dietetic and psychology support due to the transfer of department of health (DOH) funding to primary care’ (quote from consultant).

Table 2-33

Best aspects of diabetes care	
Best themes	**Number of counts**
Good team and multidisciplinary team working and expertise	39
Enjoyable, challenging and satisfying	25
Good quality, well organised service and facilities	20
Patients and developing long term relationships with patients	19
Good network and engagement with primary care	15
Specific diabetes services supported	10
New treatments, therapies and involvement in research	8
Good staffing levels	2
Good training	2

‘Excellent team with close working relationships’ (quote from consultant).

2.4 Discussion

2.4.1 Response rate

The survey achieved fewer responses than expected from consultant physicians with an interest in diabetes. Having achieved a response rate of 77% in 2000 (41), the 2006 survey response rate of less than half (48%) of consultants from across the UK was disappointing. Responses were particularly low from Scotland, Wales and Northern Ireland. This was discussed within the working group and reasons may have been due to the political shift at the time and workforce uncertainty. Consultants were under pressure to provide information to their own management, national audits and for the first time to the formative external commissioning bodies as well as to surveys such as this.

To determine if the results of this survey were representative of consultants in general, extra analysis was undertaken. The characteristics of respondents were broadly comparable to the respondents in the RCP manpower survey (29; 76). The survey findings were strengthened by the sub-group analysis of the 123 comparable hospitals from both 2000 and 2006 with similar changes to the overall findings.

2.4.2 Status of diabetes services

In general the results demonstrate an improvement in the medical, nursing, dietetic and podiatry staffing levels since 2000. As podiatry and dietetic support had increased, there appears to have been a shift in the way diabetes services were delivered as a function of a multidisciplinary team as opposed to a medical service delivery. This was an expected outcome after the introduction of the NSF for Diabetes and a national commitment to enhancing diabetes specialist services although there was no dedicated central Government funding to the NSF to ensure implementation. Consultants also identified specialist team members as being one of the key strengths of their service and described these individuals as being highly skilled, expert and motivated. Many described excellent team working as one of the best aspects of their diabetes service.

The extent of improvement and the improvements themselves seemed to be jeopardised by cuts in specialist services identified by the consultants in the qualitative sections of the survey. This was confirmed to some extent by a survey of DSNs carried out by Diabetes UK where up to a third of respondents reported staffing cuts or identified one or more cuts to their service (77).

Even though the number of consultants had increased, 10% of all services still operated with the support of a single handed consultant and the number of consultant physicians providing diabetes services remained lower than the Royal College of Physicians and specialist organisations recommended level (29; 76).

Single handed consultants were less able to provide a well-resourced service. Where there was more than one consultant, it was easier to manage the workload from acute medicine and other internal hospital pressures, as well as to develop the diabetes services and to provide leadership when working in the community with primary care. It also appeared that despite the increase in the number of consultant diabetologists, the time devoted to diabetes services had not increased proportionately.

In 2000 consultants reported that they devoted at least 40% of their time to diabetes compared with 26% in 2006 (78); however, changes in the methodologies used in the two surveys and changes in the consultant contract make direct comparison difficult. With three quarters of current consultant diabetologist job plans devoted to non-diabetes related activities, at the time of the survey, it was estimated that at least three whole time equivalent consultant diabetologists would be necessary to serve a 250,000 population in order to meet the standards set out in the NSF (78). Since the survey was undertaken, this has been reviewed and the number of physicians needed to deliver diabetes services and to lead the multidisciplinary diabetes team in any area is dependent on the number of sessions devoted to diabetes care (79).

The number of DSNs had increased since 2000 although as with the consultants' figures, this was still below the number recommended following the year 2000 survey (35). As noted before, this increase may have been superseded by cuts identified by the Diabetes UK DSNs agenda for change survey (77). The impact of the relocation of specialist services into the community upon the working patterns of DSNs was unknown and is explored in more depth in the survey of DSNs (Chapter 5). However, it is fair to assume that there will be greater demands on hospital based DSNs with the increase in the prevalence of diabetes and the subsequent staffing requirements for inpatient diabetes care. In a similar way, there have been improvements in dietetic and podiatric support, although numbers, as with other members of the diabetes specialist team, remain below recommendations made previously (42-44).

2.4.3 Well-resourced score

Overall services achieved lower scores in 2006 compared to 2000 with significant regional and national variations. In some clinical areas, improvements were achieved such as educational input and joint antenatal diabetes specialist services.

The impact of the introduction of the QOF into general practice in 2004 may have been responsible for the improvement in the measurement of key diabetes medical indicators such as lipid profile and microalbuminuria. However, a significant number of important but non-medical indicators of diabetes care still require development, including erectile dysfunction, care for the elderly, the supply of adequate integrated information systems and collaborative working with ophthalmology and paediatrics.

Indeed some aspects of service provision were still considerably under-resourced such as access to psychological support, which had been identified by a series of reports (41; 47; 80) despite being a core standard in the NSF (1). It may be that those services where funding had been ring-fenced, such as retinal screening and GP-based registers, services had been able to develop. In contrast where this funding was not available, service development was restricted. Therefore previous lack of investment meant that the well-resourced score overall did not improve from 2000 to 2006 despite increases in staffing levels and additional resources to improve diabetes services and fulfil the NSF.

The well-resourced score used in the year 2000 survey demonstrated regional and national variation between services and this was also evident within the 2006 survey; in England, services in the North tended to be better resourced and those in the eastern region had the lowest resourced levels. Diabetes services and consultant staffing levels in Northern Ireland were shown to be under-resourced compared to the other nations. The differences between the nations may reflect the different stages of health reform being undertaken at the time of survey, such as practice based commissioning which was unique to England and devolution not having taken place in Northern Ireland at the time of the survey.

2.4.4 Working methods in hospital

Consultants with a special interest in diabetes and endocrinology seem to be facing a growing tension between providing diabetes specialist services and acute and general medicine. As senior physicians from other specialities opt out of acute medicine, a greater burden is being placed on consultant diabetologists to provide these services. Consultants felt that they did not have enough time for their speciality and found it difficult to balance both roles. On the one hand, involvement in acute medicine was seen positively by diabetologists as acute medicine was seen as central to the role of the consultant, as being enjoyable and diagnostically challenging, providing important leverage with trust managers and many enjoyed the opportunity to develop long term relationships with patients. Many of these themes identified were also voiced in the study by MacLeod (45) where consultants were concerned about the amount of time spent in general medicine preventing them from fulfilling other roles and the trend for colleagues opting out of general medicine.

There were demonstrable problems with the sheer volume of work, poor ward facilities and pressure to meet targets without compromising care. The impact of the European Working Time Directive, which reduced the hours of junior doctors and significantly altered the way in which physicians of all levels could be utilised, meant there was less support available from junior doctors. It was felt by consultants that junior doctors were becoming comparatively de-skilled and inexperienced as a result of less time and exposure to a wide range of disciplines and they were becoming increasingly dependent on senior staff. These pressures also meant there was less time available to develop the diabetes service, to train and recruit junior doctors into diabetes and to provide leadership and training in the community to primary care colleagues. This was also corroborated by MacLeod (45) where respondents were concerned about the continuity of diabetes care for patients being compromised by the changing shift patterns for junior doctors and also about trainees experience of diabetes and the amount of time they were able to spend on diabetes as a speciality.

2.4.5 Recruitment

Recruitment of new consultants was adversely affected by the perception of a reducing role for specialist care as a result of the perceived shift of diabetes services into the community under the direct control of GPs and primary care. There were concerns that this could in the future lead to a skills gap with fewer specialists available to deliver care and to train primary care staff. MacLeod also identified a consensus that the demands of general medicine combined with the impact of the

European working time directive may have an adverse effect on the ability of diabetes services to encourage junior doctors into the specialism. Both MacLeod and this present survey described how a lack of exposure to the more stimulating aspects of diabetes could deter junior doctors.

2.4.6 NHS System reform

In England, at the time of the survey in 2006, the Government policy was to shift care closer to the patient's home via primary and community care services. There were considerable concerns voiced by the consultants that they were not engaged with primary care in the planning and commissioning of diabetes services and it was felt that moving complex cases into the community without specialist involvement in the service reconfiguration could jeopardise patient care. This shift in patient care within diabetes had led to fears that hospital services were being cut and would be cut further despite the work load actually increasing due to the increasing prevalence of diabetes.

Very few consultants accurately knew the proposed monetary value of new tariff prices, and as a result consultants felt that the lack of engagement in practice based commissioning and payment by results could divide and fragment diabetes services. Consultants also felt that without specialists being involved in service redesign, commissioners may not be aware of the complexity of diabetes, which may result in diabetes not being prioritised, being poorly valued and that services may lose essential investment to ensure sustainability. This led to low morale, possible future problems in recruiting and feelings of uncertainty for the future of diabetes services.

2.4.7 Conclusion

The survey was not able to describe whether diabetes services were achieving the standards set out in the NSF, unlike the surveys of psychological services and paediatric and adolescent services which are described in later chapters, where specific questions were asked against quality standards. This was because there were few numeric standards against which data could be gathered. Despite this, the survey was able to provide a clear picture of the status of diabetes services at the time of the survey in 2006 from the consultant and secondary care perspective, of the increases in staffing levels and changes in other aspects of service delivery since 2000 where there had been mixed responses and geographical variations.

Psychological services for people with diabetes

3.1 Introduction

It has been estimated that up to 41% of people with diabetes also suffer with poor psychological well-being (48; 81) which can have an impact on the diabetes self-management (82). It is vital that there are services in place to support the person with diabetes with the day to day challenges of living with a complex condition.

The aim of this study was to describe and quantify the provision of psychological services for adults with diabetes and the extent to which national guidance was being met. It aimed to examine all diabetes services in the UK, to examine perceived gaps in services and identify what deficiencies and improvements in services were needed.

3.2 Method

3.2.1 Role of the working group

The following relevant experts made up the working group for the psychological survey:

- Khalida Ismail – Senior Lecturer, Department of Psychological Medicine, Institute of Psychiatry, King's College London.
- Peter Trigwell – A representative of the Healthcare Delivery Working Group of Diabetes UK and Consultant in Liaison Psychiatry/ Associate Medical Director for Specialist Services, Department of Liaison Psychiatry, Leeds General Infirmary/ Leeds Partnerships NHS Foundation Trust.
- Tim Nicholson – Research Fellow, Department of Psychological Medicine, Institute of Psychiatry, King's College London.
- John Paul Taylor – Clinical Lecturer in Old Age Psychiatry, Institute for Aging and Health, Wolfson Research Centre, Newcastle University.
- Charlotte Gosden – Information Analyst, Policy Care & Improvement Team.

3.2.2 My role in the research process in this study

- Develop research questions, questionnaires, respondent lists, data analysis protocols, reporting mechanisms.
- Hold and manage contact database and overall timeline.
- Distribute questionnaires and data collection of questionnaires.
- Guide data analysis through discussion, email, telephone contact and meetings.
- Assist report writing through discussion and commenting on drafts.
- Assist journal publication through discussion and commenting on drafts.
- Support the oral presentation of results at national conference.
- Co-ordinate meetings with the working groups, take minutes, distribute minutes, organise meeting rooms and follow up on actions raised during meetings.
- Distribute results through Diabetes UK and partner agencies to support policy work and provide detailed information to support the lobbying function at Diabetes UK. Act as the representative and information expert for Diabetes UK to partners working groups such as NHS Diabetes, Department of Health, Royal Colleges and Kings Fund to disseminate findings.
- Inform the results of the research to Diabetes UK membership via newsletters, website and magazines, to other teams for press releases, parliamentary questions and lobbying.

3.2.3 Setting

The research was carried out in adult diabetes specialist services in both acute and primary care trusts across the UK.

3.2.4 Study participants

For Part one of this survey design, I sent questionnaires to consultant diabetologists in all diabetes services in the UK (n=464). The list was generated from:

- Diabetes UK internal database of diabetologists derived from earlier surveys.
- Binleys Directory of NHS Management (83).
- The Directory of Diabetes Care. Loughborough: CMA Medical Data, 2006 (84).

Paediatric and special purpose units, for example, retinal screening units, were excluded. Often there were two contacts for each service, most frequently a doctor and a nurse. However, some had only a nurse contact and a few just had a doctor contact. Where there were multiple nurse contacts for a service, I sent the survey to the senior nurse (if indicated) or the first on the list. Where there were multiple doctors within a service, contact was made with the first diabetologist on the list, or if none, the first consultant physician on the list, or if none, the most senior doctor, for example, a general practitioner with a special interest (GPwSI).

In the questionnaire the diabetes team were asked for the contact details of the 'psychological' experts working within or associated with the multidisciplinary team. These experts included; counsellors, psychologists, liaison psychiatrists, psychotherapists, or 'other'. Of the three services which provided more than one contact, Tim Nichols and John-Paul Taylor asked for the most appropriate individual to take part in the second part of the survey design which was a structured telephone interview.

3.2.5 Survey development

3.2.5.1 Aim of the survey

The aim of the psychological survey was to examine the existence and nature of psychological services for people with diabetes aged 17 years and older in all UK diabetes services. The survey was developed using information from the Dr. Foster 2004 survey on the provision of psychological services and pilot work by Dr. Peter Trigwell (consultant psychiatrist, Leeds).

3.2.5.2 Special issues: brief background

At the time of survey design, it was estimated that approximately 41% of people with diabetes suffered with poor psychological well-being, and that the rate of depression was doubled in people with diabetes. Treatment for psychological problems, such as depression, can lead to reduced symptoms and better glycaemic control. However, many diabetes services do not have access to psychological support and little was known about the nature, scope and extent of services available.

3.2.5.3 Topics

These included the:

- Availability of any service element that specifically focuses on the psychological needs of people with diabetes.
- Nature of such service elements, where they exist.
- Discipline/ professional group of those providing the service; counsellors, psychologists, liaison psychiatrists etc.
- Level of diabetes experience of the professionals providing the service.
- Nature of psychological problems seen within the service.
- Style of input and types of therapeutic approaches.
- Size and scope of the service; sessions available per week, settings in which it is provided.
- Accessibility; waiting times, urgent/ non urgent elements of the service.
- Relationship between those providing any specialist psychological service and the rest of the diabetes care team; whether or not the psychological service element was seen as integral to the diabetes team.
- Other elements of the service offered in addition to direct clinical care; liaison with the team, educational elements, case discussion and supervision for members of the diabetes team.
- Quality and standard of existing services, as measured in relation to the requirements of the NSF for diabetes and relevant NICE guidance.
- Perceived gaps in services.
- Organisational aspects; management arrangements for those providing the psychological service, whether these were the same as or different from those of the rest of the diabetes team.

3.2.5.4 Structure of the survey

The survey was designed and carried out in two parts in order to gain the detailed information required (Appendix B).

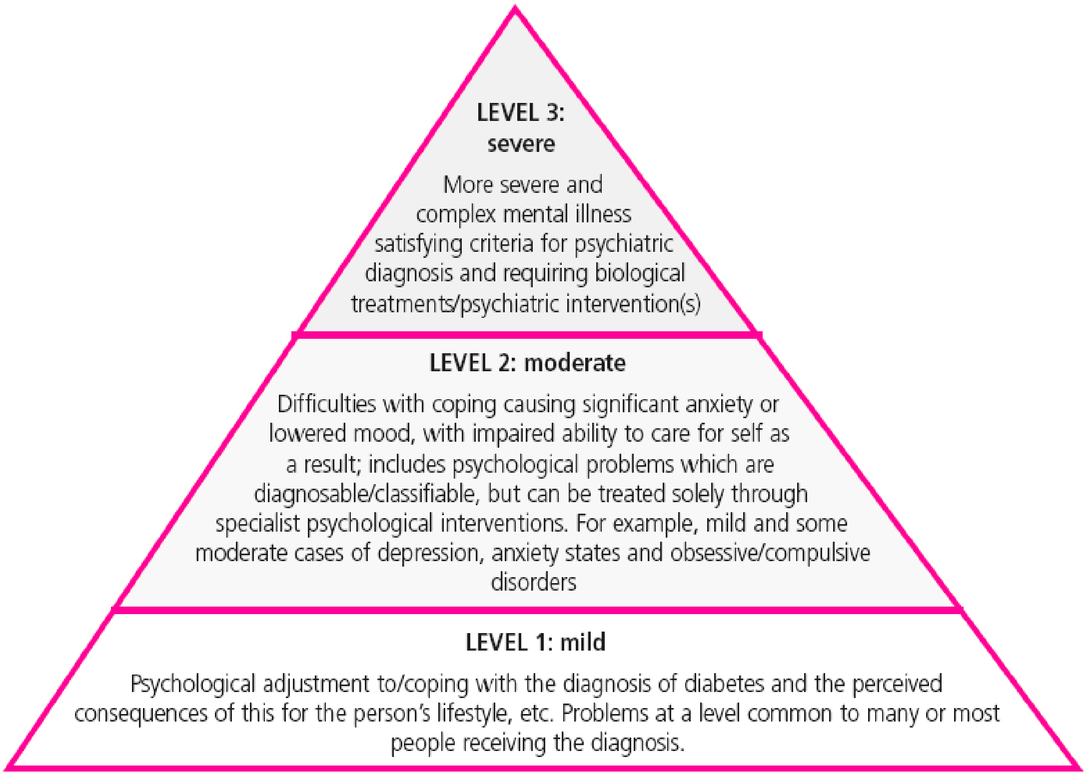
Part one was a postal questionnaire which covered basic questions on the diabetes team membership and focused on care provided by the ‘non-psychological’ members of the team, the ability of the ‘non-psychological’ specialist members of the team (for example, the DSN) to help people with psychological problems and service compliance with the relevant standards and requirements laid out in the NSF for diabetes and NICE guidance for diabetes.

One of the questions in Part one asked the responder to identify a key psychological team member if they have one (for example, psychologist, psychiatrist or other mental health professional such as psychiatric nurse) and to give contact details including email and telephone numbers. This was to allow members of the working group (Tim Nichols and John-Paul Taylor) to contact the individual for Part two.

Part two consisted of structured telephone interviews, carried out by Tim Nichols and John-Paul Taylor, with the ‘psychological’ specialist. The interviews explored the care provided by the ‘psychological’ specialist, the nature, accessibility, coverage, setting and organisation of the service and the perceived gaps in service provision for emotional, psychological and mental health problems in people with diabetes.

To help those completing the questionnaire or giving telephone interviews, and ensure a consistent approach, a pyramid detailing levels of psychological problems or needs was developed (Figure 7). Initially this contained five levels, but following the piloting process, this was simplified to three levels (85). I included the three level pyramid in the Part one postal questionnaire and it was also sent to the telephone interviewees in an introductory email at least one week before they were telephoned for the Part two interview. Both parts of the survey focussed exclusively on **LEVEL 2** (termed ‘moderate psychological problems’):

Figure 7 Figure to show pyramid of psychological problems



3.2.6 Pilots

In a similar way to the consultant survey, the psychological questionnaire was piloted with five participants who were members of the Diabetes UK Healthcare Delivery Working Group and included a DSN, consultant diabetologists, clinical psychological, diabetes service manager and a liaison psychiatrist.

3.2.7 Distribution of the questionnaires

I sent Part one of the psychological survey out as a paper questionnaire in the post and Part two was conducted as a semi-structured interview over the phone by Tim Nichols and John-Paul Taylor with selected respondents.

3.2.8 Timeline

The postal questionnaire was sent out on the 10th August 2006 and replies were collated until November 2006. A second questionnaire was sent out to all non-responders on 14th September 2006. If there were still no response, I followed this up by telephone calls in an attempt to increase the final response rate.

For Part two, email invitations to take part in the telephone interviews were sent to the named contacts provided in the postal questionnaires by Tim Nichols and John-Paul Taylor. The email included the three level pyramid of psychological problems. Those not responding to emails were sent up to two reminders before being telephoned to check that their details were correct and that they were still in post. If the contact details were incorrect (this occurred in approximately half of the cases), or the individual was no longer in post, the relevant hospital was contacted to ask for the correct details, or for the new post holder allowing a further contact by email and/or telephone. In contrast to the other surveys, where lists of contacts were available from professional bodies, previous surveys or directories, there was no pre-existing list of contacts of this kind for part two of the psychological survey. Thus a further aim of this survey was to develop a directory.

No upper limit was set for the number of emails or telephone calls that were attempted, as it emerged that a lack of, or delay in, response was not associated with being unwilling to participate and was more often a function of time pressures on the individual. Although this was an anecdotal observation, it was frequently recorded in the telephone follow up conversations, as respondents were willing to take part, once consent had been gained, as a high response rate to this part of the survey was achieved.

3.2.9 Data management and data cleaning

3.2.9.1 Data analysis

The data analysis for the psychological survey were carried out by John-Paul Taylor and Peter Trigwell and guided by the working group. In addition to the chi-square analysis for categorical data, to determine the effect of several variables on dichotomous outcomes, saturated log-linear modelling was used; for analyses considering multidisciplinary team size effects, size was divided into three groups:

- Large (greater than 15 team members).
- Medium (less than or equal to nine to 15 team members).
- Small (less than nine team members).

3.3 Results

3.3.1 Response rates

The response rate to the Part one postal questionnaire was 58%. A response rate of 80% for the part 2 telephone interviews was achieved which was considered to be representative (86) (Table 3-1).

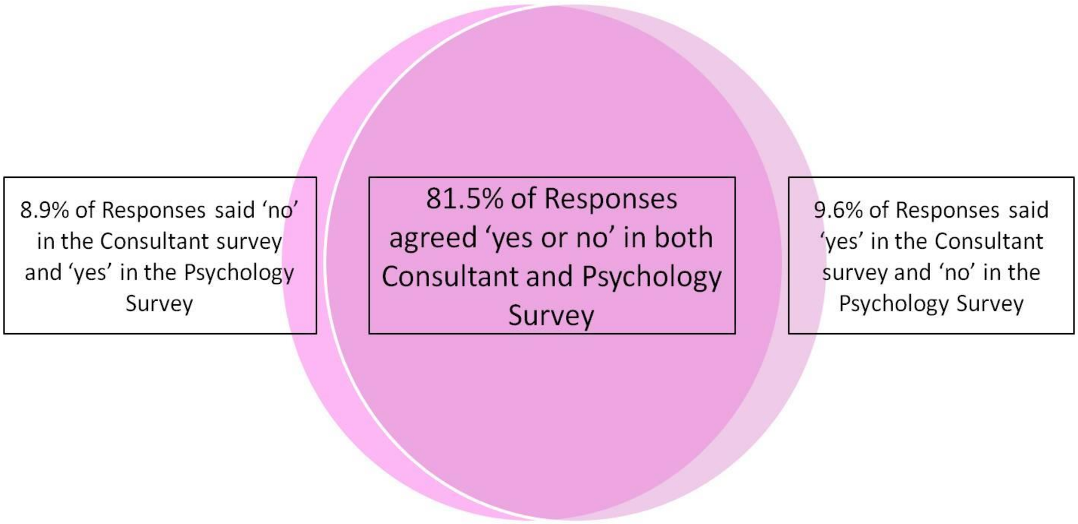
Table 3-1

The response rates to part 1 and part 2 of the survey

Part 1 (postal questionnaires)	**Number**	**Percentage**
Questionnaires sent out	464	100
Non-responders	197	42
Responders/ those included	267	58
Number with an expert provider of psychological services	84	31.5
Number providing contact details for part 2	66	25
Part 2 (telephone interviews)	**Number**	**Percentage**
Contacts attempted	66	100
Non-responders	13	20
Responders/ interviewed	53	80

Where respondents from the consultant survey matched respondents to the psychological survey, concordance was found to the basic question of whether or not the centre had access to a psychological service in 81.5% of cases. Discordant results are shown in Figure 8. The 81.5% concordance between the two surveys is a further indication of the reliability of the psychological services survey and the difference may reflect changes over time in the provision of psychological services in certain centres.

Figure 8 Figure to show concordance in response to presence of a psychological service between consultant year 2006 survey and psychological survey



3.4 Part 1 of survey: postal questionnaires

3.4.1 Teams and services

3.4.1.1 Multidisciplinary diabetes team

A broad range of professionals need to be available to care for the health needs of adults with diabetes, however, in most centres, provision for their mental health has been neglected by those commissioning services for many years.

Overall the mean multidisciplinary team size was 12.7 people. Teams in both acute and primary care settings included consultant diabetologists, diabetes specialist nurses, consultant nurses, junior doctors, dietitians, podiatrists, physiotherapists, and 'others' (Table 3-2). In the main, teams were formed of consultants and DSNs with resources from podiatry and dietetics being also somewhat limited.

Table 3-2

Multidisciplinary team composition and size	
Multidisciplinary team position	**Mean (range)**
Consultants	2.3 (0 to 8)
DSNs	3.6 (0 to 12)
Dietitian	1.3 (0 to 10)
Podiatrist	1.5 (0 to 8)
Physiotherapist	0.04 (0 to 3)

3.4.1.2 Psychological services provision/ expert psychological input

Despite the high prevalence of psychological and emotional problems experienced by people with diabetes, and the need and demand for support and care for those problems, only 32% (84/267) of respondents stated that their team had some form of specialist psychological care available to them (Table 3-3).

Table 3-3

Multidisciplinary team composition	
Psychological expert	**Percentage of services (n=84)**
Psychologist	57
Liaison psychiatrist	18
Other (psychiatric nurses trained in cognitive behavioural therapy (CBT), psychology students	18
Counsellor	4
Psychotherapist	4

Where psychological services did exist, most provision was from high level clinicians with a small percentage being provided by counselling services. This would seriously limit capacity as clinicians working at this level have a limited caseload across a range of patients. Centres employ different types of professional to provide psychological input, for example, psychologist or liaison psychiatrist. This indicates a lack of clear planning and differing rationales, and guidance for the development of these services. Many such services seem to have developed according to the interest of the local professionals, for example, if a hospital has a psychologist or psychiatrist with an interest in diabetes, this person is then available to the diabetes service, but if such a professional is not present, it is likely that access to specialist help will be absent.

3.4.2 Non-psychological team elements

3.4.2.1 Coverage of psychological care issues

In addition to the lack of specialist psychological input described above, basic psychological components of care have also been neglected. Only a third of services had a telephone advice system in place which could provide any form of psychological support and just over 10% used any defined screening and assessment tools for psychological problems. Almost 80% had no protocols or guidelines for referral of patients with psychological problems of moderate severity (Table 3-4).

Table 3-4

Coverage of psychological care by non-psychological team members (n=267)

	Yes Percentage	No Percentage	Don't know or not filled in Percentage
A telephone advice system providing psychological support	29	66	5
Protocols or guidelines for referral to psychological services for patients at level 2	15	79	6
Adequate referral route to psychiatric services for patients at level 3	49	39	13
Screening/ assessment tools for psychological well-being used by your 'non-psychological' team members	12	81	7

For those with more severe psychological and psychiatric issues, the situation was better as approximately half of the respondents had referral pathways for the care of patients with such problems. However, this may be because nearly all centres have some form of local psychiatric provision, although this was likely to be a generic mental health team in which understanding of the issues which relate to diabetes may be limited or absent altogether.

Often the needs of people with diabetes have been missed as the majority of those with psychological conditions, such as depression, eating disorders or an anxiety state fall below the threshold or specified level of severity or duration to receive a diagnosis and the assistance of the generic psychiatric teams. It is not only the higher levels of the pyramid which are lacking support but also the lower levels. Indeed from Table 3-4 it can be demonstrated that patients are not being screened in a uniform systematic fashion and progression through the pyramid of care would be at best delayed and at worst impeded.

3.4.2.2 Training in psychological therapies

Encouragingly 41% of diabetes teams had at least one ‘non-psychological’ team member who had received some training in identifying and managing psychological problems. This was mainly in counselling or motivational interviewing (Table 3-5).

Table 3-5

Training received by team members (n=267)	
Training	**Percentage of respondents**
Counselling	35
Motivational interviewing	32
Cognitive behavioural therapy	10
Group therapy	4
Other	4
Family or couple therapy	3
Psychodynamic psychotherapy	1

What was not clear from the survey was how training was defined and if this resulted in a qualification or accreditation or change in clinical practice. This was because the nature of the training was interpreted by the person responding who may not have been familiar with the depth of training received by all the multidisciplinary team. Despite this, it is encouraging that these staff members have received some instruction in the use of psychological techniques suggesting an interest from the staff in emotional and psychological support.

3.4.2.3 Guidelines for the management of common diabetes issues

There seems to be a lack of availability of guidelines within the diabetes services for the management of common diabetic issues that have a bearing on the psychological problems experienced by people with diabetes. This should be addressed in order to meet the standards set within national guidelines. Where guidelines were in place, psychological issues relating to these common diabetic issues were only considered in 36 to 66% of cases (Table 3-6).

Table 3-6

Presence of guidelines for management of common diabetic issues (n=267)		
	Yes, had general guidelines Percentage	**If yes, do they consider psychological issues? Percentage**
Difficulties with self-management (e.g. persistently high HbA_{1c} greater than 10% (86 mmol/mol))	35	37 (n=93)
Recurrent diabetic ketoacidosis	35	36 (n=94)
Low Body Mass Index (BMI)	12	55 (n=31)
Eating disorders (binging, bulimia, anorexia)	12	66 (n=32)
Morbid obesity	26	46 (n=69)

3.4.2.4 Perceived skill level of ‘non-psychological members of diabetes teams in managing psychological issues

Responders felt that their teams were reasonably skilled in managing the common tier 1 psychological and self-management issues, such as problems with self-management of diabetic medications and needle phobias. As the complexity of the psychological issue increased, the perceived level of skill decreased in the ability of the team to manage these issues, for example, depression, anxiety or eating disorders. Responders felt the more difficult or complex tier 3 psychiatric issues, such as psychosis, would be poorly managed by their teams (Table 3-7).

Table 3-7

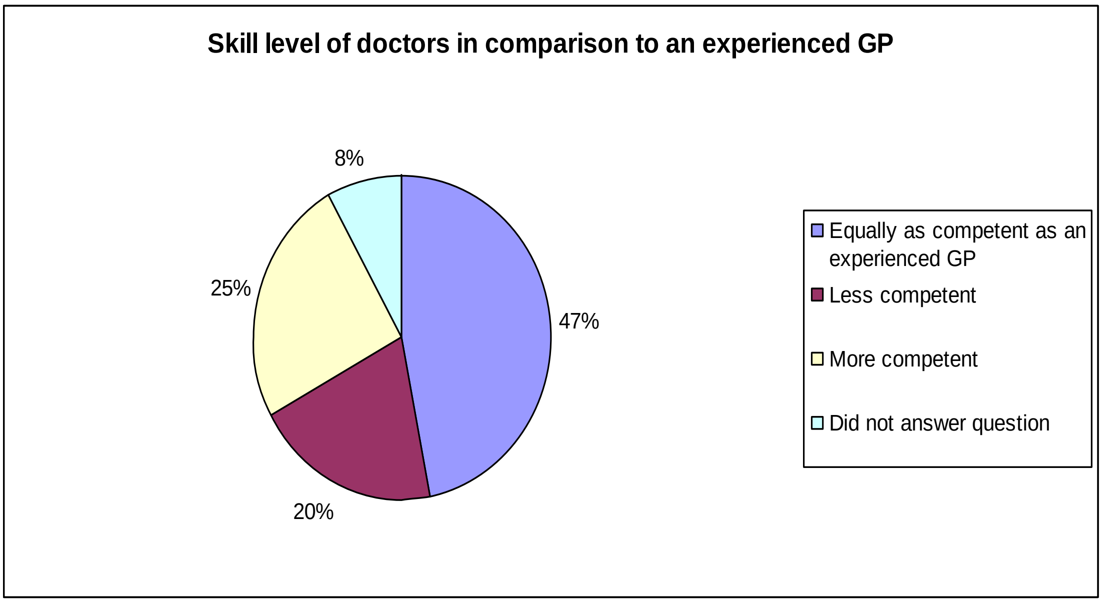
Perceived teams' ability to deal with psychological problems of people with diabetes (n=267)

		Excellent Percentage	**Good Percentage**	**Moderate Percentage**	**Poor Percentage**	**Not filled in Percentage**
Tier 1	Problems with self-management (adherence/ compliance)	14	58	24	3	2
	Needle phobia	9	40	39	10	2
Tier 2	Depression	1	15	58	24	2
	Other anxiety disorders	2	13	55	27	3
	Eating disorders	0.4	16	42	39	3
	Psychosexual problems	0.7	17	31	48	3
	Drug and alcohol problems	1	11	42	43	3
Tier 3	Suicidal patients and self-harm	2	9	27	58	4
	Psychotic illness	1	7	18	70	4

3.4.2.5 Skill level of doctors

The NICE guidance on diabetes suggests that 'for physicians a degree of competence in managing depression and psychological issues (in diabetes) at least matching that of an experienced GP is clearly desirable'. Most responders rated their doctors as the same or better than an experienced GP; however, there was still a large proportion who felt that the diabetologists' skill was less than that of a GP indicating a need for ongoing training in psychological issues (Figure 9, n=267).

Figure 9 Skill level of doctors compared to an experienced GP



3.4.2.6 Service provision issues raised by the NSF for diabetes and NICE guidelines

The overriding response from the multidisciplinary team was that nearly all thought more psychological staff were required. Most responders felt that the standards and guidelines in place are necessary. However, only 2.6% of centres complied with all six standards and recommendations. 64% did not comply with three or more of the six standards and recommendations and 26% did not comply with any. In those diabetes teams which did not feel they were able to meet with NSF 3 or 12, only a minority felt they were taking steps towards meeting them. For the NICE guidelines, most felt they would benefit from more training to meet the recommendations.

Standard 3 of the NSF requires the provision of 'person-centred care' which includes counselling and behaviour change support skills. Most respondents felt that this was necessary but only a third felt that their service was able to provide this. Standard 12 requires ‘regular surveillance for and effective management of depression’, the majority of respondents felt this was necessary but only a quarter were able to provide this or were taking steps to provide this.

According to NICE guidelines ‘multidisciplinary teams should be alert to the development or presence of clinical or subclinical depression and/or anxiety, especially if there are problems with self-management’. The majority of respondents agreed that this was necessary but only a quarter of the multidisciplinary team’s provided for this adequately. Over two thirds felt that more training of the multidisciplinary team was required and nearly all felt more psychological staff were required.

Diabetes professionals should be able to ‘detect and basically manage non-severe psychological disorders in people from different cultural backgrounds.’ Most respondents agreed this was necessary, but only a third felt their multidisciplinary team (MDT), was able to do this.

Diabetes professionals should be ‘familiar with counselling techniques and drug therapy, while arranging prompt referral to specialists, especially if there is significant interference with well-being or diabetes self-management’. Most respondents agreed this was necessary, a third felt that their MDT was able to do this.

Diabetes teams should be ‘alert to eating disorders and insulin dose manipulation if there is either, poor glucose control, low BMI or over-concern with body shape and weight. Early, and occasionally urgent, referral to local eating disorders services should be considered’. Nearly all agreed this was necessary, a third thought their MDT was able to do this, just under two thirds felt more training of the MDT was required and nearly all thought more psychological staff were required (Table 3-8).

The findings show that there is a lack of access to services for people with diabetes which is concerning and has implications for those commissioning services to ensure compliance with national guidance. Psychological experts have an important role to play in terms of providing education, training and advice as well as direct clinical care. In order to be compliant, it is vital that the whole diabetes team is aware of the requirements and develop a clear action plan to address shortfalls in service provision.

Table 3-8

Compliance with NSF standards and NICE recommendations (n=267)				
National guidance or standard	**Agreement that the guidelines are necessary Percentage**	**Currently meeting the guidelines Percentage**	**Actively addressing any deficit Percentage**	**Requirements, identified by multidisciplinary teams (MDTs), to meet guidance/ standards Percentage**
NSF Standard 3: counselling/ behaviour change support skills	97	64	39	Not asked
NSF Standard 12: depression surveillance and management	90	72	24	Not asked
NICE 1: alert to depression/ anxiety	99	24	Not asked	MDT training: 68 Psychological staff: 87
NICE 2: detect and manage non-severe psychological problems across cultures	94	37	Not asked	MDT training: 53
NICE 3: familiar with counselling and psychiatric medication	92	38	Not asked	MDT training: 52
NICE 4: alert to eating disorders	99	35	Not asked	MDT training: 60 Psychological staff: 83

3.5 Part 2 Telephone Structured interview with the specialist psychological staff

One of the most important and concerning findings of the survey was that only 32% of responding UK services had any psychological expert in or associated with their multidisciplinary diabetes team. 66 centres (25%) gave contact details of an expert provider of psychological services, of whom 53 (80%) were interviewed by telephone.

3.5.1 Psychological team elements

3.5.1.1 Specific psychological services at pyramid level two and adult age range covered

91% of responders stated that there were specific psychological services provided for people with diabetes who have psychological problems at level 2 of the pyramid. This refers to moderate psychological problems such as difficulties with coping causing significant anxiety or lowered mood. These are the core services for psychological experts to help people with diabetes.

76% covered the full adult age range from 17 years and above, 19% covered 17 to 64 years and 2% covered ages 65 years and over only. It was encouraging that three quarters of services cover the full adult age range from 17 years and above.

3.5.1.2 Types of psychological disciplines available

Teams offered a wide range of psychological therapies including:

cognitive behavioural therapy	93%
motivational interviewing	77%
counselling	72%
family or couple therapy	64%
group therapy	42%
psychodynamic therapy	28%
other (3 did not answer the question)	36%

In line with NICE guidance and the emphasis on the Department of Health’s ‘Improving Access to Psychological Therapies’ (IAPT) programme (87), over 90%

of services were offering Cognitive Behavioural Therapy. This was followed by motivational interviewing, counselling, family and group therapy as common therapeutic approaches provided.

3.5.1.3 Sessions provided

Individual psychological experts provided a median input of 2 (range 0.25 to 11) sessions per week to diabetes team (a session would last four hours, equivalent to a consultant programmed activity). Teams with psychological input, had a median of 2.5 sessions per week (range 0.25 to 11 sessions) (Table 3-9).

Table 3-9

Individual psychological expert sessional input into diabetes team (n=53)					
Per person	**Counsellors Percentage**	**Psychologists Percentage**	**Liaison psychiatrists Percentage**	**Psycho-therapists Percentage**	**Other Percentage**
Median sessions worked per week	3	2	0.75	2	0.75
Lowest	2	0.25	0.25	0.25	0.25
Highest	9	11	5	7	5

3.5.1.4 Level of experience

Most of those providing psychological input into the diabetes team were ‘a member of the diabetes team’ or had ‘experience with people with diabetes for over one year’ (80%). This level of experience should ensure that those working with people with diabetes would understand how patients cope. This experience is necessary for them to understand their patients’ issues in the context of coping with their diabetes on a day-to-day basis. However, only 6% of those providing psychological services stated that they frequently deal with people with diabetes, 6% had regular contact and 9% had occasional contact with people with diabetes. There were problems with this particular question, however, as the single question asked both for the level of experience and frequency of contact with people with diabetes and mixed two very different concepts limiting the interpretation of the question.

3.5.1.5 Involvement of psychological services

Disappointingly, just under half of the responders refer to local generic services rather than to services specific for people with diabetes (Table 3-10). Whilst the range of services is broad (as described above), it is likely that for many, these services are probably not being delivered by therapists with particular expertise in the specific range of issues faced by people with diabetes.

Table 3-10

Involvement of psychological services to people with diabetes (n=53)		
Questions	**Dedicated Percentage**	**Generic Percentage**
Are the services dedicated for people with diabetes or are they simply generic services?	59	42
Do those providing the psychological service work with the diabetes services as dedicated members of the team?	68	32

Where psychological services exist for people with diabetes, it was encouraging that all (100%) provided direct treatment for people with diabetes at the hospital and not just support for the diabetes team in dealing with mental health issues. Furthermore, over 90% provided education for the diabetes team, most offered some supervision regarding clinical cases and over half provided clinical supervision for other diabetes healthcare professionals.

3.5.1.6 Provision of diabetes services

In terms of location, psychological services were provided in the general hospital (100%), in general practice (13%), and other settings including attending diabetes outpatients and home visits (9%) but none (0%) in mental health units. With the move of diabetes services into the community, it will be important to ensure any such shift in setting is matched in a shift of provision of psychological services in a planned and co-ordinated way.

3.5.1.7 Provider organisation

In terms of the organisation which provided psychological services, most were provided by and situated at the acute trust (57%). Services were also located in the primary care trust (30%), mental health trusts (30%) and others (4%). This reflects the huge variation in the type of organisation providing psychological services. However, wherever care is provided, it is vital that the nature and standards of care are equitable whether the user accesses this service in primary, secondary care or within a Mental Health Trust. With the move towards care closer to home, it is likely that this trend will increase and it is important to ensure that such a change is managed in a planned and co-ordinated way.

3.5.1.8 Urgency, waiting times and limits to service

Most services (93%) had the capacity to see both routine and urgent cases but 8% of responders indicated that their service was only available for routine cases.

Only 42% of those were able to see patients on the same day as referral. This is concerning as it suggests that only a little over a third of people with diabetes have access to specialist psychological care on an urgent (same day) basis when needed.

Also with regards to less urgent cases, only 28% of services could see patients within one month of referral (Table 3-11). At the time of the survey, the national target was to see all patients within 13 weeks of referral. This would have been achievable for 83% of services responding to this questionnaire as 17% stated that their waiting time exceeded three months. Such a delay in access to psychological help is not acceptable in today’s health service.

Table 3-11

Waiting times for routine cases (n=53)	
Waiting times for routine cases	**Percentage of services**
< 1 month	28
Between 1 and 2 months	36
Between 2 and 3 months	19
More than 3 months	17

93% of respondents replied that there was no limit on how long the service could continue to provide psychological treatment. For the remaining eight, the limits placed on the duration of therapy provided were up to six weeks or a maximum of 20 sessions.

3.5.1.9 Perceived gaps within the service

Sixteen common themes were identified from the transcripts by two of the researchers (Tim Nichols and John-Paul Taylor) as issues or gaps perceived by at least two of the responders. Peter Trigwell and I also read the transcripts with the themes identified by Tim Nichols and John-Paul Taylor to verify the findings and the themes were discussed as a group and finalised. These were listed in order of importance which was determined by the number of responders who indicated that this was an issue for their service (Table 3-12). The proportion of those giving comments identifying a need for more resources for psychological service provision for people with diabetes was very high, and nearly half indicated a need to support children and adolescents in particular.

Diabetes teams also clearly felt a lack of expert psychological input into the team and felt that this would be beneficial. They also indicated a need for more training, education and supervision.

Table 3-12

Gaps in the service identified responders	
Main themes	**Identified by Percentage**
More resource allocation for psychological services to diabetes	81
Specific services for child and adolescent needed	42
Provision of diabetes specific service/dedicated member of team/ integrated service provision	40
More education/ training/ supervision for diabetes team	34
Eating disorders service	21
Prompts available to diabetologists to stimulate recognition and early referral and intervention	17
More basic level support required (e.g. counselling for needs at level 1)	15
Dedicated liaison psychiatry services	15
Structured approach from first contact	13
More psycho-education to people with diabetes	13
Family or group work	9
Specific services for type 2 diabetes	8
Broaden medical model	4
Application of NICE guidance	4
Sexual health problems	4
Other* (see below for details)	36
***Other (suggestions by individuals)**	
Need resources for older people and those diagnosed the longest	2
Peer support initiatives	2
Weight management and dietitians	2
More community involvement	2
Like to have some people attached with psychotherapy experience	2
Social services involvement and increase resources for those with diabetic ketoacidosis as ‘self-harm’	2
Lack of integration of services	2
Specific services for adults needed	2
Ethnic minorities	2
Application of NICE guidance	2
Drugs and alcohol co-morbidity – needs specific identification and service provision	2
Specific help for phobias (especially needles)	2

3.6 Discussion

This was the first national study of the provision of psychological care for adults with diabetes in diabetes centres in the UK. The survey relied on subjective reporting of the quality and quantity of service provision and the findings may be an overestimate of services because centres with psychological input may possibly be more likely to respond to postal questionnaires. Similarly, those interviewed by phone may have been biased in terms of optimism about services.

3.6.1 Service provision

Disappointingly only one-quarter of diabetes centres had direct access to psychological care for their patients. Of this quarter, only 59% had dedicated psychological services, amounting to 15% of services overall. Therefore 85% of people with diabetes had either no defined access to psychological support and care, or at best only in the form of local generic services.

Expert psychological care services are highly variable in nature, quantity and quality when compared between nations and also among regions of the UK, indicating a clear inequity of service provision. Service availability seems to depend on the presence of an interested psychologist or psychiatrist in the local area rather than a coherent national plan. The findings suggest that most services which have access to psychological services for people with diabetes, are provided by psychologists, and then by liaison psychiatrists. However, these two groups of professionals offer different skills and it is important that services should be needs-led, i.e. assessing need and then matching the skills of the workforce to the needs of the patients rather than relying on the skills of the already present professional and assuming they will be able to meet the needs of the population. Lack of resources also appears to be a barrier to service provision.

The presence of a psychological expert team member was found to increase the perceived skill level of the multidisciplinary team with regard to managing psychological issues. These individuals are also able to help train and support diabetes healthcare professionals to deliver emotional and psychological support at an appropriate level, provide clinical supervision, and give direct clinical care to people with diabetes. Appropriate screening tools should also be introduced into the diabetes service to improve the recognition of psychological and emotional problems of people with diabetes. Expert psychological care should be provided by someone with specific knowledge and experience of diabetes, and has adequate understanding of the issues faced by people with diabetes. Clinical services need to involve a mix of routine and urgent care and be designed so that they treat people with ‘sub-threshold’ psychological problems which have a very real impact on self-care in diabetes.

The recent results from the second Diabetes Attitudes, Wishes and Needs study have indicated that psychological services are still poorly resourced, not just in the UK but across Europe; 62.7% of respondents believed greater availability of resources to provide psychological support and care are needed including access to psychology or psychiatry support. The need for formal training in effective communication for all diabetes specialists was also recognised (63%) (88) .

3.6.2 Commissioners (joint with mental health services)

Managers and staff of diabetes services need to view psychological support and care as part of the role of all multidisciplinary members. Diabetes teams have said that they would like more help managing psychological issues and be able to refer to specialist services, as specialists themselves, it is important that commissioners and policy makers address this need to ensure the psychological needs of people with diabetes can be met.

Commissioners should require services to demonstrate that they are able to provide effective identification, assessment and treatment of the psychological problems and disorders suffered by people with diabetes in their area. Psychological services should be provided across the full age range including transition from children’s to adult services and in both hospital and community settings.

3.6.3 Government

As the population of people with diabetes grows, it should be considered a matter of urgency that the development of psychological services are put into place with clear plans of action and appropriate timelines. With the stated Government commitment to the emotional well-being of people with diabetes, further resources should be invested to improve access to psychological therapies.

3.6.4 Standards

It is a matter of concern that the majority of diabetes services did not meet national standards or guidance for delivering psychological care and mental health care and that the psychological services available are variable in nature and quality. There was variation both within and between the nations of the UK indicating clear inequity of service provision. Equity has become an increasingly important issue for patients and healthcare workers and this issue been raised by Lord Darzi’s Interim Report on the future of the NHS (89).

3.6.5 Comparison with previous studies

Previous surveys (6; 41) have pointed to the lack of psychological service availability, but have only asked a few simple questions, such as ‘do you have psychological services in your area for people with diabetes?’ and ‘do patients have access to a psychologist?’ Even those surveys, allowing such a broad interpretation of what would constitute the availability of a service, have tended to find that over 50% of centres declare that they do not have such services, however, this would be an overestimation when compared with these findings.

The Darzi Report on the future of the National Health Service (NHS) (89) states ‘*there is no physical health without mental health’* and that there has to be equity in the availability of services. Despite this, the survey has highlighted important shortfalls in psychological service provision in the UK for one of the most common physical conditions. One solution to the current inequity would be to increase access to specialist staff, ideally as integrated members of the multidisciplinary team together with increased multidisciplinary team training in detection and management of psychological issues. Another solution would be to require services to offer evidence-based identification, assessment and treatment of psychological and psychiatric problems suffered by people with diabetes. Also helpful would be the development of local and national guidelines for the resources required to provide expert and intrinsic psychological care within diabetes teams at primary, intermediate and secondary level. It is interesting to note that such guidelines, including recommendations for training of psychological professionals, already exist in Germany (90) and these could serve as models for similar initiatives in the UK.

Future studies should monitor the response to this highlighted shortfall in services to ensure national standards are achieved throughout the UK, with consequent benefits for people with diabetes. Cost-benefit analyses of providing such services are also needed.

The current move towards greater provision of services in primary care for the physical health aspects of diabetes will necessitate an accompanying shift in training and provision of psychological services. Many primary care services already have psychological services on-site and often have close relationships with local mental health teams. It is important for these teams to be aware of the specific mental health issues that pertain to diabetes in order to meet this need.

3.6.6 Strengths and weaknesses of the survey

This was the first nationwide study looking in depth at the state of psychological provision for diabetes. Although response rates were reasonable, there were several potential sources of bias. There was a risk that non-responders to part 1 were less likely to have expert psychological care and so the findings may have overestimated service provision. It was not possible to directly test this bias but when responding centres were matched with information about these centres from a recent survey (91) no evidence was found for a discrepancy that would indicate such bias. The survey relied on the subjective reporting of quality and quantity of service provision, which could have been estimated incorrectly, particularly by optimistic respondents. Responders might have felt obliged to respond in a more positive way about the need for psychological services and therefore again overestimate the nature of the provision in their service.

Whilst this survey highlighted deficiencies in provision and inequity, it did not look at the provision of psychological care for sub-sets within diabetes such as type 1 versus type 2, young adults, elderly patients, paediatrics all of whom have different needs and which should be assessed and addressed to offer a truly well-resourced and well planned service. Additional studies and literature reviews could establish further evidence behind the three tier model and identify what requirements are necessary for a comprehensive service and if there are any suitable case studies that could demonstrate best practice for other services to follow.

3.6.7 Recommendations

Twenty two recommendations were generated, for commissioners, policy, Government, standards and standardisation of service provision and funding as a result of this work. Whilst the recommendations covered numerous areas many can be directly linked to the three levels described in the pyramid of psychological problems which was introduced in the methodology. The recommendations are as follows:

- Despite the known high prevalence of psychological and emotional problems encountered by people with diabetes, their association with adverse outcomes due to impact upon glycaemic control, and the acknowledged need and demand for support and care with regard to these problems, only 31.5% of diabetes services have some form of specialist psychological care available to them. The variations seen regarding the nature of the current services demonstrate the lack of any clear plan or rationale for developing such services. All service developments should be needs-led, and the psychological needs of people with diabetes should be addressed in an organised and planned way, in order to avoid the ‘postcode lottery’ which clearly exists at present.

- It is crucial that the needs-led approach is a genuine one; assessing need and then matching the skills of the workforce to the needs which are present (as opposed to simply employing any particular psychological professional and assuming that they will have all of the skills necessary).

- The provision of a psychological expert team member is associated with a significant increase in the perceived skill level of the diabetes multidisciplinary team with regard to managing psychological issues. One role of psychological input, whether provided by liaison psychiatrists, clinical psychologists or others, should be to improve the whole multidisciplinary team’s ability to identify and help effectively with such needs.

- People with diabetes in the UK should not have to rely for their psychological help and treatment upon the best efforts of people who are not adequately trained or supported, to carry out that work. Diabetes healthcare professionals should be trained and supported to enable them to deliver emotional and psychological support themselves, at an appropriate level, with the aim of embedding this as an integral part of healthcare professional training for the future.

- Specialist psychological services need to be able to provide direct clinical care with appropriate psychological therapies and biological treatments (medication) where necessary, as well as clinical supervision, education and training for members of the diabetes multidisciplinary team.

- The size of provision of any psychological service for people with diabetes should be determined by a combined assessment of need and necessary capacity for:
    - Direct clinical care.
    - Clinical supervision, education and training of the diabetes multidisciplinary team.

- Experts in psychological care clearly have an important part to play in providing education, training, support and advice on appropriate resources, as well as direct clinical care for patients, but managers and staff of diabetes services need to see psychological support and care as, to an appropriate extent, the business of everyone in the team.

- Diabetes teams feel they need help with managing psychological presentations, and an opportunity to involve, or refer on to, specialist services for a whole range of conditions. Staff working in diabetes services are specialist and experienced and it is crucial that this declared need is listened to by commissioners and policy makers in order that the psychological needs of people with diabetes might begin to be addressed to any degree of adequacy.

- Guidelines for the management of common psychological problems in diabetes should be made available to all services and patients/ carers.

- Clinical care pathways, alongside protocols and guidelines for onward referral of patients with psychological and psychiatric problems, should be available in all centres.

- At an appropriate stage, with regard to the development of psychological services, consideration should be given to the introduction into diabetes services of appropriate screening tools to improve the recognition of psychological and emotional problems in people with diabetes.

- Around 85% of people with diabetes in the UK have either no defined access to psychological support and care, or at best only in the form of local generic services in which they will be seen by mental health professionals who may have very little or virtually no useful knowledge of their condition and the particular challenges they face as a result of it. Expert psychological care for people with diabetes needs to be provided by professionals with specific knowledge and experience in the area of diabetes. This is in order that psychological assessment and treatment will be provided in the context, and with an adequate understanding, of the particular issues faced by people with diabetes. This will be essential for services to be effective. A reliance upon the provision of existing generic local mental health services is not enough

- Commissioners should require services to demonstrate that they are able to provide effective identification, assessment and treatment of the psychological problems and disorders suffered by their population of people with diabetes.

- Only 2.6% of services felt that they were complying with all six of the relevant NSF standards and NICE guidance recommendations and 26% do not comply with any of them. Commissioners should require services to rapidly work towards, and to demonstrate, compliance with existing NSF standards and NICE guidelines relevant to the psychological care of people with diabetes.

- Specialist psychological services for people with diabetes should be provided across the full age range. Care should be taken to ensure that this includes the provision and development of appropriate psychological services at the stage of transition from children's to adult's services.

- Psychological service provision will need to be improved in both hospital and community settings, whilst taking into account the current shift of diabetes services, in some centres, away from hospitals and into the community.

- Clinical services provided will need to involve a mix of routine and urgent care, the latter being genuinely responsive psychological (including psychiatric) care.

- Psychological services must not be designed in order to only treat people with 'classifiable' psychiatric disorders (e.g. International Classification of Diseases (ICD) -10 diagnoses 62). This is important because what might otherwise be considered 'sub-threshold' psychological problems have a very real impact upon self-care in diabetes, and consequently upon morbidity and mortality, making it essential that they are seen as appropriate for assessment and treatment.

- Although there are regional variations, with regard to the four UK countries, all clearly require improved provision of psychological care for people with diabetes. It is possible that the approach in some (most notably Northern Ireland) may help others (most notably Wales and Scotland) in deciding how best to redress the current inequity in service provision. All of the four UK countries clearly lack adequate psychological care for their growing populations with diabetes. Commissioners and providers should work together to rectify this.

- The population with diabetes is continuing to grow. As a result, the problem of a lack of psychological care for these people will increase. In this context, the development of psychological services for people with diabetes must be addressed as a matter of urgency. A plan of action, with clear and necessarily challenging timeline, should be drawn up and taken forward without delay.

- The Government should match the stated commitment to the emotional well-being of people with diabetes, and the aim to improve access to psychological therapies, by prioritising the investment of further resources specifically for psychological services for people with diabetes.

- To ensure ultimate success the necessary work may be best-steered by a combined Department of Health/ Diabetes UK project group.

The service provision recommendations tend to focus on Level 1 and Level 2 of the pyramid working with the diabetes healthcare professionals in the multidisciplinary team to enhance patient care and enable these teams to deliver appropriate support and care for patients who are sub-threshold. It was also recommended that guidelines for; the management of common psychological problems in diabetes, clinical care pathways, protocols and guidelines for onward referral of patients with psychological and psychiatric problems, should be available in and to all centres.

The commissioner recommendations cover all three levels of the pyramid to ensure that the provider recommendations are in-built into contracted and commissioned services. This ensures that onward referral into Level 3 is recognised as a commissioned aspect from both diabetes as a long term condition and from mental health commissioning perspective. Indeed as only 2.6% of services felt they were complying with all six NSF and NICE standards and 25.8% not complying with any, commissioners should require services to urgently work towards and be able to demonstrate compliance with such guidance to ensure the psychological health and care of people with diabetes.

Expert psychological services were not available in the majority of diabetes centres in the UK and when present there was wide variation in the skills and services available despite the acknowledged importance of psychological issues in diabetes. These services were provided by a range of disciplines which indicated there was no clear plan or rationale for developing such services. Service availability seems to depend on the presence of an interested psychologist or psychiatrist in the local area rather than in response to a coherent national plan.

3.6.8 Future work

Similar studies should monitor the response to this highlighted shortfall in services to ensure national standards are met throughout the UK with attendant benefits for people with diabetes and possible positive financial implications. This is the first comprehensive survey of psychological services for a physical health condition; there are many other conditions with significant mental health needs, some of which have similar formal recognition and guidance but many do not. It is important to assess whether there is a similar shortfall of psychological support in these conditions also.

Retinopathy Screening - England, Wales and Scotland

4.1 Introduction

Diabetic retinopathy was the leading cause of visual loss in people of working age in the western world in 2006. Diabetic retinopathy can progress to an advanced stage without causing any symptoms, therefore regular screening is recommended to ensure preventative treatment is taken before sight loss results. At the time of the survey in England the National Screening Committee was starting to set out minimum standards for screening, photographing, reporting, quality assurance and governance (92). This survey sought to examine the progress made in the implementation of retinal screening services in the UK in 2006.

4.2 Method

4.2.1 Role of the working group

The working group consisted of the same participants as the consultant survey.

4.2.2 My role in the research process in this study

- Develop research questions, questionnaires, respondent lists, data analysis protocols, reporting mechanisms.
- Manage the process of creating, formatting, writing questions and designing forms.
- Distribute questionnaires, data collection, data analysis, report writing and assisting and writing journal articles.
- Hold and manage contact database and overall timeline.
- Manage outputs including reports, articles, website updates, presentations and conference presentations.
- Co-ordinate meetings with the working groups, take minutes, distribute minutes, organise meeting rooms and follow up on actions raised during meetings.
- Present findings at national conferences.
- Distribute results through Diabetes UK and partner agencies to support policy work and provide detailed information to support the lobbying function at

Diabetes UK. Act as the representative and information expert for Diabetes UK to partners working groups such as NHS Diabetes, Department of Health, Royal Colleges and Kings Fund to disseminate findings.

- Inform the results of the research to Diabetes UK membership via newsletters, website and magazines, to other teams for press releases, parliamentary questions and lobbying.

4.2.3 Setting

All retinal screening programmes supporting diabetes specialist services which could be identified across the UK.

4.2.4 Study participants

I contacted all 105 screening programmes in England, the one retinal screening service in Wales and all 15 Health Boards in Scotland which were linked to retinal screening programmes. I approached the service in Northern Ireland, however they did not take part as they were in the process of establishing and co-ordinating their retinal screening service at the time.

It was agreed to send the survey to the person responsible for the delivery of the screening service identified from an attendance list of the British Association of Retinal Screeners (BARS) professional conference, and to local consultants in order that the consultants could encourage the retinal screening leads to complete the survey.

4.2.5 Survey development

4.2.5.1 Aim of the survey

The aims of this survey were to determine the progress made in implementing retinal screening services across the UK and to explore any difficulties encountered by the programmes during this time.

4.2.5.2 Special issues: brief background

In the UK, the National Screening Committee launched a national programme to facilitate the reduction of diabetic retinopathy in 2003 as part of the delivery of the NSF for diabetes. The programme set out national targets to offer comprehensive retinal screening to all people with diabetes in England, Scotland, Wales and Northern Ireland and aimed to offer screening to 100% of the eligible population by December 2007. Whilst this survey was carried out before the National Screening Programme was established, it provided useful insights into the state of the screening service at that time.

4.2.5.3 Topics

These included:

- demography
- infrastructure for retinal screening service
- resource allocation
- leadership
- adherence to National Screening Committee guidance
- process of retinal photography
- population coverage
- mechanisms to deal with screen-positive patients

4.2.5.4 Structure of the survey

The questionnaire included 73 questions (open and closed) to gather both qualitative and qualitative information about the provision of retinal screening (Appendix C).

4.2.6 Pilot

The retinal screening survey was the only survey not piloted. The questionnaire was based on an existing survey created by the Professional Advisory Group (PAG) which is a group that advises the National Screening Committee on issues relating to retinal screening. As only minor modifications were made to the survey, a pilot was not felt to be necessary as the questionnaire had already been tested. The group was set up in 2002 to 2003 and continues to the present time.

4.2.7 Timeline

I sent the first survey to screening centres in England and Wales on 16th May 2006, with a reminder on the 13th June, to Scotland on the 1st June 2006 with a reminder on the 5th July, and to Northern Ireland on the 25th May 2006 with a reminder on the 22nd June 2006. A third reminder was sent out on the 3rd November 2006. I followed non responders up by telephone and post. Data collection continued until February 2007. When I identified duplicate responses, I contacted the respondents by phone. Based on guidance from the respondents, only one response per screening unit was included.

4.3 Results

4.3.1 Response rates

65% (n=105) of units in England, the only unit in Wales, 33% (n=15) of units in Scotland responded. The screening unit in Northern Ireland was unable to respond as they were still in the process of establishing and co-ordinating their programme. Results have been reported for England and summarised for Wales and Scotland, although due to the low response rate from Scotland the findings are not regarded as representative.

4.3.1.1 England

At the time of the survey, PCTs were re-structuring to reduce their number by approximately half (303 to 152 PCTs) and the acute trusts were being commissioned to provide services from a range of one to five PCTs (mean=2.3). 52% of respondents indicated that the primary care trust relating to their service was about to merge with another or numerous other PCTs, 23% had already done so leaving 26% which had not recently merged and had no plans to do so. Although commissioned services were provided on behalf of different bodies, there was relative stability within the delivering trusts in 2006 as 80% of the acute trusts were not involved in mergers, 17% had previously merged and only 2% were about to do so. 49% of responses were completed by the lead of the retinal screening service; the remaining 52% were completed by the diabetes consultant, the network member and ‘other’.

4.3.1.2 Wales

There was only one retinal screening programme operating in Wales, which was linked to the Cardiff and Vale NHS Trust. The name of the network was the ‘Diabetic Retinopathy Screening service for Wales’ and all the hospitals in Wales were involved in the programme. The Welsh Assembly Government was the commissioning body and the questionnaire was completed by the lead of the retinal screening programme.

4.3.1.3 Scotland

In Scotland, five out of 15 Health Boards responded (Fife Health Board, NHS Lothian, NHS Grampian, Shetland and Tayside) and four Managed Clinical Networks (MCN), (Fife diabetes MCN, Lothian Diabetes MCN, NHS Grampian, Tayside and one unnamed response). Between 0 and 5 Community Health Partnerships existed within Health Board Areas (Lothian = 5, Fife = 1, Grampian = 3, Tayside = 3, Shetland = 0).

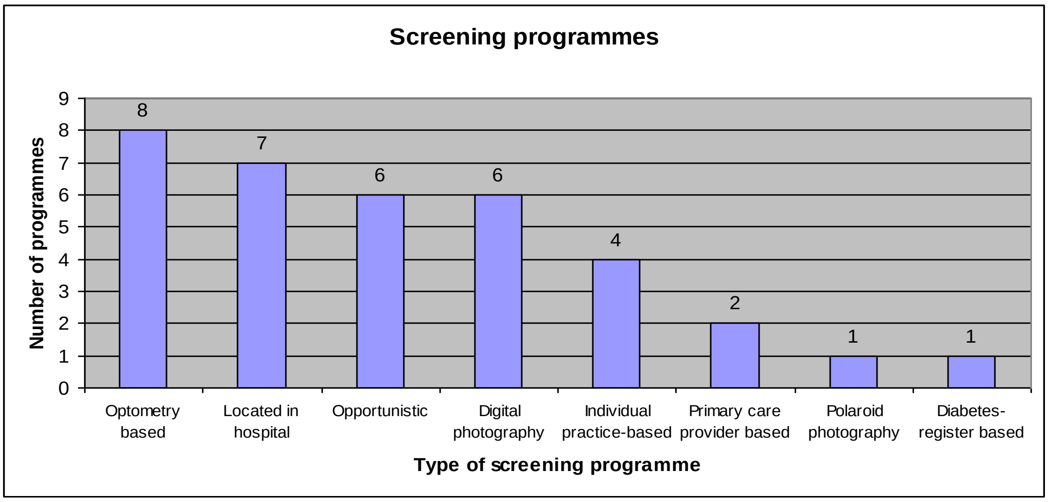
In four responses, the lead of the retinal screening programme completed the questionnaire on behalf of the screening programme and in the fifth the respondents' position was not specified.

4.3.2 Infrastructure for retinal screening

4.3.2.1 England

85% of screening programmes had a co-ordinated diabetic retinopathy screening service in the locality. Of the ten that did not have such a programme, retinal screening was mostly optometry-based and located in the hospital (Figure 10). Due to the evolving nature of retinal screening at this time and the mergers of commissioning bodies, more than one response could be selected to describe the programme.

Figure 10 Type of screening programme excluding community based services



The primary care trust was responsible for managing the scheme in 42% of cases, while the acute trust managed 34% of programmes. There was joint management between primary care and acute trust in 23% of programmes.

A digital photography scheme operated in most localities with just over half using a diabetes register. Approximately half described themselves as being structured in their format and delivery. Services were delivered fairly evenly between both hospital and community settings (Table 4-1).

Table 4-1

Schemes operating in the programme's locality	
Features of the schemes	**Yes responses Percentage (n=65)**
Digital photography	91
Diabetes-register based	54
Located in hospital	51
Structured	49
Located in community	46
Mobile system	42
Optometry based	42
Primary care provider-based	25
Individual practice-based	20
Opportunistic	19
Other (*)	11
Polaroid photography	2

* Other included: non-digital imagery and slit-lamp; service operated in mixed settings such as diabetes service and optometrists; no current funded service.

The locality of services varied from fixed (52%) to mobile sites (15%) which could offer greater flexibility and accessibility, especially in remote areas, 34% operated from both.

44% responded that if optometrists were involved in programmes (it was not asked how many optometrists might be), only selected optometrists were accredited to be involved in the screening processes, with accreditation being provided by the primary care trust, consultant ophthalmologists and training courses. Local optometrists were included as part of a centrally coordinated system in 28% of programmes. Methods of selection and accreditation varied between programmes; for example, some were selected and trained by the primary care trust whereas others were accredited by the locality network. The list of accreditation methods included:

- Selected and trained by the PCT (12).
- Selected and trained by the PCT for limited screening, such as housebound patients (2).
- Selected within locality network and trained by ophthalmologists and screeners with time limited assessment and accreditation with minimum patient contact per year (17).
- Successful completion of National Screening Committee approved training scheme (6).
- Successful completion of regional training programme (13).
- Internal accreditation to the service provider (2).
- Self-selected on basis of optometrists' willingness to purchase own digital imaging camera and trained by ophthalmologists and screeners with time limited assessment and accreditation with minimum patient contact per year (13).
- Based on agreement to be involved in screening programme (5).

Most respondents (73%) believed that local retinal screening had improved since the introduction of the NSF standards and delivery documents (1; 71). Just over half (56%) stated that a new retinal screening system had been set up since the year 2000 and 46% said that an established system not conforming to National Screening Committee standards had been withdrawn as a result. 71% of programmes indicated that a new retinal screening system was being introduced to replace an old system in response to the National Screening Committee's guidance.

4.3.2.2 Wales

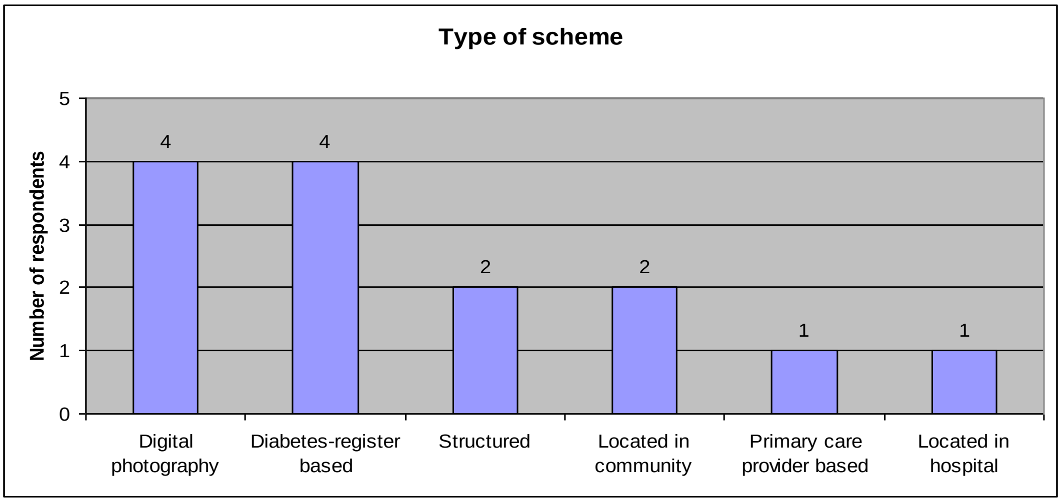
Here the service was a centrally co-ordinated, nationwide programme operating from both fixed and mobile sites and involved selected optometrists accredited by the Welsh Assembly Government. However, local optometrists were not part of the centralised system. Screening did not take place during hospital outpatients' clinics and the scheme used digital photography.

In Wales, the system had been implemented in 2000, to replace an established system that did not conform to National Screening Committee standards. The introduction of NSF standards and delivery documents had seen an improvement in local retinal services.

4.3.2.3 Scotland

Four of the five programmes had a co-ordinated diabetic retinopathy programme and the schemes that operated are described in Figure 11.

Figure 11 Type of scheme in operation



All described operating from both fixed and mobile sites and in only two Boards, selected optometrists were involved. Where applicable, selection was by undertaking training in one Board and by interview and then only for level 2 grading and slit lamp exam in the other. The four responding Boards all stated that local optometrists were not part of a centralised system.

Since the introduction of the NSF standards and delivery documents, three Boards replied that the local retinal screening service had improved. New retinal screening systems had been set up since the year 2000 (three out of five Boards). However, two schemes had an established system that did not conform to National Screening Committee standards, which had subsequently been withdrawn.

Retinal screening during routine diabetes outpatient appointments could provide useful opportunities to encourage patients to attend clinics to reduce the number of appointments they needed to attend. Screening took place during the hospital outpatients' clinics in most of the responses (three out of five); where opportunistic screening took place during hospital outpatient clinics, this had been affected by the introduction of the new retinal screening programmes in only one of the three responding schemes.

There was a service model in most health Boards (three out of four) whereby people with diabetes being managed in the community who had active retinopathy could be transferred to diabetes specialist services for their ongoing diabetes management.

For people who were house-bound or unable to access screening services, most schemes (three out of four) responded that they provided screening for these patients via dedicated transport to a fixed camera site or to ophthalmology. Others would be screened closer to home at mobile sites.

4.3.3 Process of retinal screening

4.3.3.1 England

Registers of patients with diabetes are vital to the screening process. The importance of call and recall for every patient with diabetes on an annual or more frequent basis cannot be over-stated to ensure early detection and monitoring of retinopathy. 76% of screening programmes used a centrally located register for call and recall whilst 24% used a practice based register. It is essential that the register captures every patient with diabetes, including newly diagnosed patients, and that the screening call and recall systems have access to the validated register.

It was encouraging that most services were following guidance on service delivery; 74% followed National Screening Committee guidance on implementation and delivery of the service, 13% used NICE guidance while only 13% of programmes used neither. Only half (51%) of all programmes had a fast track mechanism for the early screening of those patients newly diagnosed with type 2 diabetes.

It was disappointing that few programmes recognised methods to screen patients with other diabetic complications on a six monthly basis as advised by NICE standards; for example, only 19% screened patients on insulin or converting to insulin who also had a diagnosis of retinopathy, 7% screened six monthly patients with diagnosed hypertension, however, 52% screened patients for other clinical reasons and indicators (such as pregnancy, existing retinopathy, direct clinical referral or maculopathy).

Where other sight related conditions were an issue for people with diabetes, only half of the programmes (50%) stated that there was currently a service model whereby community based patients with active retinopathy could be transferred to diabetes specialist services for their ongoing diabetes management. Programmes also screened for other ophthalmic conditions, for example cataracts (55%) and glaucoma (9%). During pregnancy, 64% of women with diabetes were screened with digital cameras, 32% by fundoscopy and 5% did not routinely screen pregnant women.

A specified ophthalmologist provided nearly all (89%) programmes with retinopathy care; however, in terms of holistic diabetes care, only 14% had a joint clinic attended by both diabetes and ophthalmology personnel. Two thirds (67%) of the joint clinics were held weekly and 33% were held monthly. The composition and experience of teams in the joint clinics varied considerably; in 62% of cases, the clinics were attended by a consultant diabetologist, in 88% by a consultant ophthalmologist, 33% by an ophthalmology registrar in and 37% by a specialist registrar in diabetes.

The eye screening provides a useful opportunity for other aspects of diabetes care to be carried out at the same time; however, only 28% of programmes undertook checks, for example, for metabolic control, complications, including foot care.

In 59% of programmes, screening was provided during scheduled hospital diabetes outpatient clinics. In 36% of programmes, opportunistic screening during hospital clinics was provided, for example, if no record of a current digital image or outcome existed.

Programmes gave a variety of reasons why opportunistic screening was not undertaken at diabetes clinics, such as moves towards a more structured register-based approach and screening taking place at a venue closer to the patients home, such as at the GP surgery. Quotes from participants described their experiences:

- *‘We have commenced annual photography of all patients attending the ophthalmology outpatient department using the screening software’.*
- *‘Will be replaced by register based screening’.*
- *‘More patients are discharged to screening even if other ophthalmic care required’.*
- *‘Patients prefer screening at GP's, able to drive etc. Less screening now done and withdrawn from community hospitals as ophthalmoscope not applicable’.*
- *‘Screening in hospital outpatients is in plan to be implemented soon’.*
- *‘Still negotiating about how to run opportunistic screening alongside routine programme’.*

47% of programmes provided screening for people who were house-bound or unable to attend screening services. Respondents described services to meet this need within the community or at the patients’ home by the optometrist, optician or GP with portable ophthalmoscopes and some patients were assessed but not digitally screened. It was concerning that some services commented that patients, who were not able to travel to hospital, would not receive screening or that it was unknown if they had received screening. The following quotations from respondents described how these patients were screened:

At hospital:

- *‘If housebound but able to receive treatment, screened at the hospital’.*
- *‘If housebound we are unable to treat, therefore excluded. Many are brought to clinic for assessment first’.*
- *’We have recently had them brought up to special clinics at the hospital’.*
- *‘Ambulance to hospital and ophthalmoscope if too immobile to sit up’.*
- *‘Offer of ambulance transport given to patients to attend a hospital venue’.*
- *‘Small number of patients will be brought to bio-microscopy clinics’.*

Optometrist:

- *‘By optometrist but only in one primary care trust area, other primary care trust will not fund’.*
- *‘Offered Trust Optometrist examination’.*
- *‘Optometrist visits some patients (outside of main screening programme)’.*
- *‘Optometrists but not universal’.*

Not screened/ not known

- *‘Don’t know’.*
- *‘Not at present - it is hoped that they will be under the new scheme’.*
- *‘Too early to have sorted, depending on the exclusion document’.*

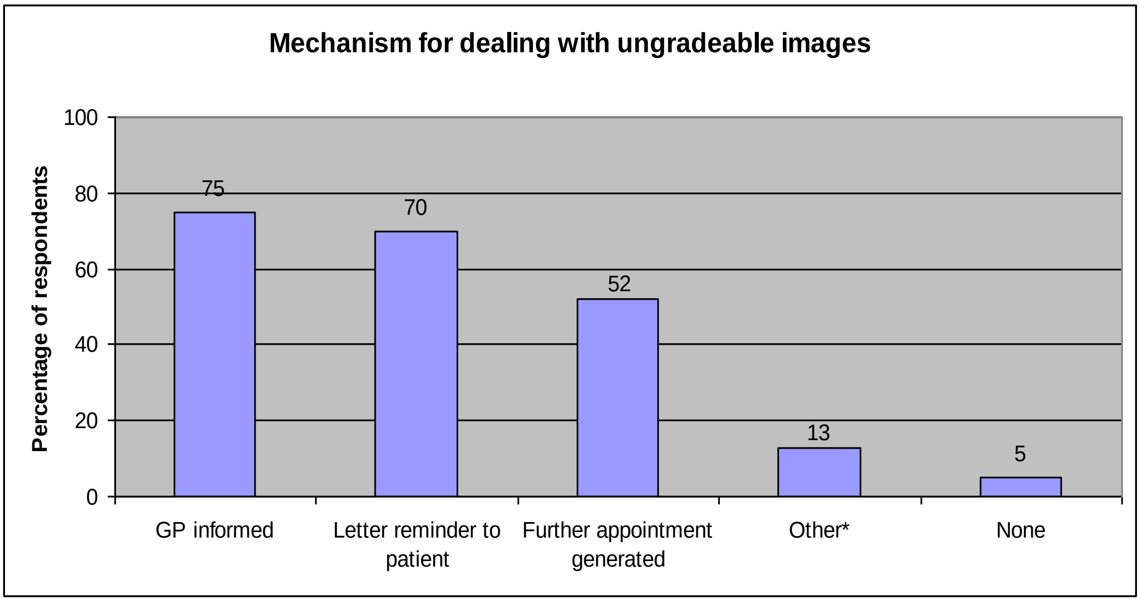
Other

- *‘Mobile camera and screening team’.*
- *‘Fundoscopy’.*

To ensure maximum effectiveness of the screening process, 87% of programmes employed mandatory papillary dilation. 96% routinely recorded visual acuity, of which 92% included a pinhole assessment.

There was a wide variation in the rate of non attendance for screening by patients at a scheduled appointment, ranging from 1% to 50% (14±9%, n=40). Three quarters of programmes (75%) had a mechanism in place to inform the GP that the patient had not attended. Nearly three quarters sent reminder letters to patients and just over half generated a further appointment automatically (Figure 12).

Figure 12 Mechanism for dealing with ungradeable images



*Others included:

- *'Three strikes and then discharged back to GP'.*
- *'After two Do Not Attends (DNAs), annual recall'.*
- *'Currently by GP and Optometrist; future central reminder system'.*
- *'Letter to patient to invite to attend by telephoning and request appointment'.*
- *'Personal telephone contact'.*
- *'Walk in session at hospital'.*

(Comments from respondents)

4.3.3.2 Wales

A central register was used for 'call and recall' and the service followed National Screening Committee guidelines. There were no mechanisms to screen patients with existing diagnosed retinopathy or hypertension six monthly if they were on or about to start insulin or being put onto an insulin regimen as advised by NICE; however, there were six monthly recalls for other unspecified clinical issues. There was a fast track mechanism for early screening for those newly diagnosed with type 2 diabetes. Patients were routinely screened for cataracts and glaucoma and screening for pregnant women took place by fundoscopy.

Diabetic retinopathy care was provided by a specified ophthalmologist but there was no joint clinic attended by both diabetes and ophthalmology personnel. Patients did not have other aspects of diabetes care covered at the same visit as retinal screening.

There was a service model whereby community based patients with diagnosed retinopathy could be transferred to diabetes specialist services for their ongoing diabetes management**.** Whilst people who were house-bound or unable to access screening services were stated as being screened, when pressed for details, the respondent admitted they were not screened at present. Papillary dilation was mandatory for screening and visual acuity was routinely recorded by pinhole.

The non attendance rate was 20% with individuals being sent reminder letters and their GP informed that a further appointment was generated.

4.3.3.3 Scotland

Four of the Boards used a centrally located register for call and recall. All schemes followed the recommendations set out by the Health Technology Board for Scotland (HTBS) for retinopathy screening. Two had a mechanism to screen patients six monthly as advised by NICE and National Screening Committee for insulin conversions with retinopathy, and only one screened patients with diagnosed hypertension.

Two schemes had a fast track mechanism to ensure early screening of people with newly diagnosed type 2 diabetes. One Board screened patients for cataracts and glaucoma whilst three Boards screened pregnant women with digital cameras, one by fundoscopy. Of great concern one did not offer screening to pregnant women.

Four Boards provided retinopathy care by a specified ophthalmologist. In only one Board was there a weekly joint clinic attended by both diabetes and ophthalmology personnel. In two Boards, patients had other aspects of diabetes care covered at the same visit.

The current non-attendance rate ranged from 2% to 20%. Patients not attending were sent reminders in these four Boards and the GP was informed in three Boards when further appointments were generated.

Unlike in England and Wales, four of the Boards reported that papillary dilation was not mandatory for screening but that visual acuity, including pinhole, was routinely recorded.

4.3.4 Results of retinal screening

4.3.4.1 England

The NSF required that by March 2006, 80% of people with diabetes should be offered retinal screening within the previous 12 months and by December 2007, 100% of people with diabetes should be offered retinal screening using digital photography within the previous 12 months.

Only two thirds (65%) of programmes provided data on the number of people with diabetes who were offered screening in the last 12 months, (17% did not answer while 18% did not know if this information was available). 61% of responding programmes knew what percentage of their population had been offered screening, had actually attended and been screened in the last 12 months. There was wide variance between programmes offering screening (mean 83%, range 30% to 100% n=41) and this disparity continued with those actually attending screening ranging between 20% and 97% of the population (mean=68%; n=41).

Disappointingly in the 61% of programmes who provided accurate data about the number of people actually attending screening, only 13 programmes achieved a rate of above 80%. There were no programmes where 100% of the population attended screening. Of those patients reported as being screened with a digital camera, programmes ranged between 0 and 100% of people with diabetes being screened (mean=69%; n=57). It would be unusual for Trusts to report that no-one had been screened with digital cameras, yet this was reported by four respondents, perhaps where no digital camera service was yet available.

In most instances GPs (96%) were sent the results of the screening, 69% of patients, only half (50%) of hospital diabetologists and 46% of Ophthalmologists.

4.3.4.2 Wales

Records were kept of the percentage of patients both offered and attending screening; however, the actual figures were not given in the questionnaire. The hospital diabetologist received the results of the screening.

4.3.4.3 Scotland

Two Boards knew what percentage of the population had been offered screening in the last 12 months. Three Boards stated that they knew the percentage of the population who had actually attended and been screened in the last 12 months. It was estimated that between 60% and 96% had been offered screening and attended in the last 12 months.

Between 60% and 100% were screened with a digital camera (four Boards). The screening results were received by the ophthalmologist (three Boards) and the GP received the results alongside the hospital diabetologist and the patient (four Boards).

4.3.5 Screening interval

4.3.5.1 England

Just over half of programmes screened patients for retinopathy on an annual basis according to a check list (Figure 13, n=64). Most programmes screened patients once a year and only a very few reported that the time between screening was variable (Figure 14, n=67).

Figure 13 Call and recall methods of retinopathy screening

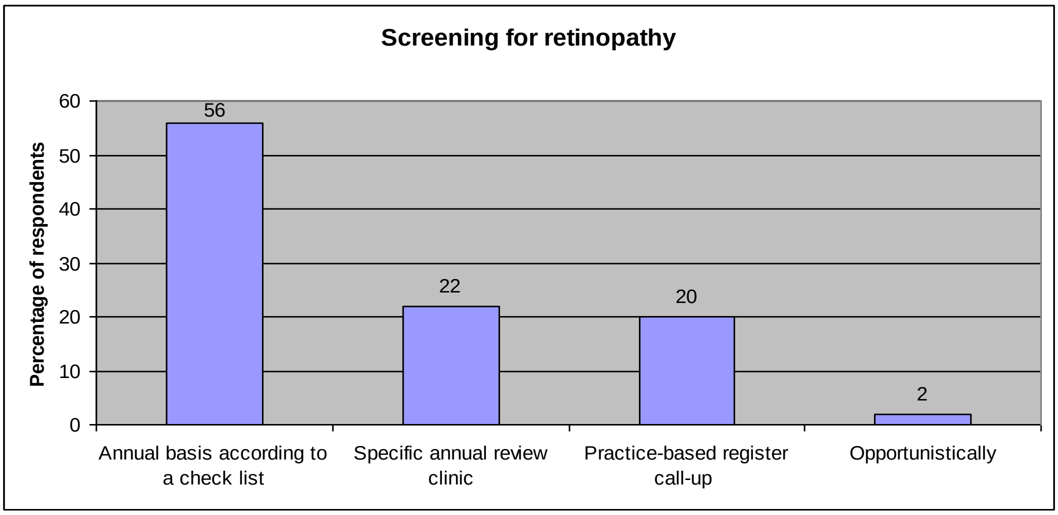
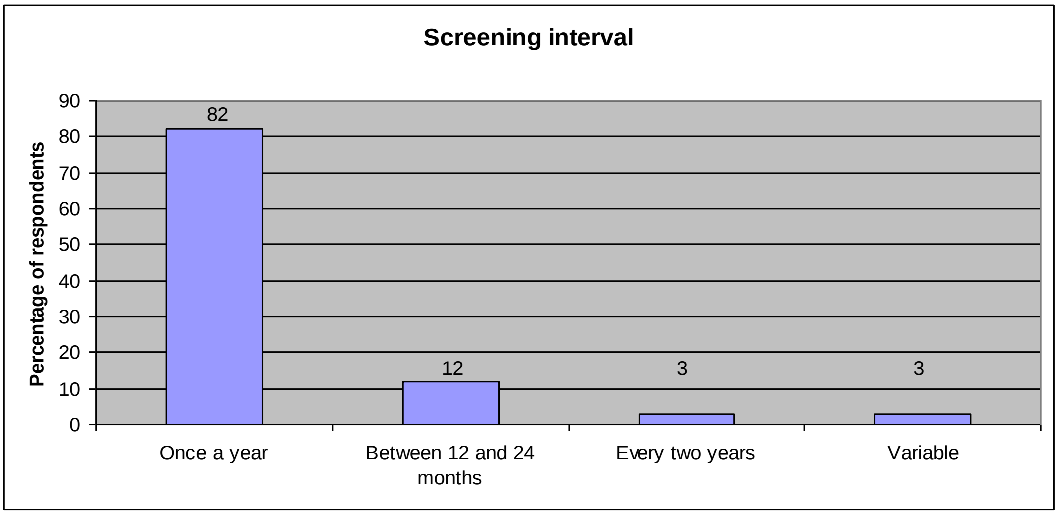


Figure 14 Interval between retinal screening examinations



4.3.5.2 Wales

In Wales patients were to be screened on an annual basis according to a checklist.

4.3.5.3 Scotland

In Scotland, most programmes screened patients for retinopathy on an annual basis (three Boards). The methods and timescale for call and recall of patient varied between boards from between 12 and 24 months (one Board), according to a checklist (one Board) and according to a practice-based register call up system (one Board).

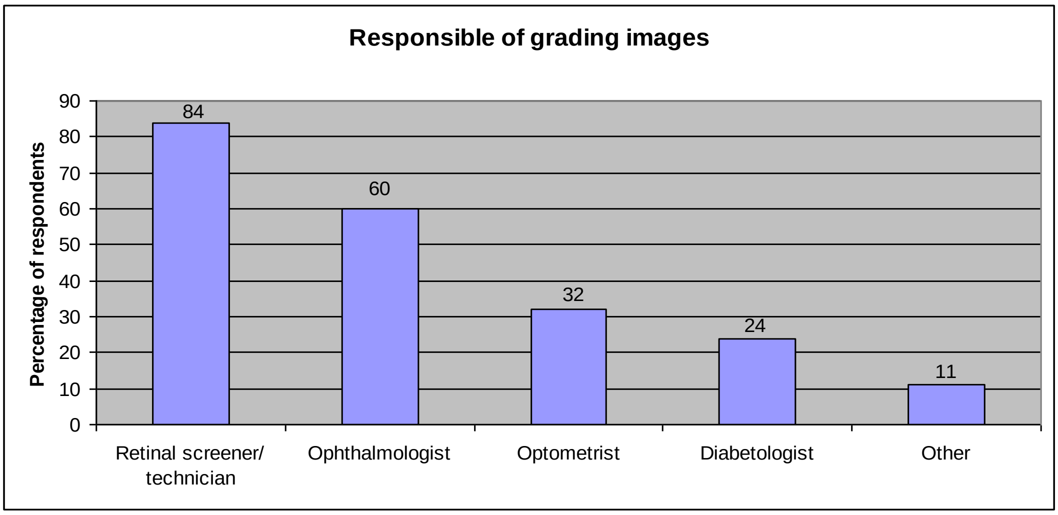
4.3.6 Grading of retinal photos

4.3.6.1 England

In order to be compliant with NSF and National Screening Committee guidance, most programmes had recruited new screening personnel within the last two years (77%), enrolled retinal screeners into training schemes (74%) and put an accreditation process in place (72%).

For the majority of programmes, the retinal screener or technician was responsible for primary grading of images (Figure 15).

Figure 15 Healthcare professional responsible for grading images



Other included:

- Healthcare professionals.
- Diabetes specialist nurse.
- GP with Special Interest in Ophthalmology.
- Graders-clerks.
- Ophthalmic photographer.
- Orthoptist.
- Retinal screening nurses.
- Trained graders.

There was a diverse range of professionals involved in grading images and despite training and competency, some images were ungradeable. Nearly half of programmes (46%) had a mechanism whereby patients were automatically seen at the ophthalmology department if needed, some were referred to an optometrist

(18%), a minority were reviewed by the consultant diabetologist (10%) and 3% had no mechanism in place to refer patients. 33% of programmes used other methods to assess images and these patients including: dedicated Biomicroscopy clinics, Intermediate clinics, review by secondary grader and re-screen and camera clinics of ungradeable maculopathy. In one instance, the programme stated there was insufficient funding to allow all patients with ungradeable images to be seen in ophthalmology.

4.3.6.2 Wales

In Wales, the service had recruited new retinal screening personnel in the last two years and retinal screeners were enrolled in training programmes for accreditation. Retinal screeners and technicians, ophthalmologists and diabetologists were responsible for grading images. Patients with ungradeable images were automatically seen at the ophthalmology department.

4.3.6.3 Scotland

The four Boards in Scotland had recruited new screening personnel within the last two years and all had retinal screeners enrolled in training schemes; however, only two of the four Boards had an accreditation process in place for screeners.

The person most frequently responsible for grading images was the retinal screener or technician (four out of five), Ophthalmologist (three Boards) and Optometrist (two Boards).

When images were ungradeable, Boards either referred patients to the optometrist or sent patients for slit lamp examination as part of the programme.

4.3.7 Dealing with screen positive images

4.3.7.1 England

In England, 48% had a waiting list for patients identified as needing treatment for retinopathy. Waiting times varied; 7% of programmes stated that it was under a week, 50% between one to four weeks, 20% between five and eight weeks and 23% of programmes stated that patients can wait longer than eight weeks before receiving further assessment and treatment.

69% of programmes reported that patients diagnosed with proliferative retinopathy (the development of new vessels) were seen by an ophthalmologist within the specified two week National Screening Committee target (Table 4-2).

Table 4-2

Waiting times for treatment				
	Waiting time for patients with neovascularisation /Proliferative retinopathy Percentage (n=62)	**Wait time for patients with maculopathy Percentage (n=62)**	**Waiting times for patients with reduced acuity Percentage (n=61)**	**Patients with unobtainable images Percentage (n=55)**
Immediate/ within 1 week	44	7	3	0
Within 2 weeks	26	16	10	0
Within 1 month	15	26	18	15
Within 2 months	3	21	26	29
Within 4 months	0	13	5	11
According to clinical needs	13	18	38	46

The National Screening Committee target was to see patients within 13 weeks, two thirds (70%) saw patients with maculopathy within an eight week period and up to 82% within a 16 week period. 57% of patients with reduced acuity were seen within eight weeks and 38% were seen at time scales varying according to their clinical needs. 44% of patients with unobtainable images, i.e. those who were not able to be photographed at the appointment, were seen within two months and 46% were seen at time scales varying according to their clinical need. No standard at the time was present, however, for identifying when patients should be seen due to a technical failure.

Some services cited repeated cancellation of ophthalmology clinics with high demand overloading ophthalmology services and long delays before ophthalmologists could review positive images requiring treatment.

4.3.7.2 Wales

In Wales, there was a waiting list for patients identified as needing treatment for retinopathy, although data about the waiting times were not supplied. Patients with proliferative retinopathy or maculopathy were seen immediately or within one week. Patients with reduced acuity were seen within one month and patients with unobtainable images were seen within one month.

4.3.7.3 Scotland

Two of the four Boards that responded had a waiting list for patients identified as needing treatment for retinopathy of between one to four weeks (Table 4-3).

Table 4-3

Waiting times for treatment				
	Waiting time for patients with neovascularisation /Proliferative retinopathy **Count of Boards (n=4)**	**Wait time for patients with maculopathy** **Count of Boards (n=5)**	**Waiting times for patients with reduced acuity** **Count of Boards (n=5)**	**Patients with unobtainable images** **Count of Boards (n=4)**
Immediate/within 1 week	2			1
Within 2 weeks	2			
Within 1 month		2	1	
Within 2 months		2	3	3
Within 4 months				
According to clinical needs		1	1	

4.3.8 IT and software

4.3.8.1 England

The National Screening Committee had recommended that programmes should acquire the Purchasing and Supply Agency (PaSA; NHS Procurement Agency) listed retinopathy management software for running the screening service and for annual reporting of data. 61% of programmes used one of the two recommended software systems (Digital Healthcare or Orion), while other systems are being used, including some that have been developed locally developed (Table 4-4). Nearly half of services (49%) identified poor IT support as being a problem for service delivery.

Table 4-4

Computer systems	England Percentage	Wales Count (n=1)	Scotland Count (n=5)
Other*	39	0	1
Digital healthcare ltd	34	0	1
Orion Imaging	27	1	0
Siemens plc	0	0	3

* Other included: Clinisys Systems (Sysmed Solutions Ltd), Which, CDRIntell DRS Module, Diabeta 3, Eyecap now, local systems, no central computer, Protos, Prowellness, Spectra, Topcon, TPP SystmOne and Haag Streit Eyecap.

4.3.8.2 Wales

The recommended Orion imaging system was used.

4.3.8.3 Scotland

In Scotland, one Board was using E-store but hoped to transfer to Siemens soon.

4.3.9 Quality assurance

4.3.9.1 England

Quality assurance is vital to ensure all programmes are delivering the required standards. Programmes varied in how they were undertaking quality assurance; some programmes followed National Screening Committee guidance or had an internal audit mechanism in place and others identified the personnel involved or responsible, for example, the ophthalmologist. Based on the qualitative information received from the programmes, there seemed to be some confusion about the meanings and differences of quality assurance, processes and annual reporting.

Programmes described following National Screening Committee guidelines for internal quality assurance and inviting external quality assurance visits. Internal audit mechanisms, including peer review programmes by the clinical lead, were used to benchmark services and the NHS Knowledge and the Skills Framework was utilised.

Generally those involved in the quality assurance process included consultant ophthalmologists, clinical directors, camera screener graders, multidisciplinary screening team and the ophthalmic clinic staff.

Methods of quality assurance varied; in some instances, ophthalmology departments reviewed a percentage of images (for example, 5% or 10%, or a random selection), with senior graders sampling a proportion of images graded by junior staff and consultants undertaking the same process for senior graders. Some processes double-graded all abnormal images and a percentage of normal images were re-graded. Third parties, for example, Moorfields Eye Hospital, were used to review a selection of negative and positive images.

Automated quality assurance processes were being developed in some areas while others were awaiting new management software. Where the software was in-built into the quality assurance process, programmes were able to analyse their yearly results, although there were some problems with the Orion software.

4.3.9.2 Wales

Each month graders within the departments reviewed a percentage of images with senior graders sampling a proportion of images graded by junior staff and consultants undertaking the same process for senior graders.

4.3.9.3 Scotland

Programmes varied in how the schemes were quality assured; 500 images were double graded per grader (one Board), a level 3 grader looked at 10% of all images assessed by others (one Board), the schemes such as the HTBS quality assurance scheme and the NHS Quality Improvement Scotland Clinical Standards for diabetic retinopathy screening were followed in another Board.

4.3.10 Issues and concerns with the service

4.3.10.1 England

Two thirds (66%) of programmes reported that there was insufficient resource allocation to sustain a high quality service. A quarter (26%) felt there was inadequate infrastructure and half (49%) identified poor IT support as a current problem to service delivery.

Other issues and concerns included: data access, changeover to new schemes, service expansion, lack of funding, staff, quality assurance, cancellation of clinics and lack of service.

Where access to data was an issue, this occurred because of geographical and professional boundaries, making it difficult to link hospital events to community services. Reliability of data was also a concern, particularly where schemes had only been running for a short duration.

The changeover from the current service to a new or merged service, caused concern because of duplication of services during the changeover. In some cases, private contractors had taken over some NHS services and poor communication was reported. There had been delays in implementing new IT systems and not all parties, for example consultants, were informed of screening dates or results. Staff competency issues existed within programmes with new appointments of staff with inadequate expertise in grading retinopathy.

Many programmes identified a lack or withdrawal of funding for programme development as a reason why programmes were unable to meet the screening or quality assurance targets of the National Screening Committee.

In some cases there was no screening programme in place, with a lack of clinical input to primary care trust commissioning delaying the implementation of National Screening Committee guidance. In some areas, the quality assurance system did not comply with national standards even though the service was deemed to be effective, cost efficient and well established.

4.3.10.2 Wales

Whilst it was reported that there were current issues with retinopathy screening locally in Wales, the nature of these issues were not identified.

4.3.10.3 Scotland

Funding and IT support were identified as issues by some of the Boards.

4.4 Discussion

Diabetic retinopathy was the commonest cause of blindness in people of working age in the UK in 2006 and, as it is frequently asymptomatic until advanced, the only means of reducing the burden of visual loss in people with diabetes is through regular screening (66). It was estimated that there were 2.5 million people with diabetes in the UK (93) at the time of the survey and approximately 20% of those newly diagnosed with type 2 diabetes had retinopathy at diagnosis (94). If identified early through retinal screening and treated appropriately, blindness can be prevented in 90% of those at risk (95). This principle was firmly established by the NSF for Diabetes and was endorsed by the National Institute for Health and Clinical Excellence.

Following the publication of the NSF for Diabetes, a national programme for reducing visual loss secondary to diabetic retinopathy was launched in 2003 and provided the impetus to facilitate screening for retinopathy. The previous ABCD survey of specialist services was undertaken before the launch of the national programme. Therefore, given the lack of questions asked in the 2000 survey, direct comparison with retinal screening services was not possible, had they been this would have been a good opportunity to assess the effects of the programmes. In 2000, 74% of respondent specialist services were providing co-ordinated retinal screening but there were no data on population coverage, suggesting that the provision of eye screening was not comprehensive at that time (41).

In England the National Screening Committee produced guidance and standards (92) on how to screen effectively and the results of the 2006 survey showed that there had been progress towards establishing a national service with 105 units providing retinal screening services, albeit at different levels of development. 96 programmes were fully operational and offered systematic screening to people with diabetes with or without diagnosed retinopathy.

However, the survey has highlighted a number of key concerns. Many programmes commented on the inappropriate level of funding, including withdrawal of funding that prevented necessary service expansion to meet the national screening and quality assurance targets.

Many programmes seemed to be struggling to work effectively with ophthalmology services to manage patients who had referable diabetic retinopathy in a timely manner. There remained several difficulties in achieving the targets set by the National Screening Committee in relation to ‘screen-positive’ patients. National Screening Committee standards stated that those patients who were referred for non-proliferative retinopathy or maculopathy should be seen within a period of 13 weeks, with proliferative retinopathy being seen within two weeks. Many units were unable to arrange ophthalmology appointments for ‘screen-positive’ patients within four months. In order to improve the situation the working relationship between ophthalmology and screening units needs to be strengthened and supported by appropriate commissioning arrangements. Local commissioners needed to commission appropriate services from ophthalmology services that should include responsibility for data feedback to the screening programme (96).

Many screening programmes experienced difficulties in receiving feedback on the outcome of an ophthalmology assessment of a screen-positive patient. There may be several reasons for this, but in the main, the lack of electronic links between the software for retinal screening programmes and ophthalmology appeared to be the cause and this needs to be addressed urgently. Those programmes striving hard to work effectively with ophthalmic services to manage patients who screen positive would be supported through a strengthening of the relationship between screening units and ophthalmology services via commissioning arrangements.

In England, much progress had been made towards establishing a national screening programme for diabetic retinopathy by individual screening units; however, lack of sufficient resource allocation has prevented compliance with population coverage for screening, quality assurance standards and provision of IT and software. There was wide variance amongst programmes offering population screening and this disparity continued with those actually attending. This situation has improved the UK National Screening Committee Annual Report found that by 2010-2011, 79% of people with diabetes who had been offered screening had received screening, this report has also raised concerns about the considerable regional variation in the proportion of people excluded from screening (97) (from 1% to 23% by primary care trust) (98).

At the time of the survey, quality assurance was in its infancy and there were no well-developed IT systems to support this activity. Since then the National Screening Committee has recognised some of the difficulties identified by the programmes and has addressed this important issue to ensure the safety and effectiveness of programmes. It has linked standards to programme objectives and ensured they can be evidence based and provide data which can be gathered over time and compared longitudinally and across programmes. This led in 2010 to the establishment of an Expert Reference Group to review quality assurance standards which included key healthcare professionals. It was anticipated that this would involve substantial software changes and would take some time to implement. The process would cover areas including data collection, using data to drive up performance, positioning service objectives to relate directly to the quality of care for patients and that standards were set at the right level.

The National Screening Committee has commenced a programme of external quality assurance visits to programmes beginning with those who were having significant difficulties meeting targets. These visits have addressed some of the critical issues such as feedback of screening results, with programmes who have received external quality assurance visits reporting that these visits have helped to resolve a number of important delivery issues. Structured feedback to the commissioners from the external quality assurance should drive further improvements in the way programmes are funded and supported (99). As part of the process, revised standards were signed off in April 2011 and the next step was started in July 2011 with an aim to implement new systems to collect these data by April 2012. Local programmes are now required to submit annual reports to assess their progress towards achieving service objectives and quality assurance standards.

In Wales, the service had been established for some time and largely complied with National Screening Committee standards. However, two areas for further development were identified; reports from people with diabetes and from the Diabetic Retinopathy Screening Service for Wales to Diabetes UK Cymru stated that the screening interval, in practice, can extend up to 15 months and that the target of universal screening by the end of 2006 had not been achieved. Data from the Diabetic Retinopathy Screening Service for Wales in 2007 recorded that 82% of patients had been offered screening and 57% had received screening (100).

The Diabetic Retinopathy Screening Service for Wales had made significant progress in addressing key issues still outstanding in some parts of Wales, but screening capacity remained an issue. There were no data on the proportion of people who have received screening and so it has not been possible to see if this has increased. However, particularly given the increasing prevalence of diabetes (4.1% in 2006 to 4.4% in 2008 and 5% in 2011) (75; 101; 102) in Wales the Welsh Assembly Government will need to ensure the service has sufficient resources to offer screening to all people with diabetes in Wales.

There were only five respondents in Scotland and so it was not possible to generalise these findings to the rest of the Boards. Since the survey, the Scottish Diabetic Retinopathy Screening Programme Annual Report stated that 2010-2011, 85% of the total number of the currently eligible population was successfully screened which may well verify the success of the programmes and was an increase of 4% from the previous year (103). Similar issues existed for these Boards when compared to the other nations such as IT support and funding. External quality assurance has been imbedded into a biannual cycle and has been used as a tool for continual service improvement. A national survey of users was carried out in Scotland for the programme 2011 annual report and users gave their feedback of the service. Users found the service to be efficient and prompt and flexible, however, they were not always given enough information and waited too long for results. Having someone there to answer questions and being given their results at the time of the appointment would improve the service as a letter was seen as too impersonal, also eye screening at the same time as other diabetic appointments would improve the experience for users (103).

Since the time of the survey in Northern Ireland, the Diabetic Retinopathy Screening Programme has been developed to offer screening to eligible people with diabetes aged 12 years and over. Screening is carried out at GP practices and static sites and of the 60,000 people in Northern Ireland diagnosed with diabetes, 45,000 were offered screening in 2009. Primary care practices hold registers of people with diabetes and the information in the registers are used to identify those needing to be screening (104).

The aim of all diabetic eye screening programmes is to reduce the risk of sight loss among people with diabetes. Early detection and treatment of retinopathy can improve and sustain quality of life for the individual, which has benefits to family members, carers and the wider community. Evidence from the survey has provided a clear picture of the level at which programmes were performing, and their variations, at a crucial time of change. The merging of commissioning bodies and programmes presented huge challenges for programmes faced with delivering a service to an increasing number of diabetes patients and this was reflected in the survey findings. The lack of clarity concerning programme leads and named commissioners at this time could also be one possible reason why some programmes did not respond to the survey.

The National Screening Committee has addressed some of the issues highlighted by the survey by improving quality assurance as an ongoing annual process and assessing IT software issues. A recent study by Liew has since shown that for the first time in five decades, diabetic retinopathy/maculopathy is no longer the leading cause of blindness in adults of working age (105). This may be related to the combined efforts of the National Screening Committee, the impetus provided by the NSF for diabetes and the introduction of the QOF payments to GPs. However, without adequate funding to support these improvements, people with diabetes remain at risk of developing retinopathy.

Diabetes nursing survey

5.1 Introduction

The role of the Diabetes Specialist Nurse (DSN) was first introduced over 60 years ago to help educate people with diabetes in the use of different types of insulin and self-monitoring of blood glucose. The number of DSNs has increased, particularly since the 1980's and the role of the DSN in the multidisciplinary team has evolved not only as diabetes care has changed but also in response to government policies and strategies. The aims and objectives of this survey were to explore the specific clinical roles, provision of education and the infra-structure of diabetes services.

5.2 Method

5.2.1 Role of the working group

The working group participants were the same as for the consultant survey.

5.2.2 My role in the research process in this study

- Develop research questions, questionnaires, respondent lists, data analysis protocols, reporting mechanisms.
- Manage the process of creating, formatting, writing questions and designing forms.
- Distribute questionnaires, data collection, data analysis, report writing and assisting and writing journal articles.
- Hold and manage contact database and overall timeline.
- Manage outputs including reports, articles, website updates, presentations and conference presentations.
- Co-ordinate meetings with the working groups, take minutes, distribute minutes, organise meeting rooms and follow up on actions raised during meetings.
- Present findings at national conferences.
- Distribute results through Diabetes UK and partner agencies to support policy work and provide detailed information to support the lobbying function at Diabetes UK. Act as the representative and information expert for Diabetes

UK to partners working groups such as NHS Diabetes, Department of Health, Royal Colleges and Kings Fund to disseminate findings.

- Inform the results of the research to Diabetes UK membership via newsletters, website and magazines, to other teams for press releases, parliamentary questions and lobbying.

5.2.3 Setting

All diabetes specialist services across the UK, including both acute and primary care locations.

5.2.4 Study participants

For the DSN questionnaire, I identified 361 diabetes services across the UK, including both primary and acute trusts. The sources for this information were databases supplied by Diabetes UK and ABCD, the Directory of Diabetes Care (84), Binleys Directory of NHS Management 2006 (83) and the membership of Diabetes Inpatient Specialist Nurse (DISN) group.

The diabetes lead from each service was asked to complete the questionnaire on behalf of the service. The first question was designed to examine whether the local service operated across primary care and specialist services. Where services were not integrated, the recipient was asked to copy the questionnaire to obtain responses from both primary care services and specialist services.

5.2.5 Survey development

5.2.5.1 Aim of the survey

This survey aimed to:

- Establish the employment localities and management of hospital DSNs, nurse consultants in diabetes, community DSNs and diabetes healthcare assistants across acute hospital trusts, primary care organisation and general practices.
- Establish where both acute trust employed nurses and primary care employed nurses worked across hospital and primary care localities.
- Determine if service level agreements existed between primary and hospital care providers and named nurse contacts for patients.

- Identify the specific clinical role components of nurses, pharmacy assistants and educator facilitators, their role in research and prescribing.
- Explore the general nature of in-patient diabetes care, clinic facilities and data collection.
- Clarify the scope of education sessions available to patients and carers and provision of continuing professional development for nurses.

5.2.5.2 Special issues: brief background

As the role of the DSN has evolved considerably over the last ten years, the year 2000 ABCD questionnaire no longer reflected the current role played by DSNs and so considerable modification to this questionnaire was necessary. We added questions relating to the role of DSNs in implementing guidelines, qualifications, education provision (for groups, staff, patients on pump training and both structured or unstructured education in delivery), on insulin implementation (within a group of people with diabetes) and complications. Open questions were used to elicit the views of DSNs.

5.2.5.3 Topics

These included:

- Employment and management of nurses.
- Work settings (role in research, specific clinical roles, prescribing behaviour, grades and bands).
- Access to clinic facilities (interpreting services, helpline and nurse-led clinics).
- Data collected by nurses on extra activities carried out such as patient drop-in activity education for people with diabetes and staff.
- Continuing professional development.

5.2.5.4 Structure of the survey

The survey consisted of 80 questions, both open and closed, to collect qualitative and quantitative information regarding the organisation and provision of diabetes services relating to DSNs (Appendix D).

5.2.6 Pilots

The questionnaire was piloted with 14 inpatient DSNs, Hospital DSNs and primary care based nurses in a similar way to the consultant survey.

5.2.7 Timeline

I posted the DSN questionnaire in February 2007 and replies were collected until December 2007. I sent a second questionnaire to all non-responders after one month followed by telephone calls to the centre concerned to try and increase the final response rate. I contacted all non-responding centres by phone and if new contacts were identified I sent new questionnaires. Some centres were removed from the database if there was no diabetes nurse present. The final reminder was sent on the 12th July with 218 reminders sent in the post. I approached the Diabetes Inpatient Specialist Nurse group and National Diabetes Support Team (NDST) to circulate the questionnaire to their members. To promote participation, I advertised the survey in the websites of NHS Diabetes, Diabetes UK and leaders in the Journal of Diabetes Nursing.

5.2.8 Data management and data cleaning

5.2.8.1 Data analysis

The data were analysed using Excel and SPSS (version 16) using both parametric and non-parametric tests according to the distribution of the data in a similar method as described more fully in the consultant survey.

5.2.8.2 Pre-specified sub-group analysis

I identified localities providing responses to both the years 2000 and 2007 surveys to compare trends in service provision between this sub-group and the complete sample of respondents in both surveys.

5.3 Results

5.3.1 Response rate

44% of services responded to the survey (159 out of 361); responses by nation varied (Table 5-1) but there was a fairly even split between acute trust (45%) and primary care providers (38%). The response rate was similar to that achieved by the consultant survey, a sub-analysis of hospitals who responded in both 2000 and the 2007 was undertaken to strengthen the validity of the findings. These hospitals are referred to as the comparable hospitals.

Table 5-1

Proportional response achieved by each nation	
	Percentage
England (n=283)	42
Scotland (n=17)	71
Wales (n=39)	26
Northern Ireland (n=17)	88
Isle of Man (n=1)	100
Guernsey (n=1)	100
Jersey (n=1)	100

5.4 Role of diabetes nurses

5.4.1 Clinical roles

The role of the DSN is diverse and includes clinical, educational and other aspects of nursing care (Table 5-2). Most DSNs undertake patient management and the role also includes specialist clinic work such as insulin pump training, foot clinics and pre-assessments for surgery. Hospital DSNs have become the main provider of education to healthcare professionals (compared to community DSNs and nurse consultants) and two thirds of nurse consultants prescribe diabetes drugs.

Table 5-2

Roles undertaken by DSNs					
	Hospital DSN N=132	**Community DSN N=104**	**Paediatric DSN N=67**	**Nurse Consultant in diabetes N=29**	**P value**
	Percentage	**Percentage**	**Percentage**	**Percentage**	
Patient management	99	96	93	76	
Prescribing	49	56	27	66	
Non-medical prescribing	47	46	9	55	
Dose adjustment only	68	62	63	17	
Pump training *	55	36	43	21	0.003
Hypertension clinic *	22	11	5	21	0.019
Cardiovascular risk factor management	30	20	3	28	
Foot clinics *	34	14	2	10	<0.000
Renal clinics *	27	9	2	14	<0.000
In-patient work *	98	36	54	24	<0.000
Ante-natal *	72	40	12	35	<0.000
Pre-assessment clinics prior to surgery *	23	5	0	7	<0.000
Education for nursing staff *	98	89	88	90	0.007
Education for medical staff *	92	81	73	76	0.008
Education for other allied healthcare professionals	91	91	70	79	
Education for patients	94	95	75	76	

* significant differences between hospital DSN and community DSN

To qualify as a DSN, clinical practice must be wholly within diabetes care, with adults or children or both. However, 11% of nurses covered clinical, educational or research roles not solely within diabetes, which was a slight increase since 2000 (8%). The analysis of comparable hospitals (i.e. those who responded in both 2000 and 2007) presented similar findings (11% in 2007 and 10% in 2000), suggesting that this practice has not changed.

The survey in 2000 predicted that nurses would take on more responsibility for prescribing and this was confirmed by the current survey (Table 5-3). Nearly all nurses were involved in the education of nursing staff in both 2000 and 2007. The extent of nurse involvement in the education of medical staff, allied healthcare professionals and patient education was not identified in 2000 and so cannot be compared.

Table 5-3

Role of all nurses compared to 2000						
	All hospitals			**Comparable hospitals**		
	2007	**2000**	**P value**	**2007**	**2000**	**P value**
	Percentage	**Percentage**		**Percentage**	**Percentage**	
Patient management	99	97		99	100	
Prescribing *	49	31	0.002	54	31	0.02
Dose adjustment only *	68	77		61	76	0.03
Education for nursing staff	98	98		99	98	
Education for medical staff	92			93		
Education for other allied healthcare professionals	91			91		
Patient education	94			93		

* indicates where there are significant differences

Nurse-led clinics have been increasing in number in recent years to help to meet healthcare capacity and resource needs of the NHS, increase the scope for nurses to operate more autonomously, offer opportunities for nurse development and provide appropriate care to people with diabetes. 90% of services had independent diabetes nurse-led clinics; in 2000 this question was not asked owing to uncertainty at the time about whether this role was being undertaken. Nearly two thirds of service (64%) now operate four or more nurse-led clinics a week (mean=3).

5.4.2 New roles

Two new roles had emerged since 2000; the first were nurse consultants who combine expert practice, leadership and consultancy, education and training, as well as research and service development. The second was the role of diabetes health care assistant who undertake activities that often form key elements of the annual diabetes health check (Table 5-4).

Table 5-4

Activities carried out by the diabetes care assistant	
Activities	**Percentage (n=105)**
Weight, height, body mass index	95
Urine check for microalbuminuria	91
Blood pressure	83
Waist circumference	47
Exercise advice	31
Check injection sites	28
Smoking cessation advice	27
Foot screening	27
Pre-conception discussion	18
Medication review	16
Other	10

Other activities included: blood glucose monitoring, dietary advice and arranging clinic appointments.

5.4.3 Nurse prescribing

As roles have extended and become more specialised with increased autonomy, nurses were involved in advising, prescribing and adjustment of diabetes medication; this was more recently had been accompanied by formal qualifications. 77% (n=56) of services have had a nurse attend a course for prescribing (mean=1, range 0 to 3).

Only 53% (n=111) of services had one or two nurses qualified in prescribing, 13% had none (mean=2, range 0 to 9), 34% had more than three or more. 48% (n=48) of services had more than one nurse putting prescribing into practice while 20% had none (mean=2, range 0 to 9). Where services had trained nurses who were not putting their prescribing knowledge into practice, many reasons were cited including:

- trust policy preventing or delaying implementation
- awaiting protocols to be developed
- formularies in development
- lack of study leave
- lack of funding
- new in post
- newly qualified
- maternity leave

5.5 Continuing professional development of staff

To further the professionalization and career development of specialist nurses, it is essential to have access to continuing professional development. 48% of respondents had protected time for continuing professional development but only 15% had a protected budget. This varied regionally within England with those in the South being more likely to have protected funding for training compared to other regions (South=27%, North=9%, Midlands=5%, p=0.013).

5.6 Research role

Despite research being a feature of the DSN role (30), disappointingly only one in five (22%) of either DSNs or nurse consultants had a formal role in diabetes research compared to 48% in 2000 (p<0.000). The commitment to research demonstrated by the 2000 findings had reduced, despite the recommendation in 2000 that this should become an integral part of the training of DSNs as it is for medical staff. Comparable hospitals experienced a similar decline in research commitment (23% in 2007 and 58% in 2000).

5.7 Paediatric DSNs

5.7.1 Number of Paediatric DSNs per service

The Royal College of Nursing had recommended that there should be one qualified paediatric DSN for every 70 children with diabetes (106). 7% of services reported having no separate paediatric DSN, 58% had one and 38% had two or more paediatric DSNs. In 2000, 41% had no separate paediatric DSN which shows that services had become better staffed between the surveys. Despite this apparent increase, the mean WTE of paediatric DSNs per service was only 1.3 (range 0.4 to 3). The mean number of children to paediatric DSNs was 109 (range 15 to 300) and this varied widely between services; for example, one service at the lower end reported only 0.4 WTE paediatric DSN who held no formal paediatric qualification despite a caseload of 270 children.

5.7.2 Paediatric qualification

Encouragingly 97% of paediatric DSNs had a paediatric qualification in 2007.

5.8 Presence of a named DSN nurse contact for each patient

The NSF for diabetes delivery strategy (71) recommended that each service offered a named contact to act as an initial point of contact to help people with diabetes navigate the service and access other members of the multidisciplinary team as needed. Only 63% of hospitals and 69% of community services fulfilled this recommendation. This named contact is particularly important at those times when care is most difficult, such as at diagnosis, when changing treatment and during adolescence and transition.

5.9 Education and structured education

5.9.1 Education sessions

NICE guidance in 2003 on structured education recommended this be available to all people with diabetes at diagnosis and then as required based on regular assessment of need. 97% of services had education sessions available for patients and carers. Services held these in both primary (76%) and acute (73%) settings.

5.9.2 Topics covered in education sessions

Educational sessions covered a broad range of topics (Table 5-5). Some had not changed since 2000, such as the nature of diabetes and why metabolic control is important, but there were new topics, for example, carbohydrate counting with insulin dose adjustment. A cause for concern in 2000 was the lack of education about footwear (76%) but this has improved to 87%.

Table 5-5

Topics covered in education sessions			
Topics	**Percentage 2007 (n=151)**	**Percentage 2000 (n=183)**	**P value**
Nature of diabetes	99	99	
Why metabolic control is important	95	97	
Impact of diet and exercise	95	97	
Coping with diabetes during illness	94	98	
Hypoglycaemia	94		
Driving	93	94	
Home blood monitoring*	90	98	0.002
Travel	89	91	
Insurance	89	92	
Employment	89	86	
Smoking	88		
Footwear*	87	76	0.008
Injection technique*	86	97	<0.000
Carbohydrate counting with insulin dose adjustment	83		
Prescription charges	81	83	
Contraception	76	81	
Pre-conception counselling	74		
Erectile dysfunction	71		
Home urine monitoring*	44	73	<0.000
Group initiation of insulin	41		
Alternative intensive management scheme	22		
Other (empowerment, setting personal goals, psychological support; pump education)	15		

* indicates where the percentages are significantly different

The same trends were observed when the comparable hospitals were analysed.

In 2000, 73% offered training in home urine monitoring compared to 44% in 2007, reflecting a shift towards blood glucose monitoring for both type 1 and type 2 diabetes. However, by 2006, just over half of services (56%) reported that despite services offering education on self-blood glucose monitoring, there had been recent guidance for patients to be restricted in the number of tests they could perform within a time period, if at all. This guidance was received mostly from primary care organisations (79%), as well as from the GP (50%), acute trust (25%) and informally (16%), partly for economic reasons and partly, where appropriate, in favour of HbA_{1c} monitoring only.

5.9.3 How education is delivered

NICE guidance recommends that education should be delivered to groups of people with diabetes, unless group work is deemed unsuitable for the individual. The majority of education sessions were delivered one-to-one for those newly diagnosed with type 1 and in a group for those with type 2 diabetes (Table 5-6).

Table 5-6

Delivery of education

Delivery	**New type 1 diabetes Percentage (n=143)**	**New type 2 diabetes Percentage (n=139)**	**Ongoing type 1 diabetes Percentage (n=138)**	**Ongoing type 2 diabetes Percentage (n=134)**
One to one	99	61	80	78
In a group	27	74	56	56
Information provision	47	44	54	55
E-learning	4	4	6	5

In 2000, 64% of services offered group and one-to-one education sessions, 34% offered one-to-one and only 1% offered group only education. It was not possible to compare these results directly as type of diabetes and if newly developed or ongoing was not asked in relation to education.

5.9.4 Timing of education sessions

Most services offered education sessions during the week within office hours (97%) only 19% offered evening courses with few (4%) offering weekend courses.

5.9.5 Frequency of education sessions

Nearly one third of services held sessions either once a week or once a month. In 2000, education services seemed to be held more frequently with nearly two thirds being held at least as often as fortnightly (Table 5-7).

Table 5-7

Frequency of education sessions			
2007	**Percentage (n=138)**	**2000**	**Percentage (n=156)**
		Daily	8
Twice a week	14	Twice weekly	13
Once a week	31	Weekly	34
Every two weeks	15	Fortnightly	13
Once a month*	30	Monthly*	16
Less frequently	14	Less frequently	9
		As required for the individual	3
		Ad hoc	3

* indicates where percentages are significantly different. The same trends were observed in the comparable hospitals between 2000 and 2007.

5.9.6 Staff involved in the planning and delivery of education sessions

NICE guidance recommends that education should be provided by an appropriately trained multidisciplinary team. In most services hospital DSNs were involved in planning and delivering education sessions (Table 5-8), but medical staff were less likely to be involved than in 2000.

Table 5-8

Hospital DSN involvement in planning and delivery of education sessions			
Staff members	**Plans education Sessions Percentage (n=153)**	**Delivers education sessions Percentage**	**2000 Who carried out education? input was received from these personnel Percentage**
Hospital DSN	78	76	13 (DSN, ward and district nurses)
Medical Staff	14	23	66
Podiatrists	32	44	84
Dietitians	64	72	88
Pharmacists	5	6	8
Diabetes nurse educator	15	15	
Other	23	24	3 company reps, Psychology, team effort

A similar pattern was found when the comparable hospitals between 2000 and 2007 were analysed.

5.9.7 Is structured education offered?

85% of respondents in England provided structured education as per NICE guidance. 115 services named the structured education programme provided of which 57% were type 2 courses (31% were Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND), and 26% were X-pert) and 28% were type 1 Dose Adjustment For Normal Eating (DAFNE). 56% had developed their own course in line with the principles of structured education leading to 115 separate courses being named in the survey which could lead to confusion amongst patients, clinicians, commissioners and national bodies such as the Department of Health and Diabetes UK.

5.9.8 How programmes were quality assured or peer reviewed

Just over a third of services (39%, n=96) quality assured their education programme either by course guidance, 21% by audit and 21% by peers or colleagues. Other methods included external assessment, evaluation or pro-forma. 39% (n=109) used the National Diabetes Support Team (NDST), and Diabetes UK self assessment tool.

Of the 75 services who peer-reviewed programmes, services described using either external reviewers or peers and colleagues to carry out the review. Some reviewed their courses as per type guidelines and others by observation.

5.9.9 Education courses provided for people with diabetes from hard to reach groups

NICE guidance recommends that sessions should be accessible to the broadest range of people, taking into account culture, ethnicity, disability and geographical issues and should be held either in the community or at a diabetes centre. Educational programmes should use a variety of techniques to promote active learning and be adapted to suit the individuals' needs and preferences. Whilst most services were able to offer education to those newly diagnosed with type 2 diabetes, few could offer courses to those with disabilities, homeless or with severe mental illness (Table 5-9).

Table 5-9

Education sessions offered to hard to reach groups	
	Percentage (n=143)
Type 2 newly diagnosed	81
Type 1 Ongoing	66
Type 2 Ongoing	61
Type 1 newly diagnosed	48
Young adults/ teenagers	27
Children and parents	24
Older people	15
Black and minority ethnic groups	11
People with language barriers	11
Disability	6
Prisoners with diabetes	5
Travelling community	4
People with severe mental illness	3
Refugees and asylum seekers	2
Homeless	2
None of these	1
Other	0.7

5.10 Infra-structure of diabetes services

5.10.1 Service integration

Since the introduction of the NSF, there has been a shift in policy guidance advocating that people with diabetes should experience a seamless integration of primary and specialist services so that they can move throughout the health service and receive all the care they require from the most appropriate healthcare professional at a time it is required, while avoiding gaps and duplication which could result in poor treatment and outcomes.

65% of services reported to be integrated across primary and specialist settings, but this varied nationally with Wales being less likely to have integrated services

(Wales=40%, England=62%, Northern Ireland=79% and Scotland=91%; p=0.06). Within England, there were significant regional differences, with services in the South being more likely to be integrated (North=29%, Midlands=29%, South=42%; p=0.02). Where services were not integrated, most respondents were based in specialist services (76%). Just over half of respondents had only one commissioning body associated with their service (56%) but this ranged from one to eight.

Comments from DSNs on integrated working:
'We used to all work together as a team now very separate and less communication if any'.

'We are aiming to shift from acute base to integrated locality base service covering acute trust and primary care'.

'Working covers primary and secondary care and work closely with practice nurses, community nurses and care staff in nursing and care homes, plus liaison with schools'.

5.10.1.1 Presence of a liaison role between hospital DSNs and primary care practice nurses

The DSN role has traditionally involved the education and support of other healthcare professionals. This is particularly important when much of the patient care has been shifted into the community. However, fewer hospital DSNs in 2007 (83%) had a liaison role with primary care practice nurses than in 2000 (96%; p<0.000), which may reflect the increasing fragmentation of the service (this trend was reflected in the comparable hospital findings, 85% in 2007 compared to 96% in 2000).

Following are some comments from respondents on how this liaison role took place:
'Practice nurse interest group for diabetes started by DSN in specialist care'.

'Practice nurse forums, pilot structured education undertaken by practice nurses, nurses observing DSNs'.

'Practice nurses seek advice from specialist team'.

‘Communication with practice nurses is difficult because of surgery closing times’.

‘DSNs based in primary care have close contact with practice nurses and district nurses and GPs’.

’Hospital DSN arrange/organise evening meetings for practice nurses and provide on going education in diet, weight management, podiatry, obesity and compliance’.

’Lots of work carried out in GP surgeries and education provided for practice/district nursing staff’.

‘Hospital DSNs refer patients to community based DSNs who liaise more closely with practice nurses and allied HCP’.

5.10.1.2 Presence or absence of service level agreements between the hospital or primary care provider to provide services in the community or hospital

Service level agreements are contracts agreed on a time limited basis to provide a diabetes service to a specified standard and performance level. 56% (n=146) of services had a service level agreement in place between the hospital and primary care provider to provide services in the community or hospital.

5.10.1.3 Presence of other hospital based nurses engaged in diabetes specialist service provision.

39% of services engaged diabetes nurse facilitators in diabetes specialist service provision and other hospital nurses involved included midwives, general medical nurses and facilitators.

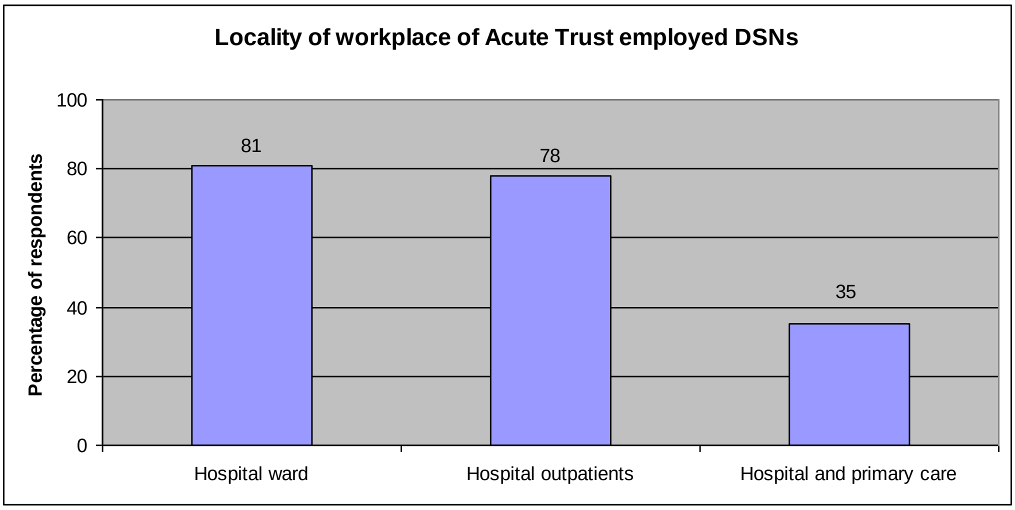
5.10.2 DSN employment, management and locality of work

In virtually all services, diabetes nurses were managed by the employing body (i.e. primary care or acute trust).

5.10.2.1 Hospital DSNs

Most services employed hospital DSNs (83%, n=159). Of these, 95% (n=132) were employed by the acute trust but 89% were managed by the acute trust. Most acute trust employed DSNs worked in the hospital setting (Figure 16).

Figure 16 Locality of workplace of acute trust employed DSNs

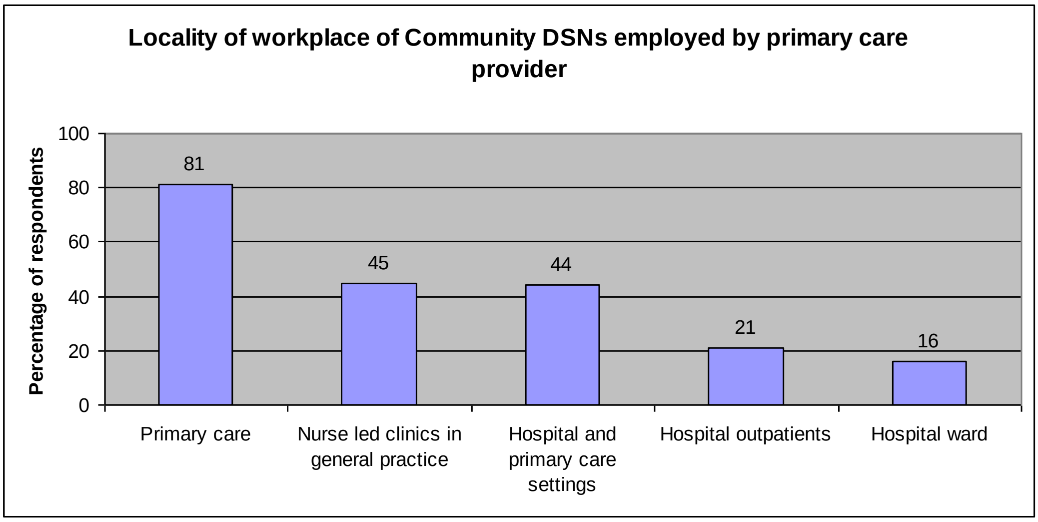


Only half (46%, n=66) of hospital DSNs employed by the primary care provider worked in primary care.

5.10.2.2 Community DSNs

68% (n=159) of services employed community DSNs. 87% of these (n=108) were employed and managed by the primary care provider and most community DSNs worked in primary care settings (Figure 17).

Figure 17 Locality of workplace of community DSNs employed by a primary care provider



Comments from Community DSNs on locality of working:

'All DSNs are based in the diabetes centre and are led and managed by nurse consultant in diabetes'.

'DSNs community work very closely. As we are managed in primary care trust, there are close relationships between all DSNs and nurse leaders with GP and practice nurses'.

5.10.2.3 Nurse consultants

18% (n=159) of services employed nurse consultants. 48% were employed by the primary care provider, 38% by the acute trust, 3% by both and 10% by 'other' employers. 92% of those employed by primary care were managed by primary care; similarly 89% of those employed by the acute trust were managed by the acute trust.

60% (n=15) of acute trust employed nurse consultants worked in either the hospital ward or outpatients and 73% worked across both hospital and primary care. 27% worked solely within a hospital setting. Primary care employed nurse consultants tended to work in primary care (73%) and 53% worked solely in primary care. Only 20% worked in both hospital and primary care. Acute trust nurse consultants were significantly more likely to work across both the hospital and community than primary care employed nurse consultants (p=0.003).

5.10.2.4 Diabetes healthcare assistants

20% (n=159) of services employed diabetes healthcare assistants of whom 61% were employed by the acute trust and 40% by the primary care provider.

5.10.3 Locality of working

The locality in which nurses worked dramatically changed from 2000 to 2007. In 2000, 85% of nurses worked across both hospital and community settings. By 2007, this had reduced to only 35% of hospital DSNs employed by the acute trust and 44% of community DSNs employed by the primary care provider. These findings were also seen in the comparable hospitals where 91% of nurses in 2000 comparable services worked across the hospital and community in 2000 compared to just 30% in 2007 (p<0.000).

5.10.4 Contracts and bands

It was concerning for service continuity that approximately one third of services employed DSNs on short term contracts (38% of hospital DSNs and 38% of community DSNs).

5.10.4.1 Process of Agenda for Change

Agenda for Change was a pay system introduced in 2004 designed to provide equal pay for work of equal value amongst nurses. 94% (n=150) of diabetes specialist nurses had undergone Agenda for Change banding across all four nations (England 98%; Scotland 82%; Wales 100% and Northern Ireland 75%).

5.10.4.2 Provision of a written job description for the role of hospital DSN

Despite having been through the Agenda for Change process, only 78% of diabetes specialist nurses had a specific personalised job description (86% in 2000) despite the Agenda for Change banding being dependent on this. This suggests that banding may have been undertaken as a group. Of the comparable hospitals, fewer DSNs in 2007 (80%) had a job description in 2007 than in 2000 (93%; p=0.03).

5.11 Hospital Diabetes Services

5.11.1 Clinic accessibility

To be accessible to people with diabetes from different nationalities, interpreting services are essential. Most services (91%, n=148) had access to interpreting services. For those who work or have childcare responsibilities, flexible appointment hours are of great help, but only 32% of services provided out-of-hours clinics (n=149), of these 26% (n=47) held weekend clinics and 90% (n=47) held evening clinics.

5.11.2 Availability of an in-house telephone helpline service

The majority of diabetes care is self-care by the person with diabetes at home with relatively infrequent contacts with healthcare professionals. A helpline service can provide an invaluable bridge between appointments. Most services provided a telephone service (Figure 18) which was mostly available during weekday office hours (Figure 19) and operated by the hospital DSN (Figure 20).

Figure 18 Availability of an in-house telephone helpline service by diabetes speciality

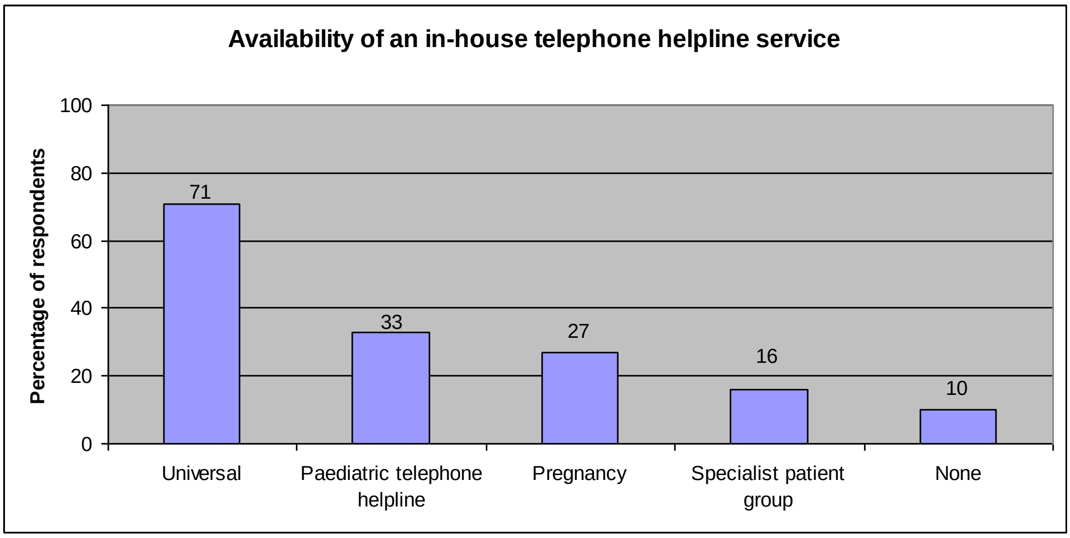


Figure 19 Opening hours of helpline

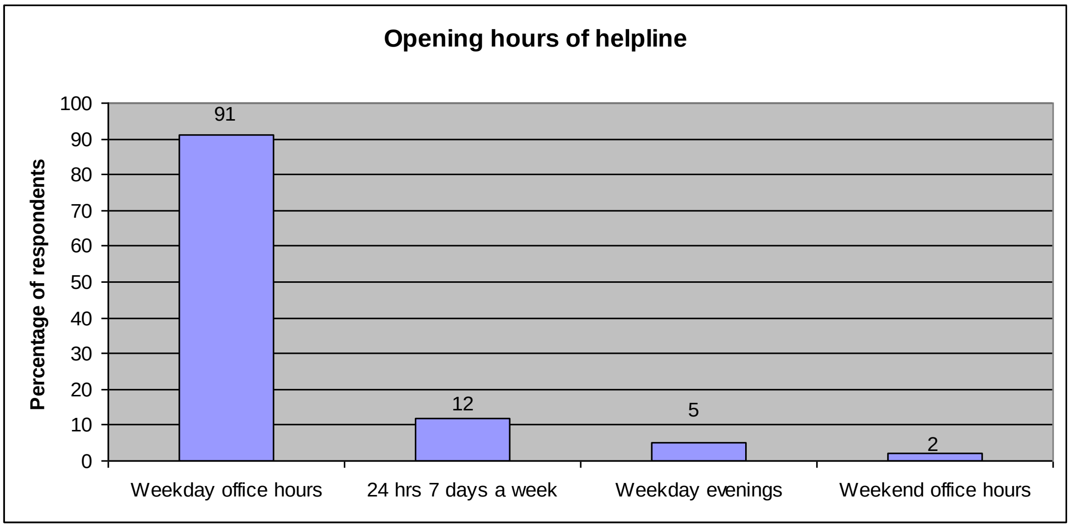
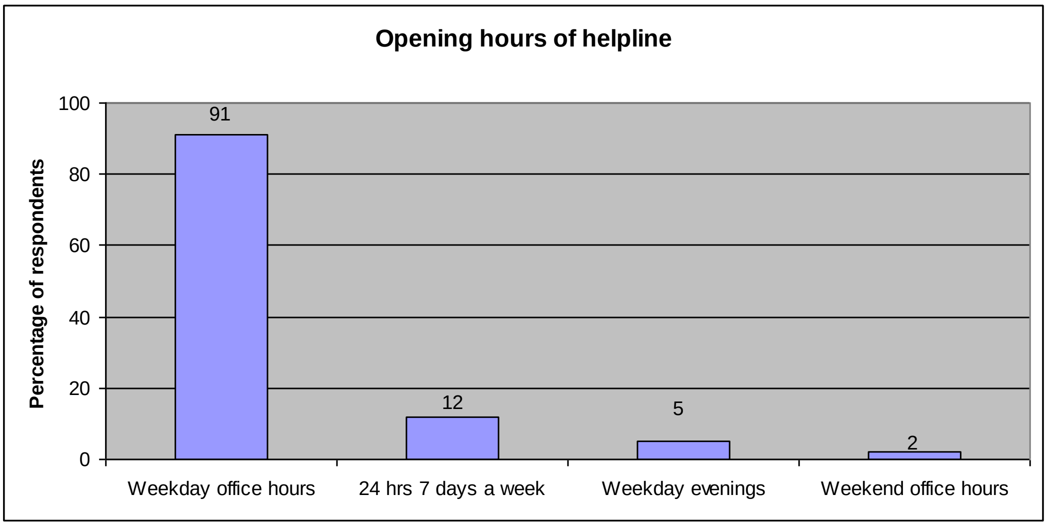


Figure 20 Staff members who operate the helpline



5.11.3 General diabetes clinics

95% of services (n=151) operated general diabetes clinics (i.e. not sub-speciality clinics), a consultant, hospital DSN and Specialist Registrar (SpR), were generally available for diabetes support in the diabetes clinic (Table 5-10). Of these, 72% had an independent nurse-run clinic list and in only 63% (n=90) of services this was a costed activity.

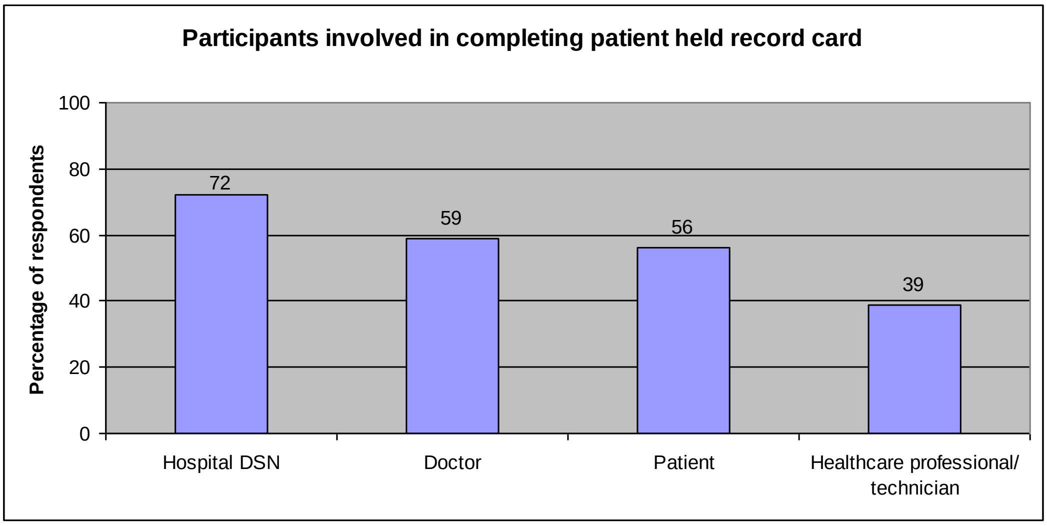
Table 5-10

Staff who are generally available for diabetes support in diabetes clinics	
	Percentage (n=152)
Consultants	98
Hospital DSNs	80
SpRs or equivalent	80
Dietitians	79
Podiatrist	69
Community DSNs	40
Hospital practitioner/ GP with Special Interests (GpwSI)/ Clinical assistant	38
Diabetes health care assistant	26
Senior house officer (SHO)	24
Psychologists	15
Orthotists (provide care for anyone requiring an artificial limb)	13
Associate specialist	12
Men’s health nurse	4
Other	2

5.11.4 Patient held record

The Diabetes NSF delivery strategy stated that primary care trusts by 2006 should ensure systematic treatment regimens were in place with regular reviews, based on a diabetes record and a care plan developed and agreed jointly between the person with diabetes and a member of the diabetes team. 28% (n=151) of services used a patient held record card (20% in 2000). In most services this was completed by the hospital DSN (Figure 21). Services were significantly more likely to provide care plans by 2007 (59% compared to 21% in 2000, $p<0.000$).

Figure 21 Participants involved in completing patient held record cards



5.12 In-patient Diabetes Care

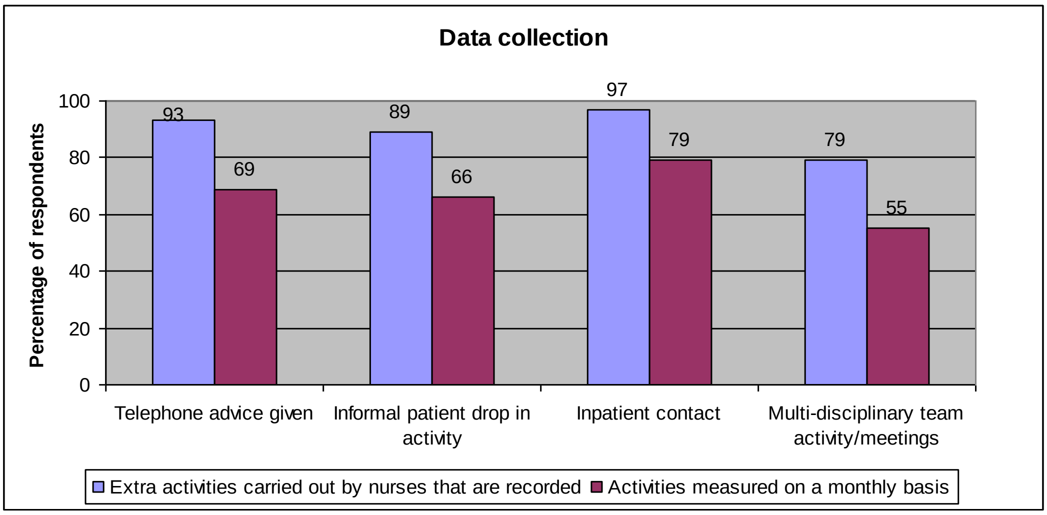
Recommendations in the 2008 National Diabetes Support Team ‘Improving emergency and inpatient care for people with diabetes’ (107) stated that all clinical areas should have access to the specialist medical, nursing, podiatric, dietetic and psychological competencies required by people with diabetes when in hospital. 84% (n=154) of services provided ready access to the diabetes specialist team to support people with diabetes when admitted to hospital. 68% (n=152) had a designated ward for specific diabetes-related hospital admissions.

The NDST review of admission and patient experiences report (107) recommended that a written discharge summary should be sent to the GP, diabetes team and relevant others, for example, social care, and ensure that all people with diabetes in hospital have comprehensive and routine admission and discharge diabetes care plans. 39% (n=135) of services had bed managers that routinely transferred diabetes-related hospital admissions to the designated diabetes ward. 55% (n=145) had a discharge follow-up pathway to primary care for ward discharges and 63% from wards to diabetes out-patient specialist care.

5.12.1 Activity recording

Most services recorded telephone advice when given, although fewer measured these activities on a monthly basis (Figure 22).

Figure 22 Recording of clinical discussions and frequency of contacts



5.13 Discussion

5.13.1 Role of Diabetes Specialist Nurses

This survey of diabetes nurses has demonstrated the diverse and expanding role of the DSN in the seven years since the previous ABCD survey. It has shown the integral role played by DSNs in the clinical care of people with diabetes and within the multidisciplinary diabetes team. DSNs are taking on more complex aspects of clinical care and education previously carried out by doctors.

As the work of DSNs has become more complex to meet the challenge of new therapies and technologies and the move to integrated diabetes care, two new roles have emerged, that of nurse consultant and diabetes health care assistant. Nurse consultants have strong leadership and clinical skills, and were expected to arise from senior hospital DSNs; in practice nurse consultants have been adopted by both primary care and acute trusts, with more nurse consultants working in primary care.

While the role of nurse consultant was predicted in the 2000 survey, the creation of the diabetes health care assistant or diabetes care technician role was not. This role has developed in response to the need for a wider skill mix in diabetes care and incorporated competencies aligned to the diabetes annual review. The majority of these posts were found within the acute trust and not within primary care where many of the annual reviews are now undertaken. This diversification should be seen as a positive step forward as these new roles have led to the development of a new career structure for diabetes nursing and have supported the shift of DSNs towards increasing specialisation in diabetes management. An evaluation in 2012 of nurse consultant and diabetes specialist nurse-led intermediate care clinics has helped to demonstrate their value showing that people with diabetes achieved significant positive clinical outcomes in HbA_{1c} and cholesterol reduction in the direction of NICE targets and feedback from people with diabetes demonstrated high satisfaction that their concerns were being met (108).

The number of paediatric DSNs working entirely with children with diabetes has greatly increased, with only six services (7%) in 2007 reporting no separate paediatric DSN compared with 41% in 2000. Although there has been clear expansion of this role, it still falls short of the levels recommended by the Royal College of Nursing. There is marked variation in provision between hospitals, and some services appear particularly stretched with large case loads per nurse.

Other survey findings corresponded to these results; the Diabetes UK Primary Care Trust progress survey 2006 (109) found that three quarters of PCTs did not meet the Royal College of Nursing target and that the mean case load was 109 children per paediatric DSN, identical to these survey findings.

There have been many changes in the role of DSNs since their inception 60 years ago and it is likely that these changes will continue. There has been a widening of the clinical role, which now includes responsibilities for nurse prescribing, pre-assessment clinics, ante-natal, renal, foot clinics and pump training. More nurses are working independently, as shown by the frequency of nurse-led clinics. DSNs have also adopted new working practices to meet the changing demands of people with diabetes. Most services offer telephone help-lines that are staffed by DSNs. However, the innovation in nurse prescribing has been impeded by trusts failing to provide pathways to implement this new skill.

As nurses become more autonomous and run independent clinic and make decisions about clinical care and medication, funding becomes an issue as traditional hospital payment mechanisms are insufficiently developed to track this activity. It was concerning that the survey demonstrated that only two thirds of trusts were able to cost this activity. This reflects a similar issue to that of nurse prescribing, where payments have traditionally followed doctors and nurses described lack of funding to support this activity. In the future it will be necessary to redesign and renegotiate funding streams to allow for this change in delivery models. This work has since been commenced within paediatric diabetes with a shift from medical activities such as appointments being costed towards an annual payment for the treatment of every child and young person (110).

5.13.2 Education

DSNs are playing an increasingly crucial role in patient and healthcare professional education. Although there is still a multidisciplinary approach to course planning, it is the DSNs who lead the planning and delivery of education programmes. The programmes have also become more sophisticated mostly following the NICE guidance to introduce approved structured education. Given this additional complexity, it is reassuring that so many services now offer these programmes.

Despite the apparent success in development and delivery of structured education, 115 separate courses were named by respondents as being delivered locally. This many courses could lead to confusion for people with diabetes, carers and health professionals as to which course would be most appropriate for the person with diabetes. At this point in time, many areas had only just merged primary care organisations, meaning even relatively small areas may have been offering several courses, post restructure changes were still being made to the commissioning of patient education. Many different education courses were being undertaken but not controlled as part of a central commissioning function. Even within network areas, as diabetes services expand, can so many education courses be sustained and resourced whilst ensuring quality and content? It also made it difficult for organisations such as Diabetes UK to be able to advise members as to what courses were on offer in their locality and the content of such courses and for central bodies such as Care Quality Commission to monitor quality.

Over half of respondents have restrictions on self-monitoring of blood glucose, put in place by the primary care organisation. This was despite guidance from Diabetes UK at the time which advocated that decisions about blood glucose monitoring should be made on a case-by-case basis and not by blanket removal of strips from prescriptions by local policies (111).

5.13.3 Hospital diabetes services

At the same time as these new developments and initiatives, Agenda for Change was being implemented to assess pay and conditions. After this survey, Diabetes UK carried out a survey in 2007 on specialist staffing cuts which revealed considerable variation in grading and responsibilities of DSNs (77). Although the Agenda for Change process appears to have reduced geographical differences in pay as highlighted in the 2000 survey, almost one-fifth of nurses banded by 2007 had no job description on which to base pay bands. This suggests that some DSNs may have been banded accorded to generic group job descriptions. It is therefore unlikely that the new expert clinical roles being taken on by DSNs are being recognised in terms of pay progression. This, together with a number of barriers to role progression, may lead to frustration among DSNs.

Furthermore, specialist knowledge and skills need to be underpinned by continual professional development. The lack of time and resources dedicated to continuing professional development and research is worrying at a time when many new and more complex treatments are becoming available.

This was further corroborated in the Diabetes UK survey of specialist staffing in which 40% of DSNs reported that time for study leave had been reduced, 45% that funding was reduced and 40% that requests for study leave had been denied (70). Since then the joint position statement issued by Diabetes UK and TREND-UK has shown this has not improved, in 2013 a survey by TREND-UK of nurses attending their conference found that 50% of nurses reported problems getting time to attend training and 55% reported problems securing funding for training (112).

The successful integration of DSNs into advanced clinical care is in danger of being undermined further by lack of commitment to support nurse engagement in research. One-third of hospital DSNs and community DSNs are employed on short-term contracts, funded by external sources. This lack of long-term job security may further affect recruitment and retention of highly skilled specialist nurses. It may also hamper the retention of skills in diabetes services when these contracts expire.

Access to high-quality integrated care at the right time by the right person for people with diabetes is a central tenet of both ABCD and Diabetes UK and in the current economic climate (2011) it is essential that services are able to deliver high quality care with fewer resources. DSNs have demonstrated their ability to deliver cost effective care, as evidenced through a randomised controlled trial by Davies et al in which DSNs reduced lengths of stays in hospitals potentially saving costs (31).

There is evidence that since 2000 there has been a fragmentation of services which threatens the ability of the health service to provide high-quality integrated services. In 2000, diabetes specialist services were characterised by cross-boundary working of diabetes nurses. Since then, there has been significant splitting of services between primary and secondary care settings. This is contrary to the concept of integrated care, and the long-term effect it will have on the diabetes nursing profession and care of people living with diabetes remains to be seen.

5.13.4 Limitations to the survey

There are a number of limitations to the survey. Overall the response rate was only 44% and therefore there is a possibility of responder bias. There are important differences between this survey and the previous ABCD survey in 2000. In 2000, the answers were completed by consultants answering on the nurses’ behalf and therefore may not be directly comparable. Nevertheless, when the results of those trusts that took part in both surveys were analysed separately (the comparable hospitals), there was no change in the findings, suggesting that the results are representative of services at both time points. A further limitation of the survey is that questions were not asked about the competencies and qualifications required to be a DSN.

In summary, the diabetes specialist role has expanded and developed to meet the needs of the ever-growing diabetes population and government directives. There has been considerable progress between 2000 and 2007. The lack of opportunity for study leave and research opportunities is concerning. This, coupled with lack of long-term job security, may affect the retention and recruitment of DSNs in future years. It may also be that DSN training and education needs to be underpinned by a formal training curriculum, as suggested in the 2000 survey. Fundamental changes that have led to services developing separately in primary and secondary settings may affect the continuity of care for people with diabetes.

A number of recommendations follow the findings of the survey:

- In order to facilitate best practice in the care of people with diabetes, it is essential that DSNs have protected access and funding to continual professional development in the form of study leave and through participation in research activities.
- The case-load of existing paediatric DSNs should be reduced to the levels recommended by the Royal College of Nursing to improve care of children and young people with diabetes.
- In order to promote and facilitate the ethos of integrated diabetes care, DSNs should have the opportunity to meet regularly with their peers, whether working in primary or secondary care.
- Lastly having developed a career structure for DSNs, it is vital this is enabled through accurate job descriptions on which to base pay and that job security is supported through permanent contracts.

To achieve this, a database for DSNs was proposed and developed by Diabetes UK and this is explored in Chapter 6.

DSN workforce survey 2009

6.1 Introduction

The aim of this study was to establish a database of DSNs working in the UK. It sought to find out how many DSNs and nurse consultants were in post, their job titles, where DSNs and nurse consultants worked, roles they carried out, their qualifications, banding and whether they planned to retire in the next ten years.

These data when used in conjunction with the findings from the previous chapters, and the Diabetes UK Commissioning Specialist Diabetes Services for Adults with Diabetes, which recommends a minimum staffing level for diabetes population (79), would help to predict service needs over the coming years and assist with workforce planning. Whilst this survey covered similar areas to the previous survey, such as locality of working and role, the aim of the survey was different. The previous survey sought to describe in depth how the role of the DSN has evolved and how locality of working has highlighted changes in service integration. This survey aimed to build a national profile of the workforce and highlight potential areas of concern such as retirement dates for succession planning.

6.2 Method

6.2.1 Role of the working group

- June James – Nurse Consultant, Leicester University Hospitals and Vice-Chair Professional Advisory Council Diabetes UK.
- Ursula Anderson – Regional Programme Manager NHS Diabetes.
- Charlotte Gosden – Information Analyst, Policy Care & Improvement Team.

6.2.2 My role in the research process of this study

- Develop research questions, questionnaires, respondent lists, data analysis protocols, reporting mechanisms.
- Manage the process of creating, formatting, writing questions and designing forms.

- Distribute questionnaires, data collection, data analysis, report writing and assisting and writing journal articles.
- Hold and manage contact database and overall timeline.
- Manage outputs including reports, articles, website updates, presentations and conference presentations.
- Co-ordinate meetings with the working groups, take minutes, distribute minutes, organise meeting rooms and follow up on actions raised during meetings.
- Present findings at national and international conferences.
- Distribute results through Diabetes UK and partner agencies to support policy work and provide detailed information to support the lobbying function at Diabetes UK. Act as the representative and information expert for Diabetes UK to partners working groups such as NHS Diabetes, Department of Health, Royal Colleges and Kings Fund to disseminate findings.
- Inform the results of the research to Diabetes UK membership via newsletters, website and magazines, to other teams for press releases, parliamentary questions and lobbying.

6.2.3 Setting

All diabetes specialist services across the UK including; adult, paediatric, acute and primary care locations.

6.2.4 Study participants

The aim of this survey was to reach as many individual DSNs and Nurse Consultants, whether employed within a hospital or by a community primary care trust, general practitioner or the pharmaceutical industry as possible.

I identified participants from the mailing list of the 2007 ABCD and Diabetes UK DSN survey, the membership databases of Diabetes UK, the DISN Group and the Directory of Diabetes Care 2009 (32). June James and I also approached other sources where lists of nurses operating as DSNs could be readily obtained. These included pharmaceutical companies, primary care trusts, newly formed GP commissioning groups and privately employed DSNs within the Ashfield group (a contract services organisation). The Royal College of Paediatric and Child Health database of paediatric units was also used, as this survey aimed to include paediatric

DSNs unlike the main DSN survey which was aimed at adult services only. The questionnaire was also advertised on the Diabetes UK and NHS Diabetes websites and promoted in the Journal of Diabetes Nursing.

6.2.5 Survey development

6.2.5.1 Aim of the survey

Following issues raised from the DSN survey, Diabetes UK collaborated with NHS Diabetes to carry out an additional questionnaire to elicit further information relating to the DSN workforce. The aim was to establish a database of DSNs working in the UK to help predict manpower needs over time. This would assist in the role of the DSN workforce planning by identifying how many DSNs were working in the UK, their work setting, roles being carried out, qualifications gained and band level awarded.

6.2.5.2 Special issues: brief background

Previous surveys carried out by Diabetes UK and ABCD had identified a wide variation in nurse qualifications required and grading of DSNs with regional variation. DSNs were shown to have taken on more complex aspects of clinical care and education previously carried out by doctors. However, the fragmentation of services was also notable with fewer nurses working across both primary and specialist settings.

There were a large number of DSNs who were on short-term externally funded contracts and there was a lack of protected time and funding for continuing professional development. Many trusts have one or more nurses who had attended a nurse prescribing course, although prescribing was only carried out in less than half of trusts. Few nurses had a formal role in research and some did not have a written job description for the role of hospital DSN despite most nurses having been banded for Agenda for Change (which requires a written job description on which to base a decision for a band to be awarded). New roles were also identified, the nurse consultant role providing nurses with opportunities for promotion into leadership and research roles. The purpose behind establishing the database was to:

- Track employment trends, identify employments gaps and enable workforce planning to be used to influence care.

- To provide a picture of the nature of diabetes specialist nursing in the UK to gain information to assess and plan services and to guide manpower planning in the future through repetition of the survey.
- To identify workforce requirements, qualifications, vacancies and frozen posts.

6.2.5.3 Topics

These included:

- number of DSNs and nurse consultants working in the UK
- job title
- post basic qualifications gained
- work setting
- years of experience
- band level awarded
- diabetes role (for example, adults, research, paediatric)
- expected retirement date
- hours worked in diabetes
- appointment type
- presence of a clinical lead

6.2.5.4 Structure of the survey

This questionnaire consisted of 12 closed questions to collect quantitative information (Appendix E).

6.2.6 Pilots

The questionnaire was piloted with eight participants. These included consultant nurses for diabetes, DSNs and Community DSNs from specialist and primary care settings identified from Diabetes UK membership, TREND-UK[1] membership and 2009 Directory of Diabetes Care.

6.2.7 Distribution of the questionnaires

I posted paper copies but where requested, I emailed the questionnaire as an attached word document.

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[1] TREND UK (Training, Research and Education for Nurses in Diabetes)

6.2.8 Timeline

I posted paper copies of the DSN workforce survey to 2216 DSNs on 1st September 2009, with a reminder in November. Data collection was continued until December 2009 with questionnaire being either emailed or sent as hard copies in the post. DSNs were encouraged to share copies of the questionnaire with as many colleagues as possible.

6.2.9 Data management and data cleaning

6.2.9.1 Data analysis

The data were analysed using Excel and SPSS (version 16) using both parametric and non-parametric tests according to the distribution of the data in a similar method as described more fully in the consultant survey.

6.3 Results

Of the 1363 questionnaires sent out, 838 responses were received giving a response rate of 61% across the UK. 700 were received from England, 28 from Northern Ireland, 60 from Scotland and 45 from Wales, there were five responses with no information about nationality.

6.3.1 Job titles

The proliferation of job titles in diabetes nursing which has been identified in the last ten years (113) was also apparent in these findings. 238 separate job titles were given from 788 respondents representing the role of DSN. To simplify this, the titles were grouped into the categories shown in Table 6-1. This diversity may reflect the fact that there has been no national guidance to provide consistent role description to support the development of the role of the DSN.

Table 6-1

Diversity of job titles		
	Count (n=788)	**Percentage**
Nurse Consultant	18	2
DSN	600	76
Dual role	22	3
Education	2	0.3
Facilitator	5	0.6
Paediatric DSN	128	16
Research nurse	13	2

6.3.2 Qualifications

All new in-post specialist nurses are now required to have, or be working towards, a degree-level qualification to fulfil the national job profile for band 6 specialist nursing, and senior DSNs should be working towards a masters degree level qualification for the advanced nurse job profile (114). Most respondents (793) had gained a diabetes diploma or certificate and just over half had studied for ad hoc degree modules (Table 6-2). However, 5% respondents either missed the question out entirely or did not have any post-basic qualifications. As respondents could tick more than one option, the total exceeds 100%.

Table 6-2

Post-basic qualifications gained	Count (n=793)	Percentage
Diabetes diploma/ certificate	587	74
Diabetes related degree	138	17
Diabetes related masters	65	8
Ad hoc modules degree	424	54
Ad hoc modules masters	145	18
Diabetes counselling course	126	16
Non medical prescribing	320	40
PhD completed or undertaking	11	1
General degree	80	10
Teaching	34	4
Other	51	6
None		5

6.3.3 Work settings

Since the ABCD survey in 2000, there has been a shift in the delivery of diabetes care closer to home, which has affected the settings in which DSNs operate. Nearly half of respondents worked in a hospital setting (Table 6-3) but less than a third worked across both hospital and community settings.

Table 6-3

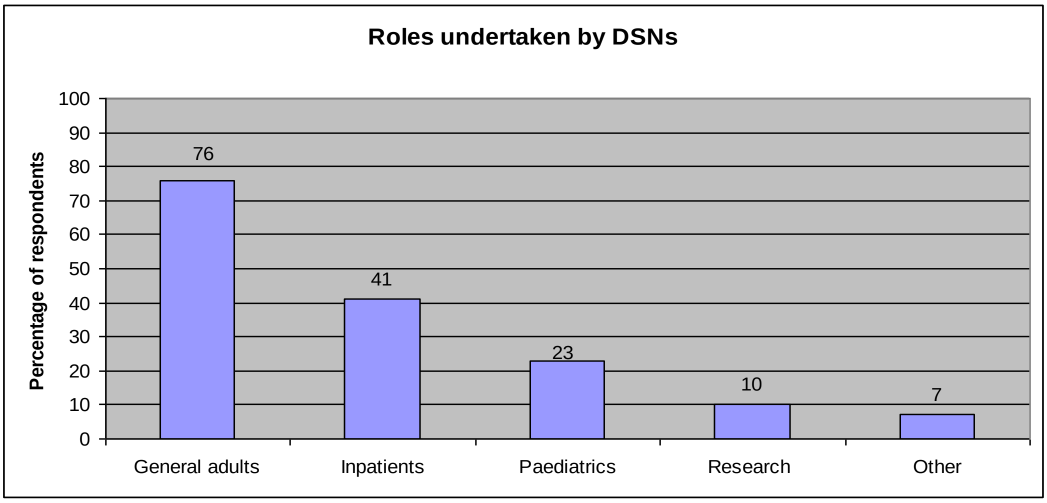
Work setting		
	Count (n=830)	**Percentage**
Hospital	388	47
Hospital and community	233	28
Hospital, community and other	8	1
Hospital and other	7	0.8
Community	182	22
Community and other	7	0.8
Other	5	0.6

6.3.4 Diabetes experience and employment

In order to meet the definition of a DSN, DSNs must work entirely in diabetes care with adults, children or both. Almost two thirds (57%, n=836) of DSNs worked solely in diabetes (37.5 hours per week) with hours worked ranging from 5.25 to 37.5 hours.

Figure 23 identified that their roles encompassed a variety of patient groups and functions. In their DSN role, three quarters had a general adult component (76%, n=810) and nearly half had a diabetes inpatient function (41%) as part of their remit. It was disappointing that so few nurses were involved in research activities when it had been stated by Castledine (30) in his definition of a DSN that this should be encompassed in the DSN role.

Figure 23 Roles undertaken by DSNs

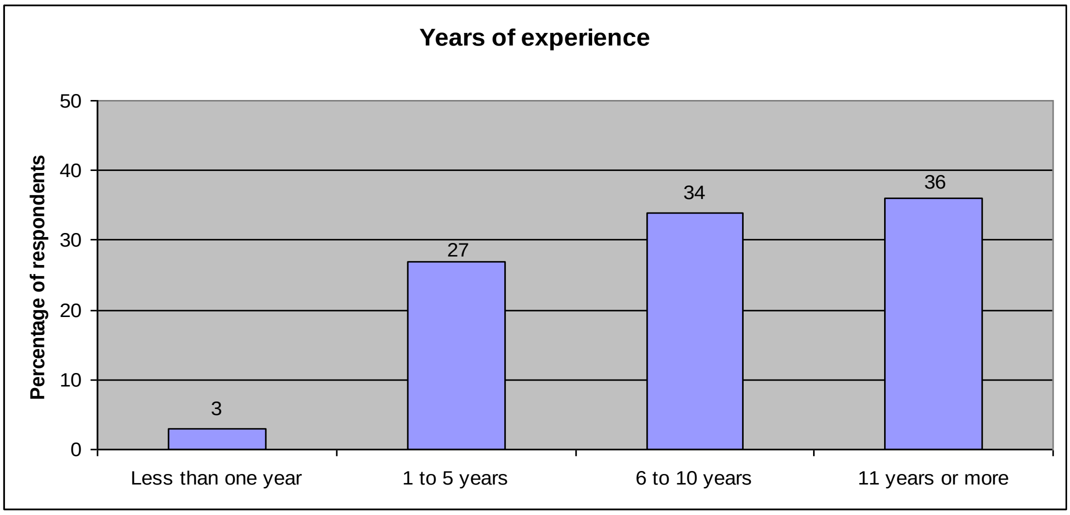


Other roles undertaken included specialist midwives, education, management, endocrinology, maturity onset diabetes of the young (Figure 23).

DSNs may be employed by a range of employers, on different contracts and with different expectations by the employer. 96% (n=810) were employed by the NHS, 0.7% by universities, 0.7% by pharmaceutical companies and 1% by ‘other’ organisations.

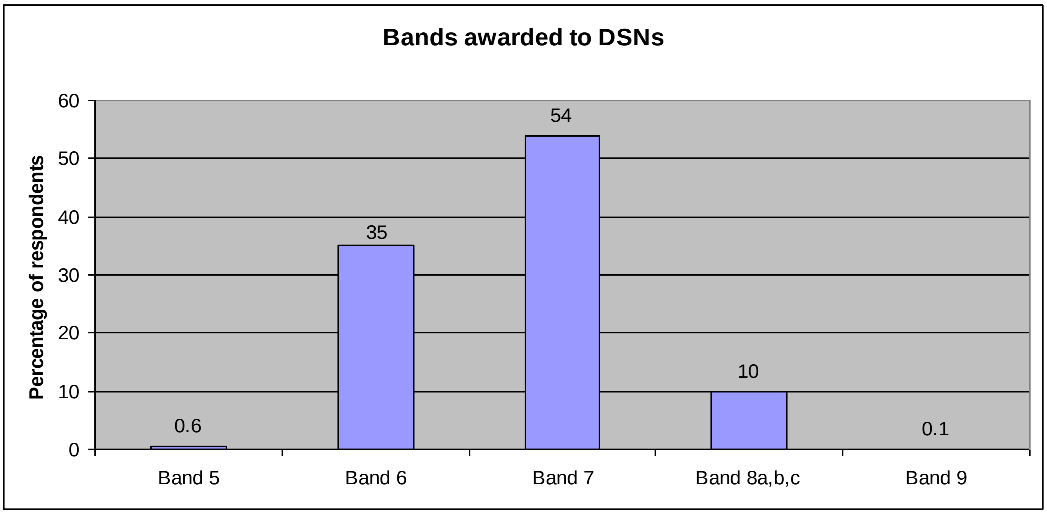
DSNs should be registered nurses and have a minimum of three years’ practice. On average, nurses had 10 years’ experience working as a DSN (n=813) and most had 11 years or more experience (Figure 24).

Figure 24 Years of experience as a DSN



The previous chapter identified that one in five trusts did not have written job descriptions for the role of DSNs, despite most nurses having been banded according to the new pay structure set out by Agenda for Change (115). Nearly all DSNs were banded (89%) either 6 or 7 (n=811), the median was band 7 (Figure 25), which is a senior specialist nurse.

Figure 25 Bands awarded to DSNs



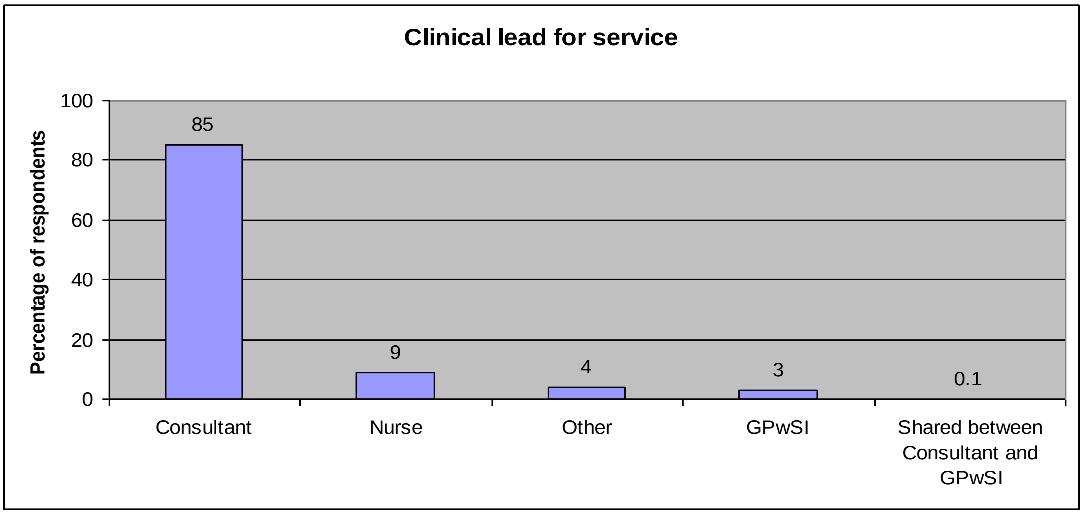
49% (n=799) of DSNs were top of their band, and 445 (n=693) were expecting to retire within the next ten years (Table 6-4) which has serious implications for succession planning to maintain these specialist skills and input into the multidisciplinary team.

Table 6-4

Retirement dates		
	Count	**Percentage**
2009 to 2014	97	14
2015 to 2020	207	30
2021 to 2025	146	21
2026 to 2030	131	19

DSNs should work within multidisciplinary teams with a consultant physician or a paediatrician as clinical lead. In most services this was the case with 89% (n=819) of DSNs reporting that they had a clinical lead for their service. Of those, 85% said this was a consultant (Figure 26, n=715) and in a small number by a nurse, or a GPwSI, 'other' included a co-ordinator, dietitian, doctor, education lead or services manager.

Figure 26 Clinical lead for the service



6.4 Discussion

The aim of this study was to establish a register of DSNs working in the UK to help predict manpower, services needs over time and assist with workforce planning. The study was designed to be repeated annually to build up an increasingly accurate national and local picture of the DSN workforce. This was to ensure that over time there will be appropriately trained individuals to deliver the increasingly complex care needed for the rising population of people with diabetes in a rapidly changing healthcare environment. It was hoped it would provide evidence to allow clear recommendations for the level of provision to guide providers and commissioners designing diabetes services. In 2010 the study was repeated by Diabetes UK and NHS Diabetes, with a focus on changes in skills and experience of DSNs, vacant posts, where DSNs work and a more detailed focus on what they undertook in their role (116). These findings are not presented here as the I was not involved in the survey process.

In 2010 the issue of numerous job titles continued as the latest workforce survey identified 167 different job titles from 587 respondents, 80% of which were DSN or a variant and 1.5% Nurse Consultant. This showed there had been no reduction in the proportional number of differing job titles provided by respondents from 2009. This could lead to confusion as to role function as described by Da Costa (113) which may ultimately negatively affect the role progression of DSNs. Standardised job descriptions and job titles should help to resolve this lack of clarity. Yet despite a wealth of guidance from sources such as Skills for Health Competency Frameworks and the NHS Diabetes Commissioning guides which aimed to provide toolkits to standardise commissioning processes and practice for delivery of diabetes specialist services, this does not appear to have improved. Also people with diabetes receive support and care for their condition by nurses in healthcare settings outside of general hospital settings and community clinics, such as hospices, prisons, residential homes and other health care settings. Therefore with such a variety of different employers, a clear definition of the DSN role with standard job titles could reduce the risk of confusion as to who is competent to deliver different aspects and levels of complexity of care to people with diabetes. This would help to ensure that all people with diabetes are seen by the right person at the right time.

The findings presented here show that DSNs are involved in a number of different roles, including general adults or paediatrics, although involvement in research is still disappointingly low despite this being a key feature of the specialist role and function of the nurse consultant role in particular. This demonstrates the multi-faceted nature of the DSN role. It is important that role diversity is recognised by those who have an influence on service design so that all aspects are taken into account when reviewing services.

These changes in the work setting and role of DSNs have been in response to the increasing prevalence of diabetes and government directives, such as moving the focus of care from specialist into primary care settings. The survey identified that nurses were less likely to work across both primary and specialist settings, and that the trend towards the fragmentation of work settings, has continued. In 2000, ABCD reported that 89% of DSNs carried out work in both hospital and in the community (35); however, by 2007, this had reduced by nearly half by 2007, when only 35% of hospital DSNs employed by acute trusts and 44% of community DSNs employed by the primary care provider worked in both hospital and community settings. This was consistent with this survey where only 30% of DSNs worked across both hospital and community or ‘other’ settings and the trend had continued in 2010 as only 22% covered both community and hospital settings (116). This is concerning as it is unknown what effect this will have on the care for people with diabetes. It also jeopardises opportunities for joint working, clinical support and sharing of knowledge and skills, such as prescribing for DSNs, which are unique to the UK.

The 2000 ABCD survey found that there was a wide variation in nurse qualifications achieved, grading of DSNs, and day-to-day roles performed (35). A suggestion was put forward for a nationally coordinated approach to training involving a standardised evaluated course for new entrants to the speciality with formal opportunities for regular training updates and the establishment of a degree course for DSNs with greater clarity in the grading structure of competency relating to tasks. This has been taken up by the Agenda for Change (117) and Knowledge and Skills Framework (118) in recent years, and the first edition of 'An Integrated Career and Competency Framework for Diabetes Nursing', was published in 2005, which was a competency framework developed by nurses for nurses (119). This has since been updated by TREND UK who published a second edition in 2010 (38). It was encouraging therefore to find that most DSNs were qualified to the minimum level required of DSNs, and that only 5% did not have further qualifications, or did not respond to the question which was an improvement since 2000 (35). This can be seen as a success of these new directives which state that DSNs should either have or be working towards a degree or masters degree. Nearly half of the DSNs surveyed also had a qualification in prescribing, however, there was not enough information available in this survey to explore further the issue identified in the previous chapter, whereby many were not able to implement their prescribing skills (120).

Alarmingly, these data show that nearly half of respondents are expecting to retire in the next ten years. This has important implications for succession planning to ensure there are sufficient numbers of DSNs to meet the needs of an increasing diabetes population and ensure they receive high quality care. This finding was supported by the survey in 2010 and later by the Joint Position of Diabetes UK and TREND-UK in 2014 in which it was reported that 48% were due to retire in the next 10 years (112). In addition, as nearly half of respondents reported that they are at the top of their band, and over half in 2010 (54% of all respondents), there is a need to ensure that a career pathway exists to support progression.

Of further concern was that nearly one in ten DSNs did not have the appropriate clinical leadership for their service, which suggests they are working without access to specialist clinical support. This may lead to inconsistencies in knowledge and skills and eventually to unacceptable variation in the competencies of DSNs which could impact adversely on the care of people with diabetes. This trend had not improved in the subsequent survey as 11% reported that there was no clinical lead for the service and there was a significant decrease in consultant leadership and a considerable increase in nurse leadership. This may be a result of cuts in resources in the acute setting and may also be a possible direct result of a shift of diabetes care into the community.

The joint Diabetes UK and TREND-UK position statement in 2014 has demonstrated that levels of diabetes specialist nurses have been allowed to stagnate at a time of increasing prevalence, that DSNs have less contact with people with diabetes and their skill levels are under threat due to lack of training time and resources. These organisations are calling on commissioners to recognise the importance of DSNs when designing a cost effective diabetes service and to support adequate workforce planning to ensure that in 2025 when it is estimated five million people will be living with diabetes, will have access to appropriately skilled and qualified nurses.

There were a number of limitations to the study. It was difficult to determine an accurate number of DSNs to whom to send the questionnaire as there were no readily available lists of DSNs employed by pharmaceutical companies, GPs or primary care commissioning groups. To reach as many DSNs as possible, the survey was promoted via the *Journal of Diabetes Nursing*, NHS Diabetes and Diabetes UK websites and other appropriate organizations. However, it cannot be certain that all DSNs in the four UK nations were given the opportunity to take part. Also, given that people change jobs and change names through marriage, some questionnaires may not have reached the intended person.

This study has provided useful information on DSN and nurse consultant roles, qualifications and banding. The establishment of an accurate database of DSNs will help to ensure that the workforce is appropriate for the needs of people with diabetes and that plans can be made to ensure that it remains or becomes so. As has been discussed, the survey was repeated in 2010 and can also be extended in future years to highlight the level of provision, time available and funding for study leave and opportunities to take part in research. It has also provided a starting point for mapping the progression and development of a key part of the workforce available to diabetes services. Additional research is required to gather information to map available competencies to the qualifications and role of DSNs if required.

Paediatric diabetes services

7.1 Introduction

At the time of the survey (2007), the incidence of type 1 diabetes had doubled in the previous ten years with the most marked increase in younger children (121). The management of children and young people had become more complex to avoid the long-term complications of diabetes and maintain a good quality of life. Findings from National Diabetes Audit data (2007 to 2008) suggested that diabetes control was consistently poor throughout the UK (122). Since 1988, there have been four surveys of UK paediatric and adolescent diabetes services (62; 123-125) ; while these have shown improvements in service provision, gaps still remained in psychological services, numbers of paediatric staff and transition to adult services (62). Since then, the National Institute for Health and Clinical Excellence (NICE) (4) and the Scottish Intercollegiate Guidelines Network (SIGN) (126) guidelines for standards of diabetes care for children have been published. This fifth national survey was carried out to assess services against these criteria.

7.2 Methods

7.2.1 Role of the working group

- Julie Edge, Consultant in Paediatric Diabetes and Head of Oxford Postgraduate School of Paediatrics, Oxford, UK
- Krystna Matyka – Senior Lecturer in Paediatrics, Warwick Medical School
- Charlotte Gosden – Information Analyst, Policy Care & Improvement Team

7.2.2 My role in the research process in this study

- Develop research questions, questionnaires, respondent lists, data analysis protocols, reporting mechanisms.
- Manage the process of creating, formatting, writing questions and designing forms.
- Distribute questionnaires, data collection, data analysis, report writing and assisting and writing journal articles.
- Hold and manage contact database and overall timeline.
- Manage outputs including reports, articles, website updates, presentations and conference presentations.

- Co-ordinate meetings with the working groups, take minutes, distribute minutes, organise meeting rooms and follow up on actions raised during meetings.
- Present findings at national conferences.
- Distribute results through Diabetes UK and partner agencies to support policy work and provide detailed information to support the lobbying function at Diabetes UK. Act as the representative and information expert for Diabetes UK to partners working groups such as NHS Diabetes, Department of Health, Royal Colleges and Kings Fund to disseminate findings.
- Inform the results of the research to Diabetes UK membership via newsletters, website and magazines, to other teams for press releases, parliamentary questions and lobbying.

7.2.3 Setting

All UK diabetes paediatric and adolescent services.

7.2.4 Study participants

I identified services through the ABCD membership, the British Society of Paediatric Endocrinologists and Diabetologists, National Diabetes Paediatric Audit, Diabetes UK and the Directory of Diabetes Care 2008. The lead consultant from all UK paediatric and adolescent services (n=205) was invited by email to complete the survey.

7.2.5 Survey development

7.2.5.1 Aim of the survey

The aim of this survey was to review the provision of paediatric and adolescent diabetes services and to find out if services had improved since the previous survey in 2002. It also aimed to determine whether services were meeting guidelines and national service framework standards.

7.2.5.2 Special issues: brief background

Since 1988 there have been four surveys of paediatric and adolescent services in the UK. The paediatric working group built on the expertise of previous paediatric surveys by using the year 2002 questionnaire as a starting point to ensure that there were some comparable questions.

7.2.5.3 Topics

These included:

- workforce
- diagnosis and initial management
- management from diagnosis
- on-going management and education
- insulin regimens
- monitoring glycaemic control
- screening for complications and associated conditions
- psychological support
- continuity of care
- transfer from paediatric
- transitioning to adult services
- management at school

7.2.5.4 Structure of the survey

The structure of the survey was guided by the recent National Institute for Health and Clinical Excellence guidance (4) in order to measure services performance against these standards. There were 72 questions including both open and closed questions (Appendix F).

Where there was more than one geographical location of clinics per service, respondents were invited to provide separate answers per clinic to certain questions.

7.2.6 Pilots

The questionnaire was piloted with six participants including consultant paediatric diabetologists and paediatricians with a special interest in diabetes. The pilots were conducted in a manner comparable to the consultant survey (Table 7-1).

Table 7-1

Number of participants for each survey and who participated		
Survey	**Number of participants**	**Who participated?**
Paediatric	6	Consultant paediatric diabetologists Paediatricians with a special interest in diabetes

7.2.7 Timeline

I emailed all UK paediatric and adolescent services (n=205) via the Opinion-taker website, and where emails were undelivered, I sent postal copies instead. I emailed or posted a second questionnaire after one month followed by a telephone reminder. Data were collected between April 2008 and December 2008.

7.2.8 Data management and data cleaning

7.2.8.1 Data analysis

The data were analysed using Excel and SPSS (version 16) using both parametric and non-parametric tests according to the distribution of the data in a similar method as described more fully in the consultant survey.

7.2.8.2 Pre-specified sub-group analysis

It was recognised that some clinical *services* would operate from more than one *clinic* in different geographical locations. Therefore some questions would relate to the *service* as a whole and some would relate to individual *clinic* provision to capture all relevant data. In the main the results to the survey were presented by service, except those where responses by clinic were invited.

A sub-analysis of those respondents who answered all questions relating to all the recommendations was also included and used to track changes from previous surveys.

7.3 Results

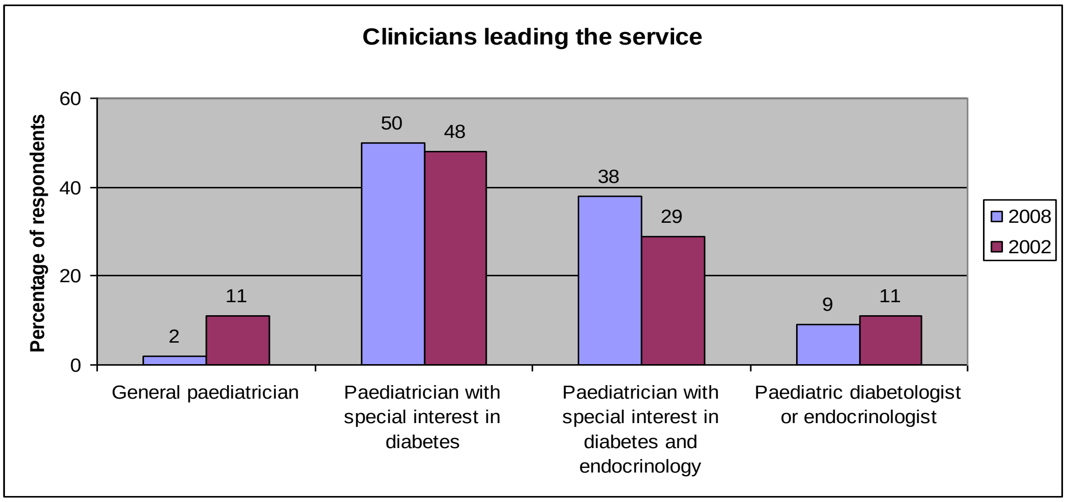
63% of services responded (123 out of 205) involving 220 clinics. Responses were received on behalf of 196 paediatric consultants caring for a total of 17,071 children and young people, 3,350 were aged 16 and over (median=25 children and young people; range 3 to 201) and 13,721 were aged 15 and under (median=100 children and young people; range 7 to 519). Slightly more children and young people were captured in 2002, 18,500 (15,400 under 16 years) when 187 consultants responded.

50% of services operated from more than one location which has implications for staff and clinic management.

7.3.1 Workforce

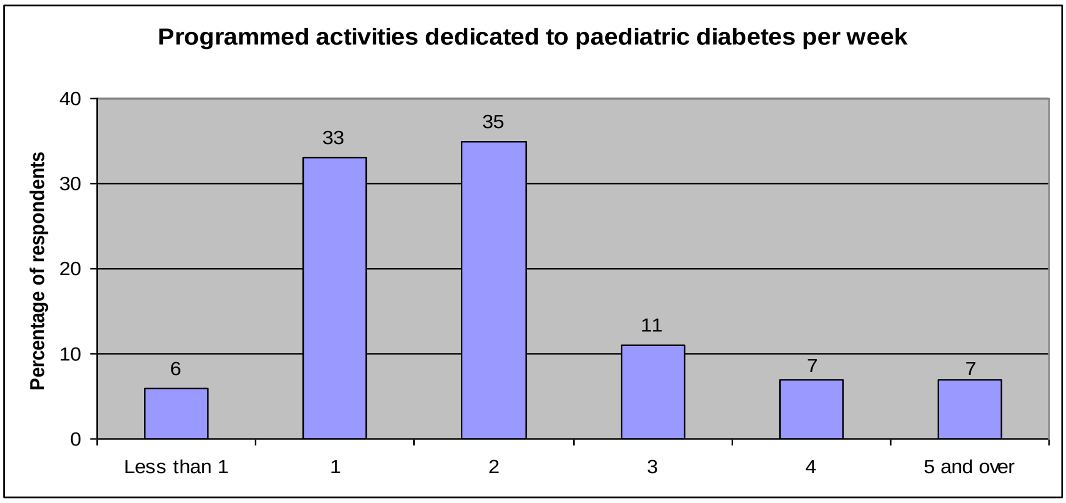
Most services were led by consultant paediatricians with an interest in diabetes, 9% were paediatric diabetologists or endocrinologists, only 2% of services were staffed by general paediatricians (11%, 2002, p=0.004) (Figure 27).

Figure 27 Clinicians who lead the paediatric service



58% (n=125) of services were run by one consultant (median=1; range 1 to 4). 68% of consultants dedicated between one and two programmed activities (4 hour sessions) to diabetes per week (Figure 28) but 7% spent over half their working week devoted to diabetes.

Figure 28 Programmed activities dedicated to paediatric diabetes by consultant per week



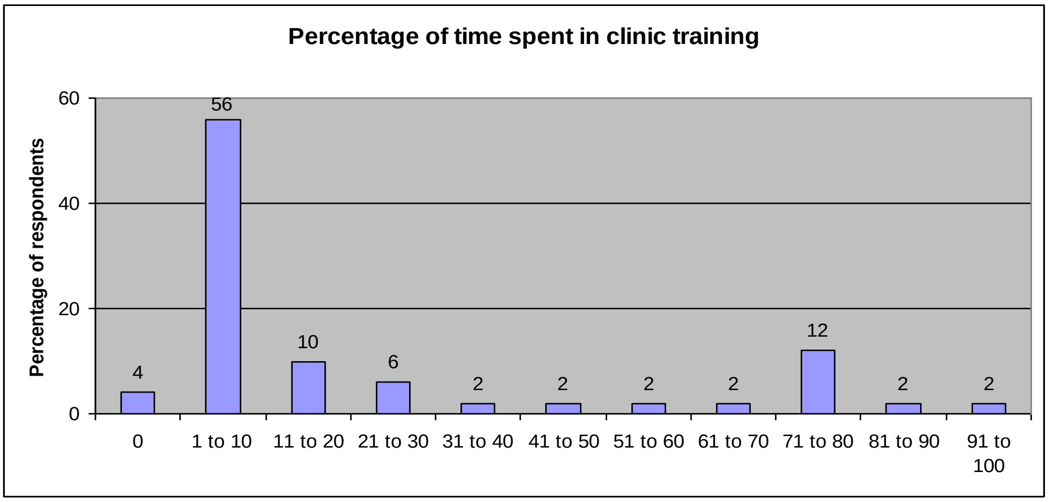
In line with NICE guidance, most clinics (94%, n=208) were attended by a Paediatric DSN (median=1). This was an improvement from 2002, where most clinics were attended by a DSN (98%, p=0.03 n=168), albeit that most had receiving training in paediatrics (132/161 said yes, 2002). 88% of services, who had a paediatric DSN, these worked solely in paediatrics (53%, 2002). 76% had no support from adult-trained DSNs. 72% of paediatric DSNs worked across hospital and community settings (91%, 2002, p<0.000).

Nursing caseloads had decreased from one nurse to 147 patients in 2002 to 1:92 (median) in 2008. 17% of services said they were meeting the Royal College of Nursing target of 1 paediatric DSN to 70 children and young people.

NICE stipulate that paediatric diabetes clinics should be attended by a paediatric dietitian with diabetes expertise. 93% of clinics offered children and young people appropriate dietetic support to help optimise body weight and glycaemic control (87% of clinics reported that a dietitian regularly attended clinics, 2002) and offered on average 2.6 hours per year to each child.

In order to ensure a succession of consultants and to encourage junior doctors to choose diabetes as a sub-speciality, 55% (n=123) of services provided diabetes training for junior doctors. 4% reported that trainees spent no time attending the diabetes service (median=10% of trainee time spent in diabetes, range 0 to 100%). 60% had trainees who spent 10% or less of their time in outpatients, where the majority of children with diabetes are seen (Figure 29).

Figure 29 Percentage of time spent by trainee paediatric doctors in the paediatric diabetes service



Respondents were invited to comment on workforce issues within the service, comments described pressure on staff with increasing numbers of children and young people, or a lack of dietitian time or psychological support, for example:

Comments from respondents:

'Have 0.5 dietitian for whole service, diabetes is always the service that seems to have to make do, when other services are protected despite having the largest number of patients'.

'Currently service under pressure because of an increase in the number of patients, paediatric DSN vacancy not filled and paediatric DSN sickness'.

'We have experienced an explosion in numbers of patients; simultaneously we are providing more complex insulin regimes. This has resulted in a severe shortfall in staffing. We need to at least double medical, nursing, psychology and dietetic staffing levels to provide an adequate service'.

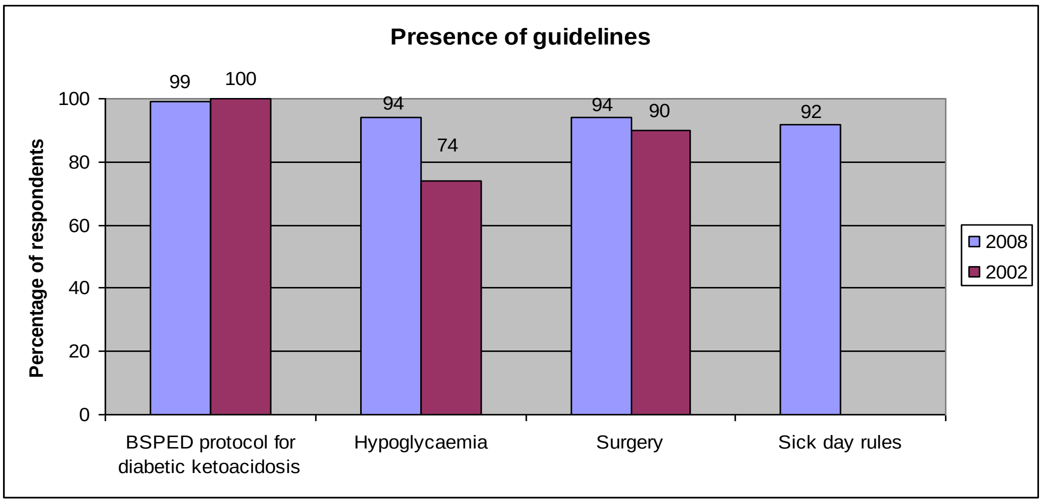
'We need much more diabetes nurse time and dietitian and more clinics. Also like everyone I suspect dedicated psychological support as integral part of the service'.

'Difficult to get recognition of the need for a psychological member of the team. Woefully inadequate dietetics, not enough medical or nursing time'.

7.3.2 Guidelines

It is essential that services have protocols in place to ensure timely support and information is provided to staff and patients as early intervention and awareness is critical for children and young people. Most services had local protocols in place for children and young people with diabetes to support diabetic ketoacidosis, hypoglycaemia, surgery and sick day rules (92%) (Figure30).

Figure 30 presence of guidelines



7.3.3 Organisation of paediatric diabetes services

NICE guidance recommends that children with diabetes should be seen in a designated paediatric diabetes clinic. 91% of children and young people were seen in a paediatric diabetes service, 8% in a general paediatric clinic, that is, not seen in a designated paediatric diabetes clinic (2%, 2002), and 0.8% in the general adult diabetes service. Age-banded clinics are desirable to help both children and young people feel at ease and for staff to structure and deliver appropriate clinical sessions but these had reduced from 71% in 2002 to 44% in 2007 ($p<0.000$).

Most services (95%) kept a register of patient data to ensure that all children and young people were followed up and monitored, as well as for contributions to local and national data gathering, performance analysis and appropriate care: 66% kept this electronically, 25% on paper, 4% had both and 6% had none (2002, 95% had a register of which 75% was electronic). 68% (n=117) of services contributed to the National Paediatric Diabetes Audit in 2006 (2002 in 75%).

7.3.4 Initial management of diabetes

Although NICE recommends that children with newly diagnosed diabetes are managed at home, only 26% of services offered this option and 68% of services managed all children as inpatients (other, 6%, further detail of what this entailed was not asked in the survey). 31% of services reported that children and young people and their families were involved in making decisions about care provided by the diabetes team through a written care plan, 65% involved children and young people but not a written plan, in 5% of services children and young people were not involved. Only 44% of services offered 24 hour access to advice from the diabetes team.

7.3.5 Ongoing management

7.3.5.1 Education

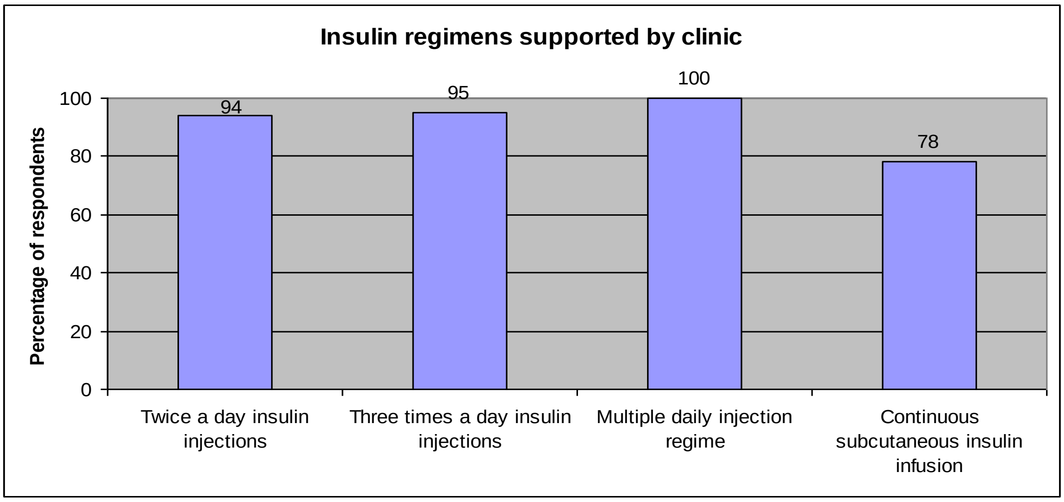
In keeping with NICE guidance, 95% of services reported that they offered children and young people timely and ongoing opportunities to access information about the development and management and effects of type 1 diabetes (in 2002: 71% have a written education curriculum for children and families). 70% offered a structured education programme for those newly diagnosed with type 1 diabetes. To young people who drink alcohol, 50% of services offered an alcohol education programme, 99% advised young people to eat food containing carbohydrate before and after drinking and 98% advised to monitor blood glucose levels regularly.

98% informed children and young people about general health problems associated with smoking and 51% offered children and young people smoking cessation programmes if appropriate. 87% of services advised about driving and 78% give contraceptive advice.

7.3.5.2 Insulin regimens

There were a plethora of different insulin regimens available which could be tailored to suit the individual needs of children and young people with diabetes. 94% of services offered support with intensive insulin regimens and 78% offered continuous subcutaneous insulin infusion (CSII) (Figure 31). Pump therapy gives children and young people flexibility to manage their diabetes to suit their lifestyle and reduce the need for injections. 78% of the services who offered CSII had a trained specialist team available to initiate insulin pump therapy. The median number of children and young people using insulin pump therapy per service was 5 (range, 0 to 69); 6% of clinics who had pump facilities had no children and young people on pumps.

Figure 31 Insulin regimens supported by the clinic



7.3.5.3 Monitoring glycaemic control

In type 1 diabetes, monitoring glycaemic control is essential to tailoring the insulin regimen and lifestyle of the individual and to minimise the long term impact of diabetes complications. The median annual Haemoglobin A1c (HbA$_{1c}$), reported by services for children and young people under 16 years was 8.6% (70mmol/mol) (range, 7.7 to 9.7%; 61 to 83 mmol/mol). Most services (97%) inform children and young people that the target for long term glycaemic control is an HbA$_{1c}$ of less than 7.5% (58 mmol/ mol).

Services take a more flexible approach to younger children and reported aiming for a mean of 7.8% (62 mmol/mol) for 0 to 5 year olds, 7.6% (60 mmol/mol) for 6 to 11 year olds and 7.5% (58 mmol/mol) for young people 12 years or older (Table 7-2).

Table 7-2

Target HbA_{1c} for children and young people			
	0-5yrs HbA_{1c} target (n=115)	**6-11 HbA_{1c} target (n=118)**	**12 and older HbA_{1c} target (n=117)**
Mean	7.8 62 mmol/mol	7.6 60 mmol/mol	7.5 58 mmol/mol
Median	7.5 58 mmol/mol	7.5 58 mmol/mol	7.5 58 mmol/mol
Range	6.5 to 9 48–75 mmol/ mol	6.5 to 8.5 48–69 mmol/mol	6.5 to 9 48–75 mmol/ mol

75% of services always ensured that HbA_{1c} measurements were available at every outpatient clinic (86% of clinics, 2002, p=0.02) as per NICE guidance. 85% of children and young people with HbA_{1c} levels consistently above 9.5% (80mmol/mol) were offered additional support.

Type 1 diabetes relies upon the measurement of blood glucose by the children and young people with diabetes to monitor to determine insulin injection in relation to eating. Services vary the recommendations about frequency of glucose testing according to the insulin regimen (Table 7-3).

Table 7-3

Recommendation by service for the frequency of blood glucose testing by insulin regimen (n=129)				
	Testing for twice a day injections Percentage	**Testing for three times a day injections Percentage**	**Testing for multiple daily injections Percentage**	**Testing for continuous sub insulin infusion Percentage**
2-3 times	41	21	5	4
3-4 times	53	66	47	16
>4 times	6	12	48	80

74% of services followed NICE guidance for optimal targets for short term glycaemic control (pre-prandial 4.8mmol/L and post-prandial less than 10 mmol/L) for 0 to 5 year olds, 90% for 6 to 11 year olds and 91% for those 12 years and older. 72% of services reported that children and young people had access to continuous glucose monitoring systems for persistent hypoglycaemia unawareness, repeated hypoglycaemia or hyperglycaemia.

7.3.5.4 Complications and associated complications

Services offered screening for diabetes related complications and associated conditions (Table 7-4) as per NICE guidance, however, this survey did not examine the patient uptake of this screening as this is recorded within the national audit (122).

Table 7-4

Services offering screening for complications and associated complications		
NICE recommended screening	**Services offering screening 2008 Percentage (n=129)**	**2002 Percentage**
Coeliac disease at diagnosis	94	
Coeliac disease every 3 yrs until transfer	89	69 annually
Thyroid disease at diagnosis	97	
Thyroid annually after diagnosis	88	83 annually
Retinopathy annually from 12 years	100	80
Microalbuminuria annually from 12 years	99	83
Blood pressure annually from 12 years	98	38 at every visit – annual figure not reported

66% offered children and young people an annual podiatric examination and 92% inspected injection sites at each clinic visit. 85% of services had access to the national retinal screening programme for all young people over 12 years old and the average uptake for services was 87%. Where the programme was available, screening was carried out by either retinal photography (n=8), non dilated fundoscopy (n=2), dilated fundoscopy by a paediatrician (n=2) or dilated fundoscopy by an ophthalmologist (n=7). High levels of uptake were achieved due to a number of different factors, for example, having a service that was easily available, in both primary care and outpatient clinics or as part of the annual review and also held at convenient times. Education at the time of diagnosis and regular reminders from healthcare professionals stressing the importance of screening and on what complications may arise, giving encouragement to young people to attend from both healthcare professionals and parents. Screening being supported by good communication across teams, such as sending details regularly every six months about the child or young person to the retinopathy service, having an efficient administration service including good liaison between the diabetic team and ophthalmologist about those children and young people who have not attended screening. Finally timely referrals to ophthalmology and regular assessment of the performance of the screening programme.

7.3.5.5 Psychological support

The previous four surveys had demonstrated that access to psychological services had historically been poor. The current survey demonstrated that only 21% of clinics had a professional with specific psychological training working as an integrated member of the diabetes team. 20% of respondents reported that a psychologist and 2% that a psychiatrist regularly attended the children’s diabetes clinic in 2002. The median whole time equivalent (WTE) available to these clinics was 0.2 (range, 0.02 to 2). Where there was no dedicated psychological professional, referrals could be made to clinical psychologists, psychiatrists, counsellors and others (Table 7-5).

Table 7-5

Healthcare professionals to whom referrals could be made		
	Referrals 2008 Percentage (n=95)	**Referrals 2002 Percentage**
Clinical psychologist (p=0.005)	73	87
Psychiatrist	40	90
Counsellor	16	18
Social worker	14	18
Nurse therapist	10	49
Family therapist	10	
Psychotherapist	6	
Health psychologist	1	

Appointment waiting times ranged from 0 to 40 weeks with the median being 10 weeks (1 week to 18 months, 2002). Most services would refer children and young people with issues with eating disorders, depression and suicidal thoughts, for psychological support (Table 7-6).

Table 7-6

Issues services would refer for psychological support			
	Yes Percentage	**No Percentage**	**Would do if service available Percentage**
Problems with self-management (n=120)	57	14	29
Recurrent diabetic ketoacidosis (n=118)	61	16	23
Low body mass index (n=112)	39	38	22
Eating disorders (bingeing, bulimia, anorexia) (n=119)	87	4	9
Disordered eating (e.g. skipping meals) (n=116)	35	37	28
Morbid obesity (n=113)	38	33	29
Depression (n=121)	86	3	11
Needle phobia (n=117)	67	13	21
Anxiety (n=119)	65	12	24
Drug and alcohol problems (n=118)	56	21	23
Psychotic illnesses (n=118)	79	12	9
Psychosexual problems (n=107)	58	24	18
Domestic violence and sexual abuse (n=113)	58	26	16
Suicidal patients and self harm (n=119)	88	4	8
Family difficulties (n=119)	69	7	24
Communication problems with the family/team (n=119)	58	13	29
Access to neuro-psychological assessments for children and young people with type 1 diabetes who had frequent hypos and/or recurrent seizures (n=122)	21	39	41

10% of services reported that they had a psycho-educational programme (e.g. one that is structured, group based, and covers all aspects of diabetes care and management in relation to the family).

Respondents were asked for their views and comments regarding the provision of psychological support and care for children and young people. These ranged from the support provided by paediatric DSNs, the benefit of national guidance to support funding requests, the roles played by other professionals such as social workers and play workers and the impact of lack of funding:

Comments from respondents:
‘Difficulty getting children seen by psychology even though we don't refer all children who would clearly benefit from their input. Much of paediatric DSN time is spent on social work duties, limited input from social services.’

‘We would very much appreciate stricter guidance for psychological support to help our case with funding.’

‘We have had a social worker attached to the clinic who has been very helpful in dealing with some of the psychological problems etc. We also now have a play worker who is adept at dealing with problems such as needle phobia.’

‘Integrated psychological support withdrawn due to local funding reallocation.’

‘We have excellent psychology support and time to appointment depends on the problem. Some of the problems listed would warrant referral to child and adolescent psychiatrist based on local protocols.’

7.3.6 Continuity of care

To support children and young people living with the condition, 96% of services gave information and contact details of local diabetes support groups and organisations and 97% of services advised on how to obtain information about disability benefits.

Some services ran local ‘fun days’ or arrange holidays for children and young people with diabetes. 51% provided fun days, 31% organised weekend camps and 10% arranged a week away. Services in Northern Ireland (50%) were more likely to arrange weeks away compared to the other nations (England 10%, Wales 0% and Scotland 0%; p=0.03).

7.3.7 Transition from paediatric to adult services

Transition was identified as an area requiring improvement by previous surveys and NICE guidance describes that service users should experience a smooth transition from paediatric to adult services, organised in partnership with each individual. 76% of clinics had specific local protocols to transfer young people from paediatric to adult services (84%, 2002). 80% of clinics felt that young people with type 1 were given sufficient time to familiarise themselves with the practicalities of transition from paediatric to adult services. A variety of models of transition were reported with services often using more than one model (Table 7-7).

Table 7-7

Models of transfer used by clinics	Percentage of clinics (n=164)
Repeated joint clinic with adult colleague, then gradual transfer	51
One-off joint clinic with adult colleague, then transfer	20
Adult diabetologist in paediatric clinic, then transfer	9
Paediatrician attends adult clinic with patient for handover	9
Paediatrician runs separate transition clinic in adult diabetes centre	11
Transfer only between consultants by letter	21
Adult nurses meet patient before transfer	27
Transfer to GP care only	0
Clinic Other	1

Transfer started at 16 years (median; range, 11 to 18 years) ending at 18 years (range, 14 to 25 years). In 2002, transfer took place between 11 and 25 (mean 17).

7.3.8 Managing diabetes in schools

As children spend one third of their waking hours within school, it is essential that they are well supported by school staff to ensure their well-being. All services reported that the diabetes team liaised regularly with school staff to offer diabetes education and information.

Both primary (Figure 32) and secondary schools (Figure 33) experienced difficulties in arranging for children and young people to do their own blood glucose testing and administer their own insulin injections. 38% of services found it difficult or very difficult to arrange for children to do their own injections and 16% to do their own blood glucose testing in primary school.

Figure 32 Arranging for children to do their own testing and injections whilst at primary school

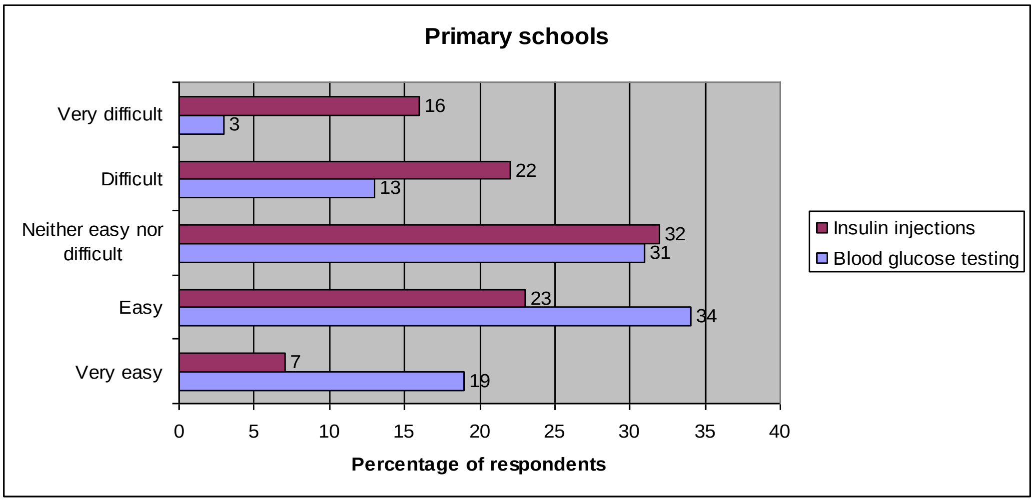
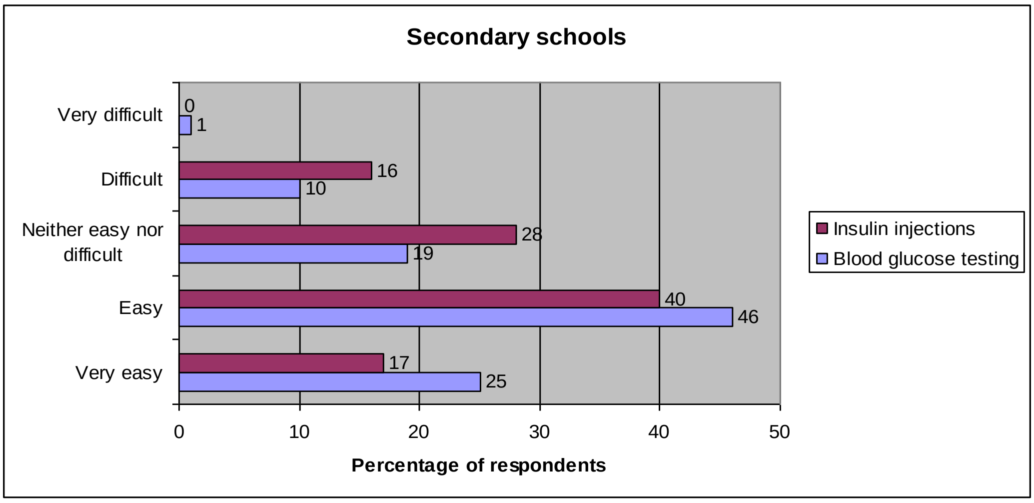
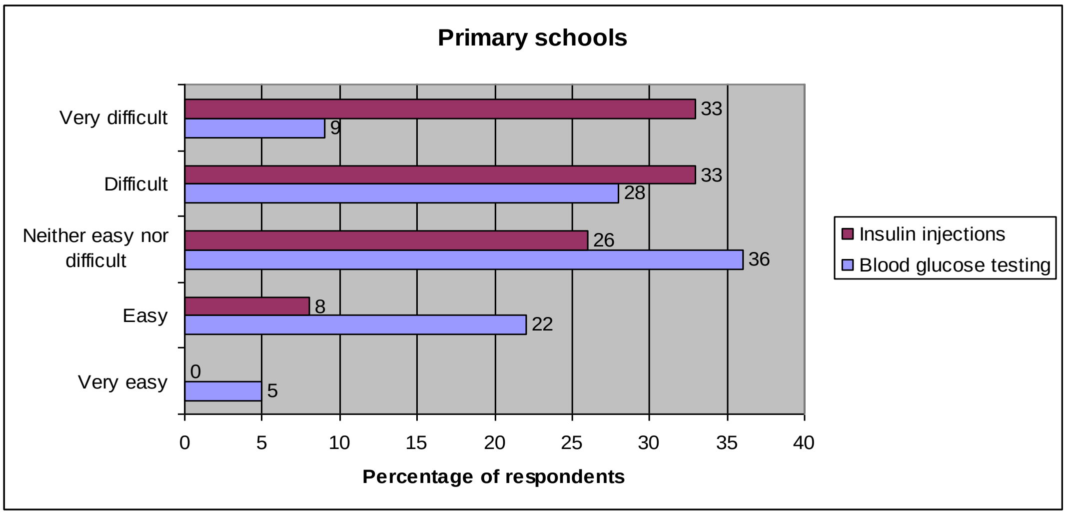


Figure 33 Arranging for children to do their own testing and injections whilst at secondary school



36% had found it difficult or very difficult to arrange for someone at primary school to carry out blood glucose monitoring and 66% found it difficult or very difficult to find someone to administer insulin (Figure 34).

Figure 34 Arranging for an adult to carry out blood glucose testing and to perform insulin injections in primary schools



When a child was not able to inject themselves 83% services reported that it was their parent who provided this support in school when necessary, 33% said the teacher, 22% a first aider, 18% the school nurse and 18% another relative and 43% other school staff.

Services commented that there was huge variation between schools in how diabetes was managed and supported. Successful support depended on having time for planning, education and information. In some instances a child's insulin regimen had been changed to fit in with school timetables. Others reported there were no private areas in which to administer insulin and services were aware of the school's fears in terms of health and safety and liability. Services felt that this situation would benefit from more guidance and national leadership.

Services provided comments on the issues that have arisen concerning managing diabetes for children and young people whilst at school:

'If no one available it usually just does not happen' (insulin administration).

'Injections at school have taken a lot of planning but now in general works well.'

'It has become easier to ask primary schools to take on diabetic care within schools when information and education take place well in advance of asking them to do anything.'

7.3.9 Meeting the recommendations

In the previous surveys, services had been measured against a core set of recommendations developed by the British Diabetic Association (now Diabetes UK) in 1998. Since then, NICE and SIGN recommendations have been published, however, most of the old recommendations were still in line with the NICE criteria except for recommendation 3 and 10. Findings from respondents to both 2002 and 2008 (85 services covering 150 clinics) showed that improvements had been made in eight out of the ten recommendations (Table 7-8).

Table 7-8

Services meeting NICE recommendations				
	Recommendations	**1998 Percentage**	**2002 (80 clinics) Percentage**	**2008 (85 services) Percentage**
1	Children with diabetes should be seen in a designated paediatric diabetes clinic	91	98	91
2	Clinics should be supported and attended by a paediatric DSN	75	98	99
3	In districts with fewer than 70 children with diabetes under the age of 16 years, all should be under the care of a single designated consultant paediatrician clinic of more than 40 patients	74	94	100
4	Children with diabetes should be under the care of consultants with a special interest in and training in diabetes	78	88	100
5	Current HbA_{1c} measurements should be made available for use and/or discussion in outpatient clinics	88	86	92 (75% always and 17% sometimes)
6	Children with type 1 diabetes should be offered microalbuminuria screening	66	83	100
7	Children with type 1 diabetes should be offered retinopathy screening	87	80	100
8	Paediatric diabetes clinics should have regular attendance of a paediatric dietitian with diabetes expertise	65	68	97
9	Joint or combined hand-over clinic to adult services: all young people with diabetes should experience a smooth transition of care from paediatric diabetes to adult diabetes services. The transition should be organised in partnership and agree with each individual.	78	48	91
10	Clinics/services should be supported and attended by a paediatric DSN with children and diabetes training and a maximum caseload of 100 children per nurse (full time equivalent)	53	39	61
	Number of services meeting recommendations			
	8 recommendations	58	55	79
	9 recommendations	29	33	72
	10 recommendations	12	2	48

7.4 DISCUSSION

Overall paediatric services seemed to be improving across the UK, however, there were wide variations geographically, and significant shortfalls in key areas such as access to dietetics, transition and psychological support, which have remained static for 14 years despite the emphasis placed on these areas in national guidance. It was encouraging that the specialisation of clinicians has continued and nearly all services were led by consultants with a special interest in diabetes. This, however, may be in jeopardy within some services where very limited time was spent by junior doctors in the diabetes speciality on training rotations. Another positive was the improvement in the provision of specialist nursing care with the majority being paediatric nurses.

The process of transition remains problematic, as not all services had local protocols for transitional care nor operated age-banded clinics despite data which suggest children and young people prefer being seen in clinic with their peers (127). A number of different methods of transition were used reflecting the lack of robust data on the most successful methods of transfer (127). There were services where transfer was arranged by letter only which is unlikely to prepare adolescents or parents adequately for transition.

The difficult issue of diabetes care in schools described within this chapter was also highlighted by a Diabetes UK survey I carried out (128) in which parents described difficulties obtaining support from teaching staff within schools, in particular giving insulin injections. Where children were not able to inject insulin themselves, it was usually parents who provided this support. Parents described having to go in every day to give injections or monitor blood glucose levels and having to be at the end of the phone just in case the school needed to contact them. Pumps presented even more problems for staff. A study, in which the I collaborated, of the perspective of primary school teachers demonstrated concerns about being responsible for children with diabetes in class, fears stemming from inexperience and lack of knowledge about the condition. Teachers felt it imperative to keep policies and procedures formal and clear for their own self-protection. Formal training was felt to be a key strategy to validate the role of the teacher as ‘qualified carers’ along with better communication with healthcare professionals and the child’s carers (129). As children spend up to a third of their waking hours at school during term time they need support to manage their diabetes in this environment if overall control is to be improved. Encouragingly, a set of stakeholder agreed guidelines was launched in 2013. These provided specific guidance for all key parties on the roles and responsibilities in the day-to-day care of children with diabetes developed in the East of England and have been adopted throughout the county. There are plans to extend this work to create a ‘Diabetes Charter Mark’ providing excellent encouragement to schools to attain accreditation and give parents confidence in the care their children will receive in the school environment (130).

Services felt they provided support through education and engagement with children and young people through collaborative care planning and structured education. Most services offered locally developed programmes as at the time there was no validated educational programme available for children. Most offered a wide choice in insulin regimen, although alarmingly not all those providing pump therapy, complied with NICE by ensuring that all staff had received the necessary training. Given the increasingly complex nature of diabetes management, it was also concerning that fewer than half of services offered 24 hour access to advice from the diabetes care team. Despite services *offering* screening for microvascular complications and associated conditions, data from the National Diabetes Audit (NDA) at the time recorded that only 60% of children and young people had their blood pressure measured and 26% were screened for retinopathy (122). It was not possible to link the survey data with NDA data so the reason for this discrepancy remains unclear. Having electronic registers in services, which may have helped with data collection and correlation between surveys, had not changed since 2002.

At the time of the survey and the lack of accurate registers, the total number of children and young people with diabetes in the UK was unknown and consequently the standards of care provided by individual services could not be compared or contrasted. The predicted increase in the prevalence of diabetes in coming years, a need to track children and young people year on year to monitor complication development and changes within the individual and movements within and out of an area all supported calls for the establishment of a national database. In 2009, the Royal College of Paediatrics and Child Health, funded by NHS Diabetes, led a project to establish for the first time, the total number of children and young people with diabetes of any type, under the age of 18 years in England. A total of 22,783 children and young people were identified (131).

This led the Chief Medical Officer, Sir Liam Donaldson, to say ‘*children and young people with diabetes should have access to the best clinical care that empowers them to manage their condition on a day to day basis. This care should extend beyond hospital settings, to ensure children and young people with diabetes can lead their daily life at school and home in a way that is clinically optimal and personally and psychologically right for them*’ (131).

Following this, Diabetes UK in 2010 developed a Children’s Charter for Diabetes (132) with the involvement of children and young people with diabetes, their families and carers and healthcare professionals. The Charter stated what must happen to ensure high quality care and achieve good physical and emotional wellbeing. This vision of care included recommendations on how each statement within of the Charter could be achieved.

Alongside this NHS Diabetes were working with healthcare professionals to establish paediatric networks to bring together best practice, up-to-date guidance and tools which aim to reduce variation in the quality of care across the UK. A set of 13 standards were drawn up and these were applied from April 2012 (133), many of these standards supported the statements within the Children’s Charter (Table 7-9).

Table 7-9

Best practice tariff thirteen standards	
1	Every child or young person with diabetes will be cared for by a specialist team of healthcare professionals (consisting of a doctor, a nurse and a dietitian as a minimum) who have specific training in paediatric diabetes.
2	The doctor must be a consultant or speciality doctor with training as detailed by the British Society for Paediatric Endocrinology and Diabetes, the nurse must be a paediatric nurse with training in children’s diabetes as detailed by the Royal College of Nursing and the dietitian must be a paediatric dietitian with experience and/or training in diabetes. If the doctor is a Specialist Registrar who wants to specialise in paediatric diabetes, they must be supervised by the consultant or speciality doctor.
3	When a new diagnosis of diabetes is made in a child or young person, this must be discussed with a member of the specialist team within 24 hours of the diagnosis. The child or young person and their family must be seen by a senior member of the specialist team on the next working day.
4	The diabetes team should offer a structured education programme at diagnosis and with updates as needed, aimed at the age and understanding of the young person and their family.
5	Every child or young person with diabetes must be offered at least 4 clinic appointments a year with the doctor and specialist team.
6	The HbA_{1C} must be checked at every clinic visit and the result available in clinic for the appointment. It is recommended that this is checked at least 4 times a year.
7	Every child or young person with diabetes should be offered an appointment with the dietitian at least once a year.
8	At least 8 additional contacts per year (phone calls, e-mails, school visits etc) by members of the team are recommended.
9	Every child or young person with diabetes must have an annual review done as detailed in the NICE guidelines on managing diabetes in children and young people (blood tests every year, plus blood pressure check and screening for eye and kidney problems from age 12).
10	The team should check that the child or young person with diabetes is coping psychologically at least once a year and they should have access to psychology services as needed.
11	The team should provide 24 hour access to advice on emergency management of diabetes for the family and other health professionals
12	It is also expected that the team will take part in the National Paediatric Diabetes Audit, attend their local Paediatric Diabetes Network meetings regularly and have a clear policy for transition to adult services.
13	Each team must have a clear policy which should cover what they do to try to help children and young people with high HbA_{1C} values improve their control and what they will do if a child or young person keeps not coming or is not brought to clinic, among other things.

A new paediatric tariff has been brought in so that if paediatric diabetes teams can demonstrate that they meet these standards, they will receive a set tariff (a funding increase) from commissioners. Those not meeting the standards will have one year to improve their service, for example, by employing more people, linking in with other services, otherwise from April 2013, the service is in danger of not receiving funding, although this does not mean that the clinics will close.

It is hoped that by introducing this tariff, service standards will improve by ensuring that those who look after children and young people with diabetes are fully trained, have the right amount of staff to provide care, that every children and young people with diabetes will receive the same high standard of care, better outcomes will be achieved with lower overall HbA_{1C} levels, fewer admissions to hospital and fewer young adults developing complications of diabetes such as blindness or kidney failure. The National Paediatric Diabetes Audit will help by continuing to monitor this process, by recording care processes, clinical outcomes and developing registers and providing a breakdown of centres locally, regionally and nationally. This would support the difficulty centres have faced in previous years of developing and maintaining their own registers.

Despite the improvements made in the quality and resources within paediatric diabetes, significant regional variations existed in the levels of HbA_{1c}. Findings from the latest report by the Royal College of Paediatrics and Child Health (who have been awarded funding for a three year project by the Healthcare Quality Improvement Programme to carry out the paediatric component of the National Diabetes Audit) in 2013 (audit period 2011-2012) shows that still only 6.7% of all children and young people with diabetes had received all care processes, up from 5.8% in 2010-2011 (134). The unit of analysis in the latest report for HbA_{1c} differed to previous years yet there is improvement in the percentage of children and young people with diabetes achieving the NICE recommended HbA_{1c} <58 mmol/mol (7.5%) from 14.5% in 2010-2011 to 17.4% in 2011-2012 (135).

Outcomes seem to therefore remain largely unchanged and compared with the rest of Europe, outcomes for paediatric diabetes in the UK are not good. Overall whilst there is an improvement of HbA_{1c} levels across England and Wales demonstrating that services have made significant clinical changes since 2000, in the past 15 years, other countries such as Germany have seen the average HbA_{1c} for children and young people with diabetes fall from 8.7% (72mmol/mol) in 1995 to 7.7% (61mmol/mol) by 2011(136), and have demonstrated that services can achieve more standards of care delivery.

There are a number of limitations to the survey. Compared with previous surveys, the response rate had declined to 63% which may reflect the number of surveys emailed to clinicians and a lack of perceived benefit in participation if no improvements arose from previous surveys. As such results cannot be generalised to all units. Furthermore, as results are based on self-report there is a risk that some units may overestimate their responses. There are also methodological considerations since the introduction of NICE and SIGN standards of care which have made direct comparisons between 2002 and 2008 problematic.

In conclusion, national guidance may have influenced service delivery since 2002, in particular, clinician and nurse specialisation and access to complication screening. Improvements are not universal and there are persistent deficiencies in dietetic provision, psychological support and the transition process. When the survey was carried out it was suggested that service delivery should be linked with outcomes, as collected by national audit, participation, in order to deliver high quality diabetes services to the increasing numbers of children and young people with diabetes who have more complex management regimens.

Views and perceptions of diabetes specialist staff concerning the status of diabetes specialist services 2000 to 2011

8.1 Introduction

In the last decade, significant changes in how diabetes care is organised have occurred. In 2002, the NSF for diabetes (1) was introduced to drive up standards and reduce inequalities in care. In the White Paper, "Our Health, Our Care and Our Say" (2), the Government set out the importance of working in partnerships across boundaries towards patient centred, holistic care delivered closer to home to improve health. This started a process of bringing service delivery out of diabetes specialist services and into primary care for the majority of people with type 2 diabetes.

Alongside policy changes, there has been a great deal of restructuring within the NHS. At the time of the NSF, Primary Care Commissioning groups were being transformed into PCTs, in 2006, PCTs merged from 305 to 152 and in 2011 PCTs were in the process of being disbanded altogether. In their stead, GP consortia were emerging and control for all healthcare services budgets was to be transferred to them via the Health and Social Care Act of 2012 (27). GP consortia later became known as Clinical Commissioning Groups (CCGs) and for consistency will be referred to as CCGs even though to the participants they were known as GP consortia.

The diabetes NSF defined minimum standards for good diabetes care including nine basic care processes, (measurement of HbA_{1c}, blood pressure, cholesterol, kidney function and urinary albumin, eye screening, foot examination, calculation of body mass index and smoking review). Combined with the QOF, recording of delivery of basic care processes has progressed which may also improve the outcomes for people with diabetes.

The first annual national diabetes audit in 2003 to 2004 reported that only 7% of people with diabetes had records of all care processes being carried out in that period (137). In contrast, in 2007 nearly 40% received all nine, (138) by 2010 this had risen to 54% (139). In 2011, 63% of people with type 2 diabetes received eight of the care processes and 43% of people with type 1 diabetes (eye screening was not reported in this year) and yet there were still wide geographical variations in the achievement of these care process delivery (140).

Continual changes over time have put pressure on specialist clinicians who are already coping with an increasing volume in workload with fewer resources. Clinicians are skilled in providing expert care to people with diabetes and are motivated to improve their service and competencies continually: however, they need support to respond to and implement the changes requested by the different commissioning bodies and changing clinical treatments to provide the best possible outcomes for people with diabetes.

8.1.1 Theoretical perspectives

In 1951 Lewin described the driving and restraining forces that precipitate change. Driving forces are those that affect a situation and attempt to push change in one direction, initiating change and keeping it going while restraining forces act to reduce the driving forces. Lewin advocated reducing the restraining forces to allow movement towards the new desired state without increasing tension within the organisation. The notion of forces has been used to distinguish both the positive and negative views expressed by participants towards change within the specialist services.

8.2 Aim of the proposed study

The aims of this chapter were to explore the views of diabetes specialist staff and their perception of the issues relating to diabetes specialist services in 2011. Comparison has been made to 2000 and 2006 providing an overview of how issues have changed over time and how new issues have emerged in this decade of service delivery. These analyses have also given an opportunity to bring together the views of different healthcare professionals’ disciplines to examine how they overlap or differ as this is the only multidisciplinary study of the thesis.

In the last decade vast amounts of quantitative data have become accessible through the QOF and national audits to help services benchmark and measure progress towards target achievement. This present study aims to extend and demonstrate how qualitative methods can add depth and a more holistic picture than can be gathered from quantitative methods alone. The next section will explain in detail how and why both a short quantitative survey and qualitative semi-structured interviews were used to gather the information required to answer the following research questions:

- What are the issues in the diabetes specialist service in 2011 from the perspective of consultant diabetologists and DSNs?
- How does the perception of issues vary between different healthcare professional groups?
- How have the issues changed over time?
- What lessons can be learnt from combining a mixed methods approach and their future suitability for reviewing diabetes healthcare services?

8.2.1 Role of the working group

- Charlotte Gosden – PhD student, Faculty of Medicine, University of Southampton
- Professor Richard Holt – Supervisor, Faculty of Medicine, University of Southampton
- Professor Rhys Williams – Supervisor, School of Medicine, Swansea University
- Professor Katherine Barnard - Faculty of Medicine, University of Southampton
- Dr Tannaze Taniti, Faculty of Medicine, University of Southampton

8.2.2 My role in the research process in this study

- Develop research questions, topic guide, questionnaires, respondent lists, data analysis protocols, reporting mechanisms.
- Manage the process of creating, formatting, writing questionnaire and designing forms.
- Distribute questionnaires and data collection with reminders.
- Design sampling framework for interviews, selection criteria and hold and manage contact database and overall timeline.

- Analysis of well-resourced score in 2011, analysis of open questions from 2000 ABCD survey to inform topic guide and track changes.
- Design topic guide from a priori themes, 2000 and 2006 Diabetes UK and ABCD surveys.
- Carry out interview procedure, contact with participants, pilot and transcription of all interviews.
- Data analysis and reporting via thesis and writing journal article
- Presentation at national conference.

8.3 Method

This section describes the qualitative and quantitative methods used to carry out the final part of this study into the views and perceptions of diabetes specialist staff working in diabetes specialist services in 2011.

It is generally understood that qualitative research is concerned with understanding the meanings people attach to phenomena (actions, decisions, beliefs and values) in their social worlds (73). Bryman expresses this as '*the way in which people being studied understand and interpret their social reality is one of the central motifs of qualitative research*' (141).

Strauss and Corbin described qualitative research as producing results not arrived at by statistical procedures or other means of quantification (142). It provides a wealth of detailed data on much smaller numbers of people and cases (143) and the results are descriptive and interpretive, not numerical. Key aspects of qualitative research include: the volume and richness of data generated the importance of the participants' frames of reference, flexible research design and different approaches to analysis and interpretation. Data are typically gathered through interviews using the words and descriptions of the participants but also through observations and excerpts from documents (144). Quantitative research by contrast asks standardised questions that limit responses to predetermined categories, allowing comparison and statistical aggregation (143).

With quantitative data, claims of generalisability can be achieved via confidence levels. It has been hotly debated in the past whether qualitative findings can be generalised to other settings (such as cancer care) or the wider population. Claims of generalisability can be strengthened by demonstrating clearly the research methods used and allowing others to assess the limitations in the methods and the boundaries of the research, showing that good use has been made of the dataset, showing the language and content of the participants responses, how they link together and offering some explanation and description of the interpretation (73).

There has been much debate in the research literature of the relative merits of both quantitative and qualitative methods; some argue that the approaches are so different in philosophical and methodological origins that they cannot be blended. Others recognise, however, that each can provide different types of knowledge about a study subject (73). Here both approaches were utilised to inform and illuminate policy and practice and most importantly that the most appropriate method or combination of methods was used to address the research question (145).

8.3.1 Design

A qualitative method that would help develop understanding and insights was deemed appropriate. In 2011, semi-structured interviews with consultant diabetologists and diabetes specialist nurses were selected. Their views would then be compared to those views expressed in the open questions from 2000 and 2006 quantitative surveys providing a perspective over a 10 year period.

In order to allow triangulation of data sources, methods and three different time periods, a longitudinal case study approach was used (146). Here the value of triangulation allows an in-depth investigation of both the retrospective and 2011 data and may help validate the findings. It extends the understanding and inferences drawn from the data and adds breadth and depth to the understanding through the use of multiple perspectives. This provides security of the interpretation by giving a fuller picture of the circumstance, if not necessarily a more certain one (147). Also using a case study was attractive being relatively low in financial cost whilst providing a clear view to understanding wider situations given few resources in terms of finance, time and people.

A quantitative questionnaire was selected to identify a sample of locations which would represent the wider diabetes specialist service community. This helped to generalise the findings from a relatively small number of case study locations to the wider community and also provided background information on the case studies which could inform the interpretation of the final interview data. Even though judging the merits of the different types of findings can be a challenge for this type of design (148), using both quantitative and qualitative approaches had benefits helping to answer the research questions.

8.3.1.1 Sample selection

In 2000 and 2006, the sampling framework included all diabetes specialist services to provide as complete a picture as possible of all services across the UK. A different approach to sample selection was used for the case studies in 2011.

The aim was to identify five case study locations. These were selected with care and not haphazardly as stated by Yin (149). The process of selection of cases should be justified, documented and reported so that the context can be provided for judging the sample (150).

To increase the quality of the research design, the selection of cases needs to be driven by appropriateness and adequacy (151). Appropriateness demonstrates a fit to the purpose of the research and adequacy relates to how much is enough or how many cases are required. Generally when information saturation has been achieved, cases become ‘information rich’ and the conditions for adequacy can be said to be attained. However, the literature does not provide an ideal number of cases to be used in a multiple case study design (144) and the final number can only be determined as a trade-off between the breadth and depth of the case study (150).

8.3.1.2 Criteria

Criteria were derived to ensure a diversity of locations representative of the wider diabetes specialist community (Table 8.1). All had to have completed all 2006 questionnaires with open responses and taken part in the 2000 survey for comparison to be possible. The aim was to recruit from all four nations, different types of hospitals, with a range of well-resourced scores (from 2000, 2006 and 2011) and serving different types of local communities.

Table 8-1

Criteria for inclusion in sample	
Essential	• completion of all five 2006 questionnaires • completion of all open questions in the consultant 2006 questionnaire • completion of 2000 questionnaire
Desirable	• representation from the four nations • different types of hospital (district, teaching and Foundation Trusts) • range of well-resourced scores, i.e. some who had increased their well-resourced score since 2006, some who had remained the same and some who had decreased their score • a range of locations in terms of the main risk factors for diabetes as defined by Diabetes Health Intelligence (152). The PCTs included reflected the PCTs identified by the specialist service as commissioners

8.3.1.3 Well-resourced score 2011

In order to obtain a well-resourced score for services in 2011 and generate interest to participate in a telephone interview, a short selection questionnaire was devised in January 2011.

Questions were based on the well-resourced score from the 2006 consultant survey. Following advice from Diabetes UK, a question on commissioning was added (relevant to England). The questionnaire length was kept short to maximise the response rate and piloted with consultants and policy experts from both Diabetes UK and ABCD. This was to test question comprehensibility and if returned data were both useful and usable for analysis (Appendix G).

The questionnaire responses were logged and a 2011 well-resourced score obtained and used to help shortlist possible case study locations.

8.3.1.4 Topic guide

A topic guide was designed in January 2011 based on questions asked in the 2006 consultant survey and emergent themes, the research questions and literature review. One aim was to ascertain if issues had disappeared, remained the same or if new issues had emerged. To help identify these, pressing issues analysed in 2006 were used as prompts (Appendix H).

By interviewing it was possible to ask more questions in 2011 than in previous years although question consistency was aimed for as far as possible so that direct comparison could be made over time. The topic ‘opportunities’ was added to complete the Strength, Weaknesses Opportunities and Threats (SWOT) analysis to help balance positive with negative views. An additional question in 2011 was asked relating to the NHS change from PCTs to GP consortia. In 2006, the policy focus had been on the introduction of practice based commissioning, payment by results and the restructure of PCTs and the impact this had on clinicians. A full description of the questions asked in each of the studies is shown in Table 8.2.

A further research aim was to ask participants if they believed their service could have achieved the NSF targets. Specific questions on retinal screening and psychological service provision were therefore included as service targets had been attached to improve service provision.

Table 8-2

Comparison of open questions asked quantitative surveys in 2000 and 2006 and interview topic guide in 2011		
2000	**2006**	**2011**
Would you describe your diabetes service as (as per 'BDA recommendations for the structure of specialist diabetes care services'): ☐ Well developed (i.e. more than one full-time diabetologist for at least 150,000 target population; dedicated diabetes resource centre etc)	Based on your answers to the previous questions, do you feel your specialist diabetes service is well-resourced? Well-resourced, Reasonably well-resourced, Not well-resourced	When considering the status of your diabetes service, what in your view, are the most pressing issues today?
☐ Reasonably well-resourced (i.e. full laboratory facilities for care; some formal shared care scheme with primary care)	Best and worst issues of Consultant post and/or most pressing concerns regarding: 65. Acute medicine 66. Diabetes 67. Endocrinology	What do you think are the main strengths, weaknesses, threats and opportunities and issues within your specialist service today?
☐ Poorly developed (i.e. recognised major deficiencies in specific aspects of diabetes service)	General strengths, weaknesses and issues within your specialist service? 68. Please offer 3 main strengths of your specialist service 69. Please offer 3 main weaknesses of your specialist service 70. Please offer 3 main threats of your specialist service 71. Any other comments	With regards to retinal screening, what if any, are the current problems/ issues with retinopathy screening locally?
Please give your personal assessment of the strengths and weakness of your service, prioritise any major deficiencies and also add any other relevant comments.		In your opinion, what gaps are there in services for people with diabetes who have emotional, psychological or mental health problems?
		What in your view will be the impact of the current changes to GP consortia commissioning on diabetes specialist services if these suggested changes should go ahead?
		In 2006, many services expressed concern over the fragmentation of diabetes services, how would you describe the integration of care and joint working with primary care in your service?
		What in your view are the prospects of delivering the NSF in 2013 at the current time within your diabetes service?

8.3.1.5 Interview procedure

Initial contact was made via email to raise interest and encourage participation by demonstrating through a list of publications and Diabetes UK campaigns the value of the 2006 survey and the current research aims.

The questionnaire was posted in April 2011 to 18 consultants identified on the 2006 mailing list, and followed up by email and telephone to ensure it had been received. This method was used as it is cheap and based on previous experience was considered likely to be effective in producing a reasonable response. If no response was received, follow up by a second letter or email took place in May 2011. A third reminder was carried out by telephone in June 2011 and if new contact details were obtained, another letter was sent to the new contact and reminders repeated.

The first completed questionnaire response was received on 18th April 2011 and logged in an Excel spreadsheet. The date of return was recorded with contact details and notes of any telephone conversations. Data were entered into the spreadsheet as returned and completed in July 2011. The services from Northern Ireland and Scotland were not included as there had been no responses to the retinal screening questionnaire in 2006.

A diary was kept during this process of ideas and insights that may have proven useful during the analytical process further along.

8.3.1.6 Pilot

A pilot interview was held with a consultant diabetologist at a General Infirmary to test the duration of the call, the functionality of the questions, the interview structure and process along with interview technique. As a result, the topic guide was updated to reflect the move from the NSF to NICE quality standards as the most up to date metrics for measuring standards of diabetes care. Call duration was shortened in recognition of the participants' workload commitments. Prompts were further developed for use during interviews to allow for expansion, clarification and encourage views to be discussed.

8.3.1.7 Interview participants

Interviews were intended to be held with the consultant and lead DSN of the service at the same time by telephone to provide a richness and diversity of perspective from different professional roles.

8.3.1.8 Interview process

Clinicians were interviewed between August and September 2011. Each was sent a copy of the questions in advance for preparation to ensure a full discussion in the available time. Appointments were timed to be convenient with clinicians. In no instance was it possible to interview both consultant and DSN jointly; reasons cited included lack of available time, one DSN did not attend as expected and incompatible diaries. Separate interviews were therefore carried out. In two cases where either the DSN or consultant was unable to attend, their notes were presented by their colleague.

At the start of the interview, each participant was given their service responses from 2006 as a starting point for discussion and asked if these had changed.

Ideally, the interviews would have been face to face and have included more members of the multidisciplinary team and people with diabetes; however, this was not possible within the study resources. A balance was sought between richness and sufficiency of data with the practicality of what was achievable within the research resources.

During the interviews, as new issues were raised, these were used to update the list of prompts with subsequent interviews, for example, recruitment issues and job freezes. This was to ensure that all current topics and issues facing services could be fully identified and discussed.

Although the majority of the interviews were completed successfully with acceptable and documented changes to the prescribed process there was no initial response from the specialist team at one city hospital, despite the earlier communications. In order to keep to the timeline the community team was approached in the area and the community consultant diabetologist interviewed. Although this participant had limited involvement with city hospital it was useful and interesting to have the community perspective views as well as the secondary care specialist service. This offered the research an opportunity to add a different dimension and increased the depth of the knowledge gained. This change to the scope was deemed to be acceptable and was accommodated within analysis and reporting.

During the interview, the community consultant revealed that their role had developed into a full-time commissioner of diabetes services. They remained confident that they were able to respond appropriately to the questions. During this phase, however, the specialist team from the city hospital in question had responded and a consultant and DSN from the secondary care specialist team were subsequently interviewed. This case study became quite challenging in terms of the amount of qualitative data gathered but also provided the opportunity to note differences in the level of knowledge of the specialist services team members regarding forthcoming changes in commissioning regional intentions. Initial analysis of the data from the hospital identified similarities in the perceptions offered by both DSNs interviewed pointing to possible commonalities within the nursing discipline that were different to the consultants.

All interviews were conducted at set appointment times and recorded with the permission of the participants. The recordings were then transcribed within a week of the interview being completed. If parts of the recording were unclear, or if during the process of transcription, a further question was raised, the participant was contacted and asked for their feedback. All participants were then invited to read their transcript if they wished, to ensure their views were accurately portrayed.

8.3.2 Data management

The results from the questionnaires and interviews were analysed using Microsoft Excel and Microsoft Word. The interviews were transcribed verbatim in word and transferred to excel during analysis. Data from the open questions from 2000 and 2006 were compared and contrasted with 2011 in Microsoft Excel.

8.3.3 Data analysis of interviews

Data were analysed using the Framework method, a matrix based method for ordering and synthesising data. The data were organised according to codes and themes as they emerged. The Framework approach was developed for use in public policy issues, in response to the growing acceptance of qualitative research to provide different and additional insights from quantitative approaches (73). It is essential that the interpretation and presentation of qualitative data is as objective and neutral as possible. The Framework method provides a rigorous process which can also facilitate the development of recommendations for practice and policy (73).

The Framework method allows for both a priori and new themes to emerge from the data. It offers a systematic organisation of the data so that the researcher can move forward and back between the different levels of abstraction therefore keeping sight of the ‘raw’ data. There are five stages to the analysis completed in this study.

8.3.3.1 Familiarisation

Interview transcripts were read several times keeping in mind the research aims, the topic guide and themes from 2006. This immersion and familiarisation at the start of analysis was crucial so that key ideas and recurrent themes emerging from the transcripts were noted.

8.3.3.2 Creating a thematic framework

An early thematic framework was derived from the 2011 topic guide, the research questions and codes from the 2006 (the a priori themes). The framework was modified as themes emerged from the transcripts. Once completed the framework became the index with codes grouped under overarching themes. These were numbered ready to be applied to the data.

One of the benefits of this analysis was that it allowed for modifications to be made to the index, collapsing some codes, removing or adding as omissions were identified. At this stage it was important for the codes to remain close in language to the terms used by participants rather than abstract concepts from the literature to ensure that the analytical process stayed grounded in the data.

8.3.3.3 Indexing

The index was applied to the transcripts. Each phrase and sentence of the transcripts was read in detail, asking the question ‘what is this about?’ Once the meaning and subject were identified, the number linked to the code from the index was written in the margin. One or more numbers were entered as appropriate. If new codes emerged during this process, the index was updated and all transcripts re-read and indexed for consistency.

Following indexing, portions of the transcripts were reviewed by my supervisor Rhys Williams (RW) and Katherine Barnard (KB), a Health psychologist, and all were second coded by Tanaze Tinati (TT) until a consensus was reached. New codes were identified, the index updated and transcripts re-read and re-indexed (see Appendix I).

8.3.3.4 Charting

The next step was to sort the data into chart form. In Microsoft Excel, a matrix chart was created for each theme on a separate worksheet.

In each worksheet the names of participants were listed in the column A and codes across the top in row one. Data were retrieved from the transcripts for each participant and located in the appropriate cell. Data were summarised to be more manageable, but contained enough content and context to avoid constant referral back to the transcript. Key terms or expressions were retained rather than long portions of verbatim material.

In some instances, a participant may have several entries of a code whereas others would have only a few or none depending on the content of their transcript. Once completed, it was possible to look down a code column to see how each participant had reported. During this process, further refinement of the themes took place, perhaps being moved onto different themes to make the structure and flow of themes more meaningful.

Even if material at first did not appear relevant or appeared contradictory, this material as much as possible was included from the transcripts in case their relevance became more apparent further on in the analysis.

8.3.3.5 Mapping and interpretation

In the last stage, charts were used to define the concepts, map the range of dimensions within the themes, and look for associations between them. This stage was influenced by the research aims and reflected the beliefs and values of the participants. The views could be compared and contrasted across all participants, professional groups, (consultant and DSN) and across the entire decade of the research using the same approach, (2000, 2006 and 2011).

8.3.4 Analysis of 2000 and 2006 data

Data from 2006 had already been analysed and reported on in previous chapters, but the closest match from 2011 was applied. However, as data from 2000 had not been analysed due to lack of time and resources in 2000, the index, chart and categories developed for the 2011 transcripts were applied to the whole dataset. A comparison of the strengths, weaknesses, opportunities and threats identified from 2000, 2006 and 2011 was carried out and is contained in Appendix J.

8.3.5 Ethics

Discussion with the ethics committee at the University of Southampton gave assurance that ethics approval was not required to approach clinicians for their time or responses to interview. It was not felt appropriate to offer an incentive to take part in the study rather that the research aims and objectives should suffice. All participants were provided with a copy of the questions which would be asked ensuring that they were comfortable with the topic and potential answers they would be asked to provide. All were informed of my intention to submit an abstract to the Diabetes UK Annual Professional Conference, publish in an academic journal and to complete my thesis. Anonymity and confidentiality was assured to all participants and that each would receive a report summarising the findings. Participants were emailed a copy of the transcript for confirmation of accuracy.

8.3.6 Limitations of the method

To fulfil the criteria only a limited number of participants could take part as a case study. An initial aim of five case study locations was sought and to achieve this, the original sample method was modified. The pilot was included to the four responding locations that were eligible, to reach the desired five case study locations.

Furthermore, the inclusion of the community consultant and the DSN and specialist service consultant took the number of participants to seven (at five locations). The extra diversity provided a useful counter-balancing perspective. A more substantial re-modelling of the selection criteria to allow more locations would have taken the study too far from the research questions and aims and not allowed sufficient comparison over time.

The next section presents the results of the well-resourced scores from 2000, 2006 and 2011 and thematic charts which summarise the findings with comparison to previous years.

8.4 Results

The multi-case study explored the views of diabetologists and DSNs on issues within and facing diabetes specialist services in 2011. It builds on and extends the issues identified from the 2006 and 2000 questionnaires.

A list of respondents and selection criteria, essential and desirable, is presented followed by key findings from seven interviews at five case study locations. The four themes which emerged in 2011 were:

- Service redesign and the experience of change
- Clinician's ability to do their job
- Team dynamics
- Emotions

These are summarised in thematic charts with direct quotes to help capture the range of perspectives and complexity of the issues experienced. Finally the issues are compared and contrasted to previous years and new issues identified followed by a discussion.

8.4.1 Response rates

A rigorous process allowed five case study locations to be selected from a possible 17. These represented a broad range in terms of questionnaire completion and change in well-resourced score over time (Table 8-3 and Table 8-4), socio-economic settings (Table 8-3) and type of hospital (Table 8-3) in England. This gave confidence that the findings may be representative of the wider diabetes specialist community. Questionnaires were sent to 17 locations in England based on the well-resourced score from 2006, 12 responded, four agreed to be interviewed and the pilot site was included to reach five locations (Table 8-5). Wales, Northern Ireland and Scotland were excluded due to incomplete questionnaire responses in 2006 and to allow focus on the political changes which were particular to England (Table 8-5).

Table 8-3

Criteria for selection of case study locations					
	Criteria				
	Essential	**Essential**	**Essential**	**Desirable**	**Desirable**
Case Study	**Response to questionnaire 2011**	**Response to questions in 2006**	**Response to questions in 2000**	**YHPHO classification**[2]	**Type of hospital**
1	Yes	Yes	Yes	Indigo/ Yellow	Designated teaching
2	Yes	Yes	Yes	Orange	Associated teaching
3	Yes	Yes	Yes	Orange/ Purple	Acute teaching hospital
4	Yes	Yes	Yes	Purple	Foundation Trust
5	Yes	Yes	Yes	Purple	Designated teaching

Table 8-4

Well-resourced scores and respondent perception of service				
Criteria	**Year**			**Desirable**
	2000	**2006**	**2011**	**Well-resourced score change**
Case study	**Score** **Perception**	**Score** **Perception**	**Score** **Perception**	
1	19=B Reasonably well-resourced	21=A Reasonably well-resourced	19=B Reasonably-well-resourced	Same
2	18=B Well developed	22=A Reasonably well-resourced	22=A Well-resourced	Increase
3	19=B No perception recorded	18=B Reasonably well-resourced	19=B Reasonably well-resourced	Same
4	25= A* Well developed	23=A Well-resourced	20=B well-resourced	Decrease
5	24=A* Reasonably well developed	22=A Reasonably well-resourced	20=B Reasonably well-resourced	Decrease

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[2] Yorkshire and Humber Public Health Observatory (YHPHO), classification
Orange – An average proportion of the population aged 40+ years with a range of deprivation levels
Yellow – A greater proportion of the population aged 40+ years with generally low levels of deprivation
Indigo - Relatively young population with substantially greater than average proportion from Black and Asian ethnic groups. Higher than average deprivation
Purple - Relatively young population and high levels of deprivation
Blue - Young population with average deprivation and slightly higher than average population from Asian and Black ethnic groups

Table 8-5

Number of questionnaire responses and case study location sites		
	Responses to the questionnaire	
Survey responses to all five questionnaires in 2006	18 from England and Wales 3 from Scotland (exception of retinal screening questionnaire) 2 from Northern Ireland (exception of retinal screening questionnaire)	Scotland and Northern Ireland were excluded. Wales was excluded to focus on England and policy changes
Nations covered		England 17 locations
Response to questionnaire posted in April 2011	12	out of 17
Response to request for interview (n=12)	2 declined 5 not eligible (incomplete responses to open questions in 2006) 4 accepted 1 pilot site	
Case study locations identified	4 1 pilot site included to achieve the preferred five locations	5
Number of interviews	5 consultant diabetologists 2 DSNs	Total: 7

8.4.2 Interview participants

At each location the consultant and DSN were invited to attend a joint interview. Five consultants and two DSNs were interviewed (Table 8-6), one DSN who was expected did not attend, one was unable to attend and one provided comments.

Table 8-6

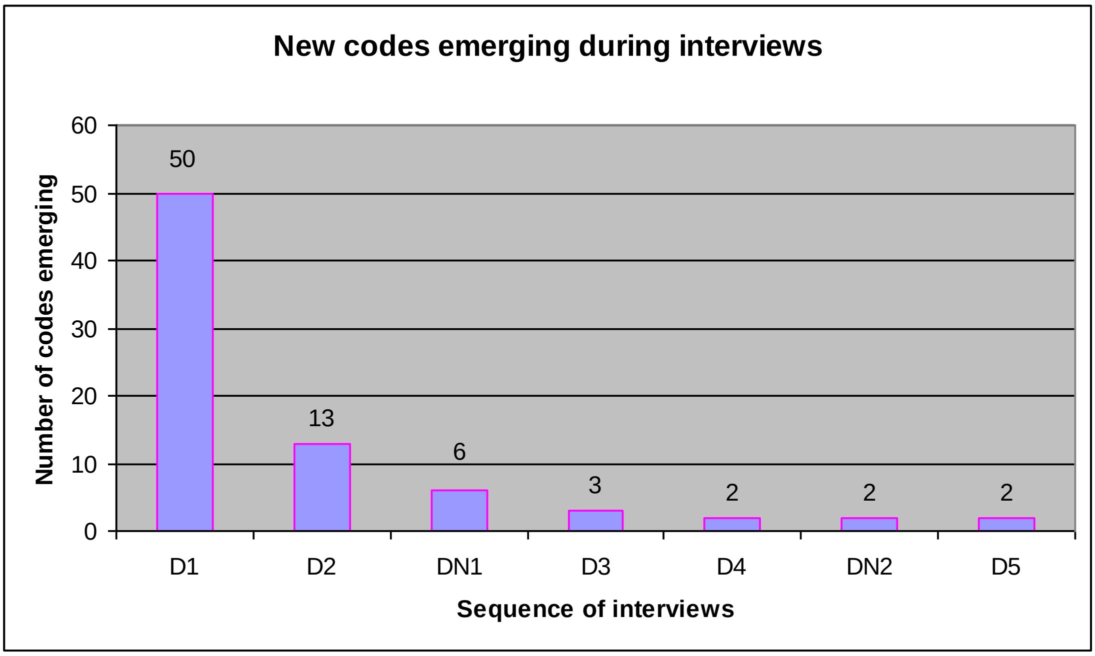
Interview participants			
Case study	**Clinician interviewed**	**Presence in service in 2006**	**Number of clinicians interviewed**
1	DSN Discussed issues with consultant before interview	Not present in 2006	1
2	Consultant diabetologist DSN provided written response	Present in 2006	1
3	Consultant diabetologist DSN unable to attend interview	Present in 2006	1
4	Community consultant diabetologist Hospital DSN Consultant diabetologist	All present in 2006	1 1 1
5	Consultant diabetologist	Present in 2006	1
		Total interviewed	**7**

8.4.3 Number of codes and data saturation

Initial coding of the interviews yielded over 200 codes and through several iterations, this was reduced to an index of 50. During this process codes were changed into different themes, deleted if not used or merged where overlaps were identified. The language and terms of the participants at this level were preserved to ensure the analytical process remained grounded in the data.

An analysis of the number of new codes which emerged with each interview suggested that data saturation was achieved (Figure 35). This was encouraging due to the small number of interviews carried out.

Figure 35 New codes emerging from the interviews



8.5 Thematic charts

Four themes emerged from the data: ‘service redesign and experience of change’ (Table 8-7), ‘team dynamics’ (Table 8-8), ‘ability to do my job’ (Table 8-9) and ‘emotion’ (Table 8-10). These themes are described in the following thematic charts with the related research question, key words, overview and participant quotes. This format was based on an example thematic chart from Dale Bloomberg (153).

Table 8-7

Thematic chart to summarise service redesign and experience of change

Theme 1	**Service redesign**
Research question: What were the current issues facing services in 2011?	
Key emergent concepts (number of participants): Restructure of diabetes service (7) Shift to primary care (6) Lack of PCT interest in specialist services (4) Service and personnel cuts (4) Demonstrating financial value of service (3)	Working differently (7) Working in new teams (7) Relationships with key personnel (7) Adaptable teams (6) Working in different locations (6)
Findings: All participants described the restructure of the NHS in 2011, whereby PCTs were being replaced by GP consortia as the primary concern that was facing diabetes specialist services. There was a perceived shift identified away from specialist care to more community based provision. Concerns were raised about whether primary and community services were ready and able to manage the type and number of people with diabetes being discussed. Specialists were concerned that the new organisations were unaware of the complexity of diabetes and concerned with their lack of engagement. In contrast clinicians saw opportunities to adapt and improve services through working in different models of care, within new collaborative teams and delivering care across traditional boundaries providing clinic support in the community. There were opportunities to develop a role in providing highly specialist tertiary services and upskilling primary care. It was vital that relationships were formed with decision makers to ensure that specialist diabetes knowledge contributed within negotiations and future service developments.	

Participant perspectives: ‘The pressing issue is the restructure of the NHS’ (DN1) ‘I don’t think we have a fragmented service, the opposite to be honest, true integration, changing culture, demolishing the boundary’ (D2) ‘We now need to look in a different way’ (D5) ‘We are making great strides in teams without walls…with the specialist team outreaching into primary care’ (D2) ‘Our biggest opportunity is working slightly differently, working in the community…as the service lead trying to reconfigure the service, it will involve innovative work and people working interchangeably, I don’t think we should be stuck in community role or hospital role’ (D3) ‘We'll be selling highly specialist services to GPs like pump service, pre-conception, they won't be able to deliver as doing general basic diabetes, we're quite good at doing that’ (DN2) ‘I think the whole way I would like to see it working would be to create a different model of diabetes care where the specialist takes ownership of a proportion of population, … and take responsibility of the whole of diabetes care for that population but determine at what level the patient may have a direct interaction or an indirect interaction with the specialist, but essentially trying to develop care models that are specialist driven but delivered by different people’ (D5)	‘When we did our modelling, we made sure the commissioning people were involved, it’s not where we got to, it’s how we got to where we are, and that process is what the learning is all about, how we discussed, involved and engaged the consultants with all people, including commissioners, the commissioners were very much on board, all stakeholders, and I think that’s the way forward because ultimately we wanted appropriate commissioning based on good outcomes, the need of the population’ (D2) ‘It is fairly difficult to understand quite what is going to happen given the fairly chaotic process happening in entire NHS’ (D4) ‘Diabetes is not prioritised, is poorly valued and has reduced investment to specific services’ (DN2) ‘New models can't be delivered due to lack of appropriate resource, people retire, have career breaks’ (D2) ‘If I were to go I would not be replaced’ (D1) ‘I’m concerned though, two WTE are on temporary contracts, one on maternity leave, when one retires she won't get replaced’ (DN1) ‘From PCT management there have been many diktats, particularly to the community team, saying you mustn’t do any hospital work, you mustn’t support the hospital work, you are the community team, and creating this divide between the two teams, which was very unhelpful and resulted in clashes and now we’re trying rebuild that and bridge the gap that was created’ (D3)
	Experience of change
Research question: What were the current issues facing services in 2011?	
Key emergent concepts (number of participants): GP consortia commissioning (7) Place in the process of change (start, middle) (6) Degree of change in issues (5) Circle of changes (4) Change in priorities (5)	Stimulus to change (3) Change in philosophy (3) Destructive force (3) Proactive force (3) Pace of change (2) Cultural change and boundaries demolished (1)

Findings:
Participants identified the introduction of GP consortia as the major structural change impacting on services. Organisational reform occurred every few years with the reintroduction of previous reforms in new guises. Different points along the process of change were described and contrasted.

The pace of change was described as increasing and some issues intensifying or disappearing. Changes in philosophy were noted, introducing competition and division, changes in how diabetes prioritised either increasing or mainly decreasing and an overriding principle to reduce cost, hit targets, to provide more services with fewer resources, which were seen as destructive.

On a positive note, some clinicians described proactive changes which had been initiated in 2006 in response to previous changing commissioning structures which resulted in breaking down boundaries and forging new relationships.

Participant perspectives: ‘The pressing issue now is the effect of the change from PCTs to consortia’ (DN1) ‘Commissioning is a threat and opportunity’ (DN1) ‘Pressing issue how we position ourselves to GP commissioning to be fit for anybody who wants to commission services from us’ (D3) ‘Resources have become an even bigger issue in current economic climate’ (D1) ‘We've made a lot of progress in a number of ways, especially integration since 2006’ (D1) ‘Issues facing diabetes haven't changed, but become all the more intense with the transfer of responsibility to consortia’ (DN1) ‘Threats in 2006 are more exaggerated now, and now because constantly under threat from commissioners on what services to provide and what they will pay for’ (D5) ‘Within threats there are always opportunities to reinvent ourselves’ (D5) ‘I always say you can destroy anything overnight but takes years and years to build up, think carefully before you destroy’ (D1) ‘Things are moving at a really fast pace’ (D5) ‘I hope in five years time, we'll be well on our way out of the recession, the money situation will be a bit improved’ (D3) ‘A big opportunity I think would be to become owned again by the GPs, moving back to the original sort of, model that I suggested, which essentially is the original Kaiser model, where everyone is part of one organisation, there are great financial reasons then to manage the patient correctly without either insufficient or too many appointments’ (D4)	‘The provider arm has returned to the Trust, along with resource, which is a positive outcome, we will have done a full circle as most diabetes services will be provided by the Trust’ (D1) ‘These services come back to the trust, so this is a positive outcome for us because we will have done a full circle as most of the diabetes services, what we call the [Name] diabetes service will now be provided by the Trust’ (D2) ‘Some of us will still work in secondary care, but we'll be going back to sort of specialist nursing I was doing in the 1990's, work part week in secondary care and part in primary care’ (DN2) ‘After 10 years of planning we have managed to make a start (psychology)’ (D2) ‘You don't know which way it is going to go, at the moment it is all undecided’ (DN1) ‘Some are further ahead and doing brilliantly, and other areas aren't’ (DN2) ‘Consortia are pretty well established, I think two will go one way and one is looking at different planning, but they won’t have the same objectives, it is very much in it’s infancy’ (DN1) ‘The million dollar question (what impact will the changes have)’ (D3) ‘No one knows what is happening’ (D4) ‘We have achieved through redesign, changing culture of primary and secondary divide, demolishing that boundary’ (D2) ‘I think the monetary side has just become so important now, we never used to work like that’ (D3) ‘The philosophy changed with community services when they split from PCTs in 2009…things have to be priced’ (D4) ‘So I don’t see a huge threat in NHS restructuring in our area, but you never know do you’ (D2) ‘I think it is the primary care commissioners who have that main power which sadly means that we would have to accept what is thrown at us’ (D5) ‘it just takes time to get the systems and processes and people in place and get them trained’ (DN2)

Table 8-8

Thematic chart to summarise team dynamics	
Theme 2	**Team dynamics**
Research question: What were the current issues facing services in 2011?	
Key emergent concepts (number of participants): Workforce planning (5) Multidisciplinary staffing levels (5) Non multidisciplinary knowledge of diabetes (4)	How we position ourselves for the future (6) Upskilling non multidisciplinary healthcare professionals (5) Clinical competency (5) Strengths of team (4) Team ethos (4)
Findings: Nearly all participants highlighted the strengths of their multidisciplinary team including competency, skill, goodwill, commitment and motivation. Workforce planning was of particular concern, many worried about sustaining teams amidst restrictions on recruitment and replacement, without putting the services at risk. Absences due to maternity leave, holiday or sickness were reported not to be covered. Cover, time and resources for continuing professional development (CPD) were increasingly rare, leading to concerns regarding competencies. Also added workload pressures reduced time available to train junior doctors. There were opportunities to provide training packages to upskill primary care helping to meet demands from increased prevalence. Also professional pride was expressed in terms of services improvements in education and inpatient care since 2006, putting research into practice and performing national roles were cited.	
Participant perspectives: ‘Lack of funding for CPD’ (DN2) ‘We are brilliant at CPD, I keep a separate budget as the Trust has embargo on training and won't pay, I have to beg, borrow and steal’ (DN1) ‘The GPwSI is important so consortia have an understanding of diabetes’ (Chris, Dr) ‘Opportunities to educate and train and upskill practice nurses and GPs’ (D2) ‘We deliver a package of training to primary care and accredit them through our locally enhanced agreement’ (DN1) ‘You might not see any patients at all if you manage to upskill general practice and give them telephone support’ (D4) ‘You have to fight to get anyone replaced, the case has to be made and it is much harder than before’ (D1) ‘Morale is particularly down’ (D2) ‘Current issues come down to financial resource and workforce planning’ (D2) ‘We are gradually losing DSNs, the policy in Trust is that if someone leaves, retires, they are not being replaced’ (DN1)	‘We're in a real strong position to influence that national agenda’ (DN1) ‘We have one of the best programmes in the country, (retinal screening)’ (D2) ‘We are doing extremely well in terms of meeting the demands of type of patients we see, includes variety of ethnic groups’ (D5) ‘Strength is the good will of the team, the service would fold without it’ (DN2) ‘Our strength is our teamwork and a well trained, competent multidisciplinary team’ (DN1) ‘We have a highly skilled and motivated team’ (D3) ‘We need to get act our together so we can say, this is what we do, how we do it and what we can do for you in future and what it will cost’ (DN2) ‘We've done a lot of building up relationships with consortia, we need to continue to foster that’ (DN1) ‘We're already on an expert reference group for the consortia’ (DN1) ‘Pressing issue is how we position ourselves to be fit for anybody who wants to commission services from us’ (D3) ‘Practice staff see us as part of the team, we know GPs personally’ (D2)

‘There is no slack in system, when people are sick or go on holiday, it is difficult to maintain the service’ (DN2) ‘Freeze on hiring staff, not able to replace people leaving, recruiting is extremely difficult’ (D5)	

Table 8-9

Thematic chart to summarise ability to do my job	
Theme 3	**Ability to do my job**
Research question: What were the current issues facing services in 2011?	
Key emergent concepts (number of participants): Lack of financial resources (6) Pressure from increased prevalence (6) Pressures on workload (6) New provider competitors (5) Lack of IT support (5) Impact of Government policy standards (5) Commissioning demands and expectations (3) Impact of new technology (2) Patients slipping through the net (2) Trivialisation of diabetes and specialist services (2) Uncosted activities (2) Postcode lottery/service inequalities (1) Incentives (1)	Care of person with diabetes (7) Integration with primary care (7) Specific diabetes services (5) Organisational infrastructure (5) Quality of care (4) Delivery of standards (7) Diabetes prioritised (3) National presence (2) Relationship with research (2) Effect of local demographics (2)
Findings: Overwhelmingly all participants described that available resources had reduced further since 2006 which further threatened the stability of diabetes specialist services. Increasing prevalence of diabetes creating a rising demand for services was putting even greater pressure on workload which was further compounded by demands from acute medicine for professional time and services. Despite this most felt that achieving the NSF would have been achievable by 2013 had this not been replaced. Clinicians felt they provided high quality diabetes services and audits such as the National Diabetes Inpatient Audits had a positive impact raising the profile and providing leverage to get support for new models to improve care. Many reported that implementation of new practices was jeopardised due to lack of resources. The importance of care for the person with diabetes was voiced by everyone. It was vital they been seen by the right person at the right time. However concerns of postcode lottery, patients slipping through the net and lack of access to specific services such as psychological support and care for all were raised.	
Participant perspectives: ‘We don't have enough capacity to cope with demand’ (D2) ‘Funding of staff, because of the pressure in the acute sector, I think the worst has passed in the PCTs but it has yet to come in the acute trusts’ (D1) ‘In the last five years, the volume of diabetes has increased tremendously’ (D5) ‘There is pressure from acute medicine’ (D2) ‘My concern is that as long as patients seen by right people and skilled people, it is fine, whether they are seen in hospital or community it doesn't matter’ (D5) ‘We are rebuilding the fragmented service, if it fragments again it will impact on people with diabetes’ (D5)	‘Locally integration is good, but it is not robust enough to survive potential turmoil, like a tender flower, it needs to be looked after’ (D1) ‘It’s finding the time to build those ties with primary care, and there is still a bit of suspicion if it’s not too strong a word’ (DN2) ‘There is a threat if new providers enter the market who don't have the expertise’ (D1) ‘There is a perception in the PCT that diabetes can be done by just anybody, you don't need to be very skilled, so the complexity of diabetes is not recognised’ (D3) ‘The current economic climate is a big issue’ (D2) ‘Pressing issue is budget cuts, efficiency savings, Trust is in difficulties as are most in the country’ (DN1)

‘We have two in-house IT systems, that talk to each other but not to GPs, that would be really good’ (DN1) ‘We have a comprehensive set of services, particularly structured education’ (D2) ‘Skeletal service for psychological support, no proactive support’ (D2) ‘Retinal screening is well established now’ (D3) ‘Lack of resources has made psychological care, podiatry and dietetics worse than before in last five years ‘(D3) ‘The specialist team have worked tirelessly to come up with a model, with primary care to meet the needs best’ (D2) ‘I don't think we have a fragmented service, the opposite to be honest, true integration, changing culture, demolishing the boundary’ (D2) ‘The relentless pressure that we’re all under, there literally is no let up…. I think that constant, you can manage ok for a period of time by being stressed and stress is a good thing in some respects, but when it is continuous and there is no let up, and it becomes part of the job’ (DN2) ‘You’re not getting any support, people’s expectations are a lot more, and as a manager, you know I feel almost driven by my staff to ensure they are safe and updated and they are not stressed and not working too hard and they get their down time, but I’m also driven from the top to make them do more, work more hours, see more patients and it’s a constant difficulty, it really is’ (DSN2) ‘At least we have a unified diabetes team working across primary and secondary care’ (D3)	‘In last five years, things have downtailed in terms of resources and availability of resources’ (D3) ‘Some services will be impossible to maintain, so gradually will have to be cut, and they have taken years to develop and are at very high level’ (D5) ‘The NSF is history now really, seen as the last Governments work, they have been reinvented under the NICE quality standards’ (D1) ‘Some audits have highlighted inadequate services like footcare so we could go back and say 'oi', so that was helpful’ (DN1) ‘On the optimistic side, I’m hoping in five years’ time, I hope we will be well on our way out of the recession, the money situation, will be a little bit improved’ (D3) ‘I think in terms of delivering a more efficient service, I think that is never going to go backwards. The pressure will always be on us to be more efficient and ‘leaner’ to use another of the in words. I’m hoping there will be more resources and money available to use more technology in diabetes to improve our IT systems’ (D3) It is all to do with efficiency savings, getting more for your bucks, but there comes a time when you can’t do anymore, and you give in’ (DSN1) ‘The rationale behind community service was to up-skill general practice and reduce referrals to specialist services’ (D4) ‘You might not see any patients at all if managing to up-skill general practice and give telephone support’ (D4) ‘From PCT management there have been many diktats, particularly to the community team, saying you mustn’t do any hospital work, you mustn’t support the hospital work, you are the community team, and creating this divide between the two teams, which was very unhelpful and resulted in clashes and now we’re trying rebuild that and bridge the gap that was created’ (D3)

Table 8-10

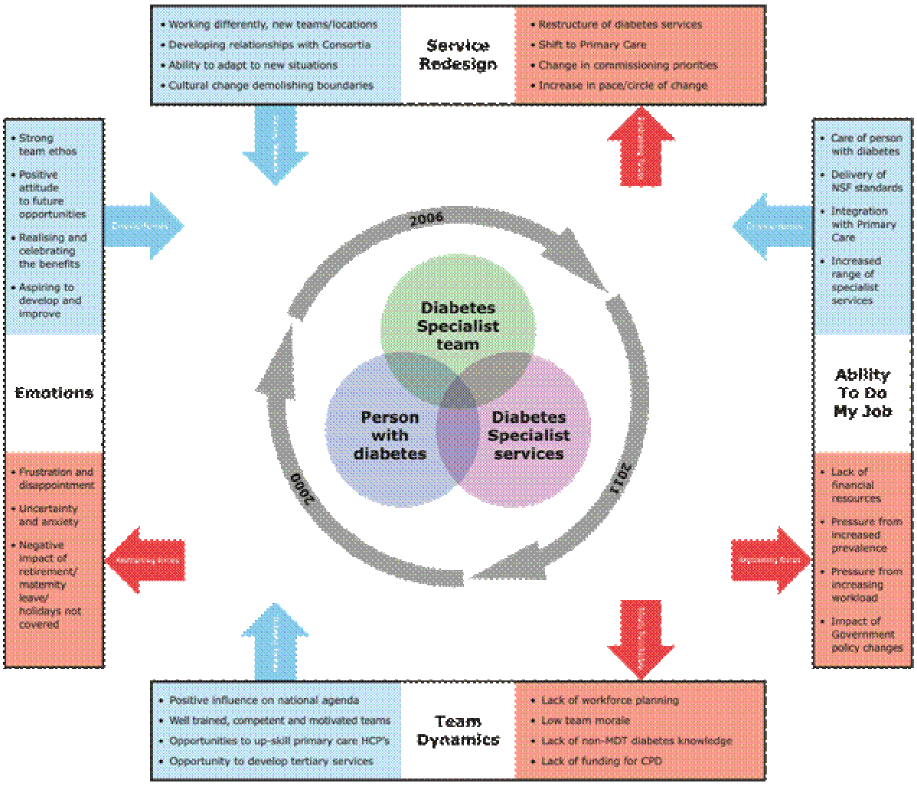
Thematic chart to summarise emotion	
Theme 4	**Emotion**
Research question: What were the current issues facing services in 2011?	
Key emergent concepts (number of participants): Frustration (7) Uncertainty (6) Expectation (6) Anxiety (5) Disappointment (5) Negotiation (5) Negative impact of retirement/ maternity leave/ holidays (4) Confrontation (3)	Group effort/ team work/ close relationships (7) Positive way forward (6) Seeing the benefit (4) Committed and motivated staff (4) Higher aspiration to provide more services to before/ strive (2) Goodwill (1)
Findings: Participants expressed mixed emotions relating to renewed service change and the effect on their ability to do their job. Clinicians felt uncertain as to the future role and function of their teams and their place in the new structure. This made the service an uncomfortable place to be during the process of change. All respondents were frustrated and disappointed at the lack of resources which impeded implementation of new models and reduced progress toward service improvement. Clinicians speculated as to the future shape of services and their role. Some were able to describe progress made since 2006 now realising benefits in terms of improved communication and integration with primary care. In describing their feelings, positives were also expressed, commitment and motivation and striving to provide more services than before utilising team work. Through this clinicians were able to see a positive way forward.	
Participant perspectives: ‘We don’t have that service, it is not funded, we are trying to develop that, but unfortunately we not getting anywhere’ (D3) ‘We’re not able to recruit the staff you would like to because of the pressures, and as a result that has a knock on effect on the quality of services we provide as well’ (D5) ‘We haven’t been able to do that despite having piloted the model, despite agreeing that it needs doing, it is a priority and has all those advantages that have been talked about and the reason is still that the Trust’s priority is to sort out acute medicine and the diabetologists are spending time sorting that out, so they haven’t been freed up’ (D2) ‘You’ve got to fight, the case has got to be made even, is much harder to make than it has been (workforce planning)’ (D1) ‘We’re trying also to make sure we’re still involved because a lot of the negotiations that have previously happened between the Trust and the PCT have happened with people who are not involved with diabetes and haven’t got a clue about diabetes’ (DN2) ‘Right now we suffer from the lack of power to	‘Well it’s fairly difficult to understand quite what’s going to happen given the fairly chaotic process that is happening in the entire NHS’ (D4) ‘I think there will be a transitional phase where how they work, a lot of staff I suspect will move into the commissioning groups or work with the cluster’ (D1) ‘I think the PCTs have been hit badly, they have been so concentrated on slimming down, I think the worst is yet to come within in the hospital sector’ (D1) ‘I hope we will be well on our way out of the recession, the money situation, will be a little bit improved, and I think in terms of delivering a more efficient service, I think that is never going to go backwards. The pressure will always be on us to be more efficient and leaner to use another of the ‘in’ words’ (D3) ‘I think we could change our name to morph, we can morph into something else…. I think we’re very good at adapting to our needs and to our surroundings’ (DN2) ‘Without the goodwill of the team, whether you’re looking at medical or nursing, but specifically nursing, then the service would just fold’ (DN2) ‘We probably had the biggest multiprofessional team as we had all these other disease services in the same office, kidney and feet and heart’ (D4)

negotiate and we seem to be completely at the mercy of commissioners and primary care who seem to be dictating terms rather than taking a much more holistic view of these things' (D5) 'I certainly feel that competing time demands doesn't allow us to spend that much time with junior doctors, and I'm certainly concerned about that' (D2) 'It's all to do with efficiency savings, getting more for your bucks, but there comes a time when you can't do anymore, and you give in' (DN1) 'No the consortia have never tried to be in touch with me, it is really sad, I have tried to be in touch with them but nobody seems to be owning up and saying look the person you need to be in contact with' (D5) 'I always say, you can destroy anything overnight but it takes years and years to build up, so you should always think carefully before you destroy anything' (D1)	'I think it will involve innovative work and people working interchangeably, in my view, I don't think we should be stuck in our community role or hospital role' (D3) 'So generally speaking, we have a lot of input at national level and we benefit from it' (DN1) 'We also have an opportunity to probably to free up some of our time and develop a highly specialised tertiary care services, for example a centre for neuropathy, or a focus on treatment for type 1 diabetes for lets say, either transplant clinics and so on' (D5) 'We're still looking for gaps and ways in which we can specialise even further, we need to be able to do the things that general practice can't do, and that's how we do it' (DN1) 'We're aspiring to do more' (D5) 'What we don't know is whether it (new model) will continue to be commissioned for the next three years because that will be up to the GP consortia' (DN1)

8.6 Conceptual framework

As part of the mapping and interpretation, the conceptual framework was developed to demonstrate the relationships between the themes, the driving and restraining forces during the course of the decade and their impact on the healthcare professional, diabetes specialist service and person with diabetes (Figure 36) (Appendix K for a larger version).

Figure 36 Conceptual framework



8.6.1 Comparison over time

Questions varied between the surveys making cross comparison complex. As analysis had not been carried out in 2000, the index developed in 2000 was applied. However, for data already coded in 2006, the closest fit was sought. This was not considered to be problematic as the codes in 2006 were used as part of the ‘a priori’ codes on which to base the 2011 index. Table 8-11 described the top issues present in 2000, 2006 and 2011 what had remained the same and what issues had disappeared and new themes to emerge (Table 8-12).

Table 8-11

2000	**Best and worst issues affecting diabetes services in 2006**	**2011** Change – same, increased, decreased Positive Negative
Research question: What is new? What has remained the same? What has disappeared?		
Service redesign and experience of change		
Working relationship with primary care (11) Lack of PCT interest in diabetes specialist services (8) Relationships with key personnel (6) New models of care; shift to primary care (5+8) Restructure of diabetes services (4) Place in the process of change (start, middle) (4)	Commissioning and negative impact of central government policy on diabetes care and uncertainty over future (94) Shift to primary care with limited capacity, lack of knowledge and experience and quality of care is variable (40) Poor communication and collaboration with primary care, PCTs and specialist services (23) Good network and engagement with primary care (15) Service reconfiguration and fragmentation (8)	Restructure of diabetes services; impact of government policy changes; GP consortia commissioning (8;5;7) Place in the process of change (start, middle) (6) New models of care (6) Relationships with key personnel (5) Degree of change in issues (5) Change in priorities (5) Shift to primary care (4) Lack of pct interest in diabetes specialist services (4) Circle of changes (4)
Team dynamics:		
MDT staffing levels (24) Gaps in the workforce (18) Team ethos (8) Clinical competency (4) Perceptions defining team strengths/weaknesses (3)	Good team and MDT working and expertise (39) Lack of staff, downgrading of posts and job losses (32); Good staffing levels (2) Loss of specialist skills, difficulty recruiting and training staff (20) Work is enjoyable, challenging and satisfying (25) Good training (2)	Clinical competency and team ethos (5+4) How we position ourselves for the future (6) Workforce planning (5) MDT staffing levels (5) Upskilling non MDT healthcare professionals (5)
Ability to do my job:		
Specific diabetes services (34) Lack of financial resources (26) Organisational infrastructure (25) Pressures on workload (12) Managerial pressure (11)	NHS funding/finances/ deficits, and no prospect of service development (47) Specific diabetes services not adequately support (education, psychology and retinal screening); poor inpatient care (24;6); specific diabetes services supported (10) Lack of understanding of complexity of diabetes, diabetes not considered a priority and poor management support (24) High workload and increasing prevalence; lack of time; pressure from acute medicine (22;10;2) Good quality, well organised	Delivery of standards (7) Care of person with diabetes (7) Integration with primary care (7) Lack of financial resources (6) Pressure from increased prevalence (6) Pressures on workload (6)

	service and facilities (20); Poor admin, facilities and IT (8)	
Emotion		
Committed and motivated staff (7) Positive way forward (6) Group effort/ team work/ close relationships (4) Frustration (4) Higher aspiration to provide more services to before/ strive (3) Disappointment (3) Uncertainty (3) Suspicion (2) Confrontation (1) Negotiation (1)	Uncertainty (see service redesign) Low morale (8)	Frustration (7) Group effort/ team work/ close relationships (7) Positive way forward (6) Uncertainty (6) Expectation/speculation (6) Anxiety (5) and disappointment (5) Negotiation (5) Negative impact of retirement/ maternity leave/ holidays (4) Seeing the benefit (4) Committed and motivated staff (4)

Table 8-12

What has emerged since 2000?	
Service redesign and experience of change: Working in new locations Adaptable teams Demonstrate value/ relationship to money GP consortia commissioning Degree of change in issues Pace of change Circle of changes Stimulus to change Cultural change and boundaries demolished Change in philosophy Change in priorities Destructive force Proactive	**Team dynamics:** National political presence Issues relating to teams Attitude to change (reluctance) Professional pride
Ability to do my job: Impact of new technology Patients slipping through the net Shared electronic access to data New provider competitors Commissioner demands and expectations Incentives Uncosted activities	**Emotion:** Anxiety Goodwill Power Seeing the benefit Taking more responsibility (for patients in service redesign) Protective Expectations Negative impact of retirement/ maternity leave/ holidays

8.7 Discussion

As stated previously the purpose of this multi-case study was to explore the views and perceptions of consultant diabetologists and DSNs working within diabetes specialist services at a time of NHS reform and service redesign in 2011. The study also examined how these views varied between professional groups, if issues have changed over time and reflected on the longitudinal quantitative and qualitative methodological approach taken.

The quantitative questionnaire ensured that a range of diabetes specialist services were represented despite their limited number. The participants all had long experience of working in services and all except one was present in the same service in 2006 and able to reflect back to that time.

The overriding findings of this study revealed that:

- Continual service redesign in the NHS and commissioning changes impacted on the morale of clinicians in already stretched specialist services, with increasing workloads and fewer resources.

- Some clinicians felt disenfranchised with service redesign, a lack of acknowledgment of the complexity of diabetes and needed support through the process of change.

- Participants, however, remained optimistic for the role that specialist teams would continue to play in the delivery of high quality care, and displayed a willingness to work in partnership and jointly lead the development towards an integrated service.

This discussion analyses, interprets and synthesises the findings and is organised by the following analytic categories, observations of changes over time and reflections on methodology:

1. Service redesign and experience of change
2. Team dynamics
3. Ability to do my job
4. Emotion
5. Changes over time
6. Consideration of methodology
7. Consideration of theoretical perspective

The themes were initially derived from the ‘a priori codes’, and then shaped by the themes emerging from the data and the literature of experiences of change and service redesign. An early review of change management models lead to the selection of Lewins’ (154) force field analysis to support interpretation of the findings. The notions of driving and restraining forces had similarities with the analytic approach taken in 2006 to describe the range and diversity of clinician views. In addition to the strengths, weaknesses and threats asked in 2006, opportunities were asked for in 2011 to complete the ‘SWOT’ analysis. SWOT was useful to help analyse how issues had changed over time in combination with the

2000 and 2006 datasets, but produced mainly descriptive observations rather than providing deeper theoretical explanations. Combining both the SWOT and the force field analysis was useful to point to dimensions within themes and to track changes over time, but also had their limitations.

The conceptual framework was developed to place the person with diabetes, with the specialist service and clinician, as the focus of the study. It visually represented this inter-relationship and operationalised the driving and restraining forces of the four themes and their impact on this relationship as this continues to change over time.

The implications of the findings are intended to give a voice to the experience and perception of specialist clinicians working in diabetes specialist services and to illuminate contributions towards identifying a positive way forward. Whilst the tone of many interviews was negative and pessimistic, on closer reading much optimism was also expressed. The chapter concludes with recommendations for practice and a discussion of the strengths and limitations of the study.

8.7.1 Service redesign and experience of change

The major issue identified by all participants was the Government's plans to replace PCTs with CCGs. Some respondents had already experienced several reorganisations and it was a time of uncertainty and anxiety.

Central to the success of redesign seems to be the development of key relationships across primary and secondary care. The level of engagement and stability of relationships ranged from not knowing the identity of the key decision makers to joint leadership and co-creation of new models of care. This was reflected in the cultures of services, from seamless, cross-boundary working to an absence of communication, tension and suspicion creating a cultural divide. Integration in some locations was described as fragile and requiring care to survive potential turmoil. Even where clinicians spoke positively of their joint collaboration, there were notes of caution of their longevity in the face of change or services being disinvested and key staff made redundant.

High levels of tension were also observed in MacLeod's (45) study in 2007 between secondary and primary care, where the changes in purchasing and commissioning created a culture of competition rather than collaboration. This was at odds with the nurturing of close working relationships, which take considerable time and resources and can impede true cross-boundary working and effective networking.

One participant demonstrated this collaboration in a way that echoed Mowles’ study (155), where the process of developing a new way of working was as important as the resultant model. All stakeholders were involved and shared a vision of a commissioned service to achieve good outcomes for their local population.

The nature of relationships becomes even more important when boundaries between primary and secondary care blur in response to the impact of government policy changes, purchasing, commissioning and service provision. Distribution of power and how it was experienced varied according to the values and personalities of those involved locally (156). Participants who felt on the outside of the decision making felt lacking in power to influence. This disempowerment was an uncomfortable experience and a challenge to their traditional roles as leaders and decision makers used to setting priorities and taking responsibility for service development (45).

Within the re-design participants were considering how they could position themselves for the future, what they could offer to CCGs in terms of a higher degree of specialisation. A key skill identified by participants to ensure the survival of the specialist service would be to adapt and find new ways in which to tailor their service. This concept of ‘morphing’ appears to be slightly different to the notion of innovation and changing practice to achieve better outcomes, rather a political skill for survival.

Periodic restructuring in the NHS has seen many new changes and it has been argued that stability is illusionary and in itself change need not be the ‘enemy of collaboration’ (157). Yet it is the type of change in service redesign, that is continual, externally-driven, imposed and organisationally disruptive which threatens collaboration and attainment of partnership (157). It is this kind of change experienced by the participants in this study that has adversely impacted upon team morale and increased anxiety levels. This at times can threaten to overwhelm clinicians and could divert them from long term activities that would improve and develop current service delivery. The concept of continual and type of change has helped to make sense of the emotions felt towards cyclical changes as identified by participants and their responses to this.

As well destructive forces within the threats identified, opportunities were found and proactive forces towards change. Despite feelings of uncertainty and anxiety towards the future, participants were able to create visions for the future of new ways of working, in new locations and in new teams. The shape of these structures differed most between hospital and community professionals. Hospital consultants viewed future models directed by the specialist service whilst the community consultants' perspective was one of bringing services back to the GP.

It seems essential that for reforms to be successful, there has to be engagement with the local situation and acceptance of variability (158). The traditional models of change, which Reinheck (159) argued are often linear, do not take account for the cyclic often chaotic change experienced today and evident from the responses. Rather than imposed standardisation, to achieve the positive way forward, all stakeholders should have responsibility to shape, change and co-ordinate care and acknowledge local differences in provision and delivery.

8.7.2 Team dynamics

The strong team ethos, pride in level of expertise, competency required to deliver complex care to people with diabetes and the ability to work with and understand new technologies was central to all participants. This view was shared in the study by MacLeod (45) in 2007 where consultant diabetologists recognised the value of team working. Kash (160) also revealed in a study of healthcare administrators that '*culture and shared values'* and '*people and engagement*' were ranked first and third respectively as top success factors for strategic change initiatives in healthcare.

Building on their expertise, clinicians saw opportunities to develop the specialist service further into tertiary areas such as amputations, as a survival mechanism during the shift towards diabetes management closer to home.

However, there were concerns expressed over the variable quality of care in primary care; as found by MacLeod (45), consultants were concerned that general practice lacked expertise and capacity to cope with increasing prevalence and complexity of diabetes care.

To resolve this and further secure their own role, participants saw another positive way forward in up-skilling general practice, as something that could be packaged and presented to commissioners. This also highlighted a difference between the primary and secondary specialists as the community consultant saw their role as existing primarily to up-skill primary care to reduce referrals. The role of up-skilling was also positively described by MacLeod, with specialist teams providing educational roles for GP's and other primary care staff which in turn would lead to better and more appropriate care.

Evidence from McDowell's (161) study demonstrated that staff working in primary care viewed type 2 diabetes as significantly harder to treat when compared to other chronic diseases. They recognised it as a serious condition and overall they were confident in their management and own actions to improve outcomes. The study also found that following education input knowledge positively affected confidence and could affect outcomes for people with diabetes.

All clinicians were highly concerned about current and future staffing levels within the multidisciplinary team, impacting upon its ability to provide a service to people with diabetes. This was particularly evident, when participants described a lack of backfill cover for training courses, sickness, holiday or maternity leave. Again this was apparent when replacements were not approved for staff retiring, leaving or completing short-term posts. Whilst this was largely a feature of lack of resources, Diabetes UK and TREND-UK's position statement has called for employers to ensure there are sufficient numbers of DSNs to care for the growing numbers of people with diabetes, to enhance their quality of life and reduce costs to the NHS (112).

This situation has not improved since concerns were raised in a previous Diabetes UK survey in 2007 where worrying trends of posts being frozen, unfilled posts following retirement, redundancies and posts being downgraded were found (77). These were found again in the DSN workforce survey in 2007 where 40% of the workforce were due to retire within 10 years of 2007 (162), presenting a serious gap in skills, leadership and experience available to the service. Doctors were frustrated with the limited time and conflicting demands to provide high quality training to junior doctors and to recruit them into the profession. Concerns were also voiced by consultants in MacLeod's study about the demands of acute medicine having an adverse effect on the training of junior doctors, with junior doctors spending an inadequate time in clinic to gain sufficient experience and knowledge.

Frequently and repeatedly discussed by clinicians was that they were committed to maintaining high skill and competency levels, but the means to achieve this were growing scarcer. Trusts had been reluctant to fund or provide backfill to enable staff training. Nurses described other means through which funds were found to facilitate training including speaker payments and pharmaceutical support being put into a separate fund. A survey of CCG's by Diabetes UK on the approach taken to diabetes health professional education in England in 2013 has shown that two-thirds (66%) of CCGs do not have a formal (written) policy on diabetes education and just over half (56%) had specifically funded time to participate in diabetes related health professional educational events (163).

8.7.3 Ability to do my job

Based on QOF data from 2013, the prevalence of diabetes in the UK has risen to 6% of the population, therefore the known diagnosed population is now 3.2 million people (164) and is predicted to increase to five million by 2025 (165). All participants felt pressure from this continual rise in prevalence, placing an intolerable burden on services at saturation point with financial resources becoming increasingly scarce. The problems with resources have intensified in the previous five years and there was a perception that although the worst had passed in PCTs, it was yet to come in the acute trusts. In contrast, there was also optimism that resources may possibly improve in five years after the recession.

To manage this dilemma of increased workload with fewer resources, the LEAN approach developed by Toyota to increase efficiency had been adopted into the NHS to improve care for people with diabetes within existing resources. An inevitable consequence of the LEAN approach was to achieve the same tasks using fewer people, to deliver better healthcare at lower overall cost (166). Yet, it would seem inescapable that in any redesign process a certain level of investment is essential to ensure a sufficient workforce and support systems are in place to achieve excellent care.

This pressure to be more efficient and ‘leaner’ may risk an increase in stress to unmanageable levels in clinicians. Some participants felt under continuous and relentless pressure which then became part of the job but which could be detrimental to both the service and care for people with diabetes. Agius (167) identified both demands on time and organisational change in the NHS as high risk factors for causing stress in clinicians.

According to Patterson (168) it would be appropriate for human resources departments to implement work practices to support and enhance employee autonomy and control during these periods of substantial organisational change. He found a positive association between increased job control on employee outcomes, such as job satisfaction, presenteeism (169) and health.

At times of organisational upheaval, when direction, roles and responsibilities are less clear, Binney et al (170) observed a preoccupation with managing often unrealistic expectations from hospital management and at the same time, ensuring the well-being of their team. This was a constant difficulty for clinicians having the ability and remit to be leaders, managing and supporting their teams to achieve targets and provide high quality care.

Being able to participate and have some control over local situation would help to reduce feelings of powerlessness and anxiety. Macfarlane (171) described how prevailing organisational theory generally emphasised the role of social factors rather than economic or efficiency factors in driving organisational change. Binney was in agreement (170), stating it is less about knowing the answer, but releasing the collective insights of organisations and helping people to find their own answers. This was clearly the case for one of the case studies who described the process as important as the outcome in developing their new service redesign. To help provide support to clinicians to develop their leadership capacity, Diabetes UK has launched the Local Clinical Champions programme. This is a national programme to empower clinicians to deliver meaningful improvements to diabetes services. This type of programme is providing not only training but social networks and opportunities for peer review in which they can call for support and ideas.

It was observed by respondents that sufficient time and periods of stability in amongst the change, to get systems, processes and people in place and trained before the inevitable next cycle of change with Government changes is necessary. This need for stability was recognised as necessary by Binney, as the speed and frequency of change does appear to be counterproductive and stability is necessary in order to survive forthcoming changes (170). The risk of continual change is staff losses combined with inadequate time for recruitment and training of future consultants and DSNs, onto whom to pass institutional knowledge, passion and enthusiasm. This would in turn lose the essence of what is at the heart of specialist services in these case studies.

Hospital consultants and DSNs described their role as training and educating, leading, integrating research and taking on leadership roles at national levels. They spoke of the value of relationships with research and how this put them at the forefront of national profiles and how they were keen to maintain this providing some level of prestige to them individually and also raised the profile of their services. It is important that this clinical expertise and knowledge of the complexity of diabetes is recognised and valued by those responsible for designing and commissioning diabetes services.

It was encouraging that all participants felt their service was on track to deliver on the standards set out in the NSF in 2011. Many described improvements in retinal screening and structured patient education. Yet despite being an area identified in the NSF for improvement, little progress in psychological services appeared to have been made throughout the decade. Clinicians valued the tools provided through National Diabetes Audits, QOF, NSF and NICE to provide valuable mechanisms with which to improve services and presented a positive driving force providing valuable leverage. Yet despite data on care processes being available through QOF, there were still gaps in the data available on outcomes, such as amputations, rates of diabetic ketoacidosis and inpatient data, or feedback as diabetologists or the Trusts' performance.

The issue of lack of IT support has persisted since earlier surveys, in particular systems within hospitals that are unable to link together or with primary care. This had been resolved in the case of the community consultant, but without this issue being addressed, true integration will remain problematic.

8.7.4 Emotion

An emotion present through all the themes was uncertainty, of the implications of service redesign, in the experience of change and what this would mean for participants' role and team. In the present study frequent references were made on the pace of change, continual change and frustration adversely affecting morale. Cortvriend (172) likened the impact on the employee to bereavement processes, resulting in uncertainty, stress, and low self-esteem. Whilst it has been noted that the rate of change has increased for organisations, as Cortvriend observes, for individuals, it can be a long drawn out process.

From this, Reineck raised concerns that change fatigue may result from relentless change (159), during which employees lose trust and faith in the service which may result in leaders becoming stressed and leaving. In this present study, however, professionals did not exhibit all signs of change fatigue, despite the negative impact changes in government policy had on morale. Clinicians were searching for new models of working and identifying positive ways forward.

Clinicians in this study appeared to feel a high level of professional pride, in providing high quality care and being part of a highly expert team, committed and motivated. This goodwill was identified as a cornerstone of the functioning of the service. This was also described by MacLeod (45) that most consultant diabetologists derived professional satisfaction from clinical practice and the provision of high standards of care for people with diabetes.

However, there were feelings of frustration by some participants in attempts to navigate new systems and from strained relationships with primary care. Likewise in MacLeods study, high levels of tension were reported between secondary care and primary care. Here close working needed time to be developed and nurtured which was at odds with the competitive culture resulting from the re-organisation and financial management of the NHS. This impeded development of a collaborative culture and true cross-boundary working and effective networking. Feelings of suspicion were apparent in the present study and to repair and rebuild relationships takes time and again a period of stability. Similar observations were made in 1991, in the Clinical Standards Advisory Group report (173) where two localities described that dialogue between providers and purchasers was inhibited by an attitude that there should be no direct communication and clinicians felt that their input into the contracting process was being discouraged.

Some frustrations and anxieties seemed to be concerned with feelings of powerlessness to negotiate and influence the future of the service, for example, anxiety that those with power, such as Trust management or commissioners, may not fully understand of the complexity of diabetes or what the specialist service had to offer.

8.7.5 What has changed over the decade in the issues facing diabetes specialist services, 2000 to 2011?

In this decade, clinicians in England have been faced with repeated Government led structural changes such as:

- payment mechanisms
- commissioning models
- PCT mergers
- PCT disbandment
- introduction of an NSF
- changes to tariffs and payment by results
- shift of care to primary settings

All of these have individually and collectively affected all aspects of service provision by the specialist diabetes teams and their individual roles within it.

8.7.5.1 What issues have emerged?

As different questions were asked in previous surveys, it was not possible to track clinicians’ experience of such changes in 2000. This information was only indirectly available in 2006 through analysis of the open questions. In 2006 whilst many described the changes as an issue for their service, their emotions were apparent in their responses. It was only in 2011 when participants were explicitly asked to reflect on how issues had changed in five years that the experience of change and the notion of the circle of change emerged; it is not likely, however, to have been a new theme. What was different to 2006 was the adaptability and resilience that was described and the mechanisms clinicians were developing to respond to the changes.

8.7.5.2 What has remained the same?

Lack of financial resources was a constant constraint on participants' ability to do their job throughout the decade. Aspects relating to specific diabetes services such as access to psychological services remained poor despite standards in national guidance and strong evidence of need. The impact of increasing prevalence and pressure on workload was also an ongoing theme. Furthermore there remained concerns over the shift to primary care, variable quality in primary care and service fragmentation.

The importance of stable relationships with key personnel for successful implementation of new changes was apparent throughout the decade. Pride in a strong workforce demonstrating high competency and skill levels has been evident since 2000, however, cuts to budgets for continual professional development and a lack of time and resources for training of junior doctors have become a pressing concern for the future workforce.

It is notable that since 2000 service reconfiguration and the impact of Government policy changes has been a persistent theme.

8.7.5.3 What has improved?

Encouragingly national programmes such as retinal screening, patient education and the National Diabetes Inpatient Audit have made a tremendous impact in improving services and highlighting areas of need. The National Diabetes Inpatient Audit provided leverage to services to innovate and introduce new models of care. Despite initial resistance in some places, changes to the retinal screening process also demonstrated overall benefits. These instruments had proven their value in supporting service improvement from the perspective of participants.

8.7.5.4 What has deteriorated?

Participants in 2000 appeared more positive compared to 2006. A greater proportion of negative emotions were expressed in 2006 with feelings of frustration, anxiety and disappointment and disengagement from NHS reform. In 2011, this continued with negative emotions reflecting the uncertainty in the changes and also low morale. In parallel, however, throughout the decade there had been positive expressions of close team working, motivated teams and an ability to see a positive way forward.

8.7.6 Consideration of methodology

This present study has provided a longitudinal qualitative case study approach in addition to the six quantitative studies in previous chapters to describe provision of diabetes specialist services. Whilst quantitative data provide answer to ‘what’ type of questions, longitudinal qualitative approaches can provide a dynamic picture of clinicians experiences and practices and how these change over time to better inform policy making (174). For this reason, the interviews carried out have provided a rich insight into the views and perceptions of clinicians working at a leadership level within diabetes specialist services. The use of case studies, whilst traditionally less frequent in health service research has provided a holistic picture combining both quantitative and qualitative data to be used in response to the research questions and provided a perspective on the experience of clinicians through the decade.

In the first instance, the research design for the quantitative studies allowed some continuity from the survey carried out in 2000 by ABCD. In quantitative studies, consistent measurement is helpful to make comparisons although as it has been seen that changes in national guidance has made this problematic. In qualitative longitudinal studies, however, there is greater flexibility by responding to what emerges from the data to inform the next stage of data generation. For example, sampling can be extended, interviews adjusted, the focus of the study shifted and multiple theoretical perspectives to be considered (174).

Future longitudinal qualitative studies of this kind should make careful consideration of ethical issues. These could include; how ethical issues may change over time, continuity of researchers and participants, how relationships are built, sustained over time and ended, and maintaining confidentiality and anonymity over time. Informed consent would need to be a continuous process rather than a one-off event with consultation through the process. Additional consent would need to be sought for material to be archived and allowing different levels of access to the data.

There are challenges to be negotiated with regards to managing and storing large, complex, multi-dimensional datasets and strategies for data analysis. Analysing across cases at one point in time, within a case and then tracking participants across time to compare and contrast themes requires multiple presentations. One solution identified by Holland (174) would be to employ a team of researchers from a range of different theoretical and disciplinary perspectives and compare the outcomes. This requires researchers to be reflexive of their own positions and resources, their role in setting the research agenda and generating knowledge. Attention the composition of the research team to include both insiders and outsider roles could be considered and their potential for influence on data collection and interpretation (175). The development of a mixed methodology employing a multi-disciplinary composition would be a new innovative development (174).

Large-scale nation-wide surveys are costly and resource intensive to carry out and response rates are decreasing over time (176), perhaps due to increased workloads and fewer resources. In 1992, Williams put forward the suggestion of carrying out surveys of diabetes services on a sample of physicians, centres or localities every 5 to 10 years to help answer questions of the future (177). Other avenues to gather data on outcomes could be explored from National Diabetes Audit and service delivery information as used to be gathered by Diabetes-e. However, a mixed methods approach combining quantitative data of service delivery and outcomes with a small number of consistent case study locations over time, gathering data of the kind in all the studies presented could enhance understanding of why variations in models of service delivery and outcomes exist.

8.7.7 Consideration of theoretical perspective

At the start of the analysis Lewins' model of driving and restraining forces helped to understand the range of dimensions expressed by participants about the categories as they emerged. The theory helped to develop the conceptual framework by demonstrating the multiple forces operating on clinicians, and operationalised the continual and circularity of changes.

However, on a further level of analysis, it became apparent that the nature and quality of relationships was fundamental to the experience of change. At this point, Mowles (155) exploration of working with staff caught up in the process of change and how best to support service improvement in healthcare settings became more relevant. In this study the theory of complex responsive processes, one manifestation of the complexity theory, took a different approach to participating in change within the NHS. In this theory a more complex understanding of how change comes about is identified as one which is tolerant of ambiguity, the unexpected and paradox, in which no one person is in overall control over what is happening and what emerges is unpredictable. Through reflection and peer review in a process that favoured a focus on problem identification rather than resolution, fresh insights emerged, interactions began to shift and transformation became possible.

A future study could incorporate a theory of this kind to open up and extend the conceptual framework developed in this study, to explore further the nature of the relationships between all aspects of diabetes service provision. The benefit of a longitudinal qualitative study however allows for multiple theories to illuminate and provide explanation as required.

8.8 Recommendations

From the findings and discussion the following recommendations could be made:

For clinicians in diabetes specialist services:

- To recognise their personal resilience and ability to adapt to changing circumstances and to lead and co-create environments in which a positive way forward can be forged.
- To develop leadership and national roles through participation in Diabetes UK Local Clinical Champions programme.
- Reflect on restraining forces and identify opportunities where as leaders they can offer expertise, knowledge and experience to new structures.
- To recognise in themselves as role models of the values and aspirations of the specialist service and their ability to act as agents of change.

For other clinical specialties:

- To evaluate success of new interventions, for example the paediatric tariff in paediatric diabetes specialist services.

For NHS services to implement:

- Human resources management practices that would support clinicians through the process of change to manage the complex interactions and not detract from delivering high quality care to people with diabetes and better outcomes.
- To celebrate the successes of and achievements of partnership working and steps towards integration and development of new models of working.

For Government:

- To consider the impact of continual change to services and commissioning structures and the discomfort it creates for healthcare professional and the impact on efforts to build shared culture, understandings and relationships to service improvement and service integration.

For further research:

- To build up a network of services where changes and issues could be tracked over time, building on the knowledge and experience of those in service for a long time who can reflect back.
- To extend the study to include primary care, dietitians, podiatrists and people with diabetes in a discussion of the issues facing the whole service and evaluation of whether the changes in England have been successful.

8.9 Strengths and limitations

A retrospective qualitative longitudinal study combined with the quantitative studies has had both strengths and limitations. Good project management was essential to manage the volume of data generated interview transcripts and open questionnaire questions. Effective organisation of large datasets, with data at different points in time and allowing sufficient time for analysis needs to be appropriately planned. A reflection on my own experience as a member of the working group, a non-clinician and past member of the Diabetes UK policy team has been acknowledged as bringing my own bias to the analysis selected and themes developed. The analytic themes and categorisation were not the only ones that could have been selected.

8.9.1 Strengths

A key strength of the six surveys carried out between 2006 and 2009 lies in the four nation scope and coverage of all diabetes specialist services reducing the risk of bias. Efforts were made to maximise response rates with additional analyses to explore non-response bias and sub-group analyses of comparable respondents from 2000 to 2006 to strengthen findings. Despite changes in national guidance, for example, new NICE guidance in 2002 for children and young people which made direct comparison problematic in 2008, it was possible and desirable to make adjustments and still satisfy the research aims.

The interviews extended the insights and depth possible to achieve from open survey questions and the evidence from Figure 35 suggests that data saturation was achieved with few new codes emerging from the final interviews. This helps to provide confidence that sufficient interviews were held with professionals from these groups. For continuity, efforts were made to ensure that the interviews were held with professionals present in the same service as in 2006 and with consultants who completed the surveys at that time. This was not possible at one service where the DSN was interviewed in place of the consultant however both met prior the interview to discuss experiences and issues from 2006. The one-to-one interview format also allowed privacy, for example, for DSNs who may have spoken more freely when separated from consultants.

8.9.2 Limitations

A limitation of the case studies was in the small number of localities selected. Efforts were made to produce a wide range of localities with different levels of resource, types of population and type hospital to deliver a degree of generalisability in the results. A larger sample of case study locations may make it possible in future studies to determine any links between well-resourced score and ability to adapt and respond to change.

A larger study would be able to include a wider range or professionals including; podiatrists, dietitians, psychological experts, primary care staff delivering diabetes care as well as commissioners and network members. Ideally this group would also include people with diabetes. The perspectives of consultants and DSNs provided valuable continuity from previous studies but do not reflect the experience of all aspects of the diabetes service. These limitations could be addressed with more resources in terms of funding, time and researcher capacity. Resources for this study consisted of my time as no external funding was sought.

Furthermore, consideration of the using focus groups may allow this diversity of participants to stimulate each other to think of and express views that may not have occurred in a one-to-one interview. To have carried out focus groups would have required more resources for travel, room booking and additional researchers to transcribe and analyse the data which were not within the resources available to this study.

The qualitative study was only carried out in England where healthcare reforms have taken a different direction to Wales, Scotland or Northern Ireland. A larger study may make useful evaluation of the success of the changes in England compared to the other nations.

Whilst the study reflects back to 2000 and incorporates responses, there was no intention in 2000 of using a longitudinal design. For the reasons stated in the previous section, planning from the start and the considerations raised, it would be useful to have in mind the repeatability of the study from the outset to guide the study design, whilst allowing change to emerge as it occurs. Overall this study could perhaps be seen as a pilot of the use of combined quantitative, qualitative and longitudinal design that could be extended in future studies.

8.10 Conclusion

Vital to clinicians’ ability to weather the continual change is their ability to lead highly skilled and effective teams, accept the flow of change and develop personal resilience and adaptability to new situations.

Clinicians have the opportunity to influence local redesign processes and commissioning models through their position as clinical experts and ability. Also clinicians need to develop and maintain key relationships, networks and collaboration with those in positions of power ensuring they understand the complexity of diabetes and its care.

As Chambers (178) warned, the consequences of structural reform on the commissioning side of the NHS in England maybe a temporary slowing down of innovation and implementation of service improvement due to ruptures in long term relationships which have begun to be productive. It is important that Government recognises the importance of relationships and the necessary periods of stability between changes in which to create environments and cultures where joint leadership can flourish. Government also need to give assurance of the importance of the specialist's role in delivering care, providing confidence for them to be at the forefront of these processes.

Experiencing change and the unknown is an uncomfortable and stressful experience, but the professionals in this study have demonstrated resilience and an ability to adapt to new models, qualities which should be celebrated and utilised. However lack of resources is still a barrier to implementation of care without which any new innovation is likely to flounder.

Conclusion

9.1 Statement of contribution to knowledge

A study of this scale and from this diversity of perspectives for diabetes services in England has not been done before, exploring core aspects of diabetes specialist services in the UK undergoing testing times, throughout a decade of service delivery.

Concerns prevailed over a growing diabetes population attending already stretched services, with the prospect of fewer resources. Services appear to be marginally poorer resourced, with a minor decline in the well-resourced score from 2000 to 2006. In addition regional and national variations in the quality of care were still in evidence particularly regarding psychological and emotional care.

Much progress has been made towards meeting NSF standards, and successes in retinal screening must be applauded. However, improvements made toward meeting recommended staffing levels after 2000 were subsequently threatened from lack of and redirected resources. Mechanisms such as the QOF and national audits are helping to monitor progress but without IT to support data and information sharing across secondary and primary care, true integration will remain problematic. It is important to ensure that those commissioning and supporting services note that persistent difficulties relating to IT and lack of resources have to be tackled to maintain and increase successful service delivery models.

The study has highlighted issues and feelings identified by clinicians concerning the many and varied NHS reform packages which have had a negative impact on staff morale. It is vital that all stakeholders are engaged in the change process, yet many clinicians felt disempowered and their expertise and institutional knowledge unacknowledged by changes imposed with little or no engagement. Important for all stakeholders' to understand is the complexity of managing change: managing emotions such as anxiety and uncertainty, the importance of key relationships and the use of joint leadership capabilities. Through engagement senior clinicians can remain advocates for people with diabetes to ensure the delivery of excellent care through any change process.

Change happens periodically in the NHS, and there will always be pressure to deliver more with less resource amidst changing structures, targets, GP incentives and provider competition. Just as important as the proposed change is how the change is implemented. Recognition of the time required and a period of stability for change to be embedded smoothly is important and for staff with local institutional knowledge, influence, experience and professional relationships to feel supported. What is notable is that despite continual change many issues reported have remained the same over time.

The employment of a mixed methods approach has allowed an exploration of the experience of issues over time. Insight into; how the issues have changed, possible causes and to some degree the impact on teams and individuals undergoing NHS reform have been enlightening:

- The qualitative element has added the depth necessary to see the context surrounding statistical data.
- What emerged from the study in 2011 was a consideration of the emotions expressed by respondents rather than purely analytical responses.
- Re-analysis of open question responses in 2000 and 2006 indicated that morale seemed to have declined over time, the impact of fewer resources, having to do more combined with uncertainty about the future eventually takes its toll on individuals and services.

9.2 Implications for practice

There are opportunities within times of change for diabetologists and DSNs to develop their role as leaders and to shape and inform the future development of diabetes specialist services. They have the expertise, institutional knowledge and relationships built up through long term clinical and demographic experience.

The Local Clinical Champions Programme launched by Diabetes UK in partnership with Novo Nordisk provides a platform for peer support, shared learning and leadership training for clinicians seeking to deliver meaningful improvements to local services. Information such as those gleaned from this study and others like it in the future could provide material to stimulate group discussions for clinical leaders and NHS management courses, identifying current issues and those faced in the past whose lessons have yet to be learnt.

Additionally, mixed methods approaches may add value to National Audits to provide context and aid interpretation of variability in findings. It could act as a tool for those with commissioning remits and support discussion within networks working towards improving local services.

9.3 Recommendations

Given the findings, the following recommendations could be made:

9.3.1 Clinicians

- To be aware of the emotional impact of continual change on self-efficacy and ability to do their job.

- To recognise the driving forces, the strengths of their teams, their capacity for improvement and change and to celebrate their achievements.

- Reflect on restraining forces and identify opportunities where their experience and expertise can offer leadership for diabetes service within new structures.

- To be aware of opportunities to engage as role models for other services to spread innovative practice through initiatives such as Diabetes UK Local Clinical Champions.

9.3.2 Diabetes service

- For human resources management practices to be put into place to support clinicians through the process of change and to manage complex interactions whilst not to being distracted from delivering high quality care to people with diabetes.

- To develop working practices that will support clinician leadership, autonomy and ownership which will support better outcomes for people with diabetes.

9.3.3 Commissioners

- To recognise and value the contributions from all stakeholders when deciding on new approaches.

- To adopt more formalised project and change management approaches to ensure that services are supported through cultural change and that change is embedded.

- Ensure service models reflect national standards and good practice for all areas of diabetes service delivery. Specified service outcomes must be achievable and sustainable within the funding provided.

- Ensure that the commissioned services cover the needs of the local population thus reducing persistent variations in standards of care, in particular to improve commitment to access for psychological support and care for people with diabetes.

9.3.4 Government

- To consider the impact of continual change on clinicians and recognise efforts towards service improvement and service integration. Recognising that building shared culture, understandings and relationships can be hampered by repeated and frequent changes with insufficient time to embed changes.

- To be aware that working practices which divide rather than support integration and diminish engagement of all stakeholders have persisted since 1991.

- To address the issue of cross-boundary working being hampered by IT which inhibits the sharing of patient information.

- To consider the use of both quantitative and qualitative methodologies such as those adopted through the course of this study to assist in evaluation of the success of NHS reform in England.

9.4 Personal reflections

This study aimed to put under the spotlight UK specialist diabetes services and bring together a unique picture of service delivery and the experience of those clinicians providing care. The study has in many ways mirrored my own personal learning journey. My role throughout has been to examine, explore and share the voices of these clinical leaders and the stresses, pressures and successes which they have experienced. For myself and the participants, the journey has been complex, non-linear, presented many frustrations, moments of breakthrough and changes of direction. Through the process I have developed new ways of working utilising different methodologies, created networks and built relationships spanning a decade of studies and surveys.

Peer support through collaboration with my supervisors, wider network and interview participants has opened up ideas and areas of study such as change management and leadership with a complexity that could not have been predicted from the start. Additionally this partnership working has helped to provide insight and ideas on alternative ways to interpret and analyse the data.

Through these relationships I have become more aware of how my experience as an employee of Diabetes UK with a longstanding membership of the working groups has shaped my own particular stance, bias and assumptions whilst also re-enforcing what my own contributions have been. Hence it should be noted that alternative methods of analysis and interpretations could have been employed depending on perspective. Throughout the research, I have aimed to look at the data from different angles, looking for both supporting and contrary explanations for the findings to give confidence to the interpretations made.

The theoretical perspective offered by Lewin (154) helped identify the driving and restraining factors within the issues. As analysis progressed, it became clear that a more complex picture was emerging in which change had been experienced. Following this experience, if I was to carry out this study again, I would adopt an additional theoretical perspective that encapsulated this complexity to inform the research design of the qualitative study.

Also a different approach could be taken, to follow a small number of case study locations over a number of years to focus on service delivery and also capture the experience of NHS reform and translation into local practice. A longitudinal approach would help ensure comparisons could be made over time. This could incorporate both quantitative and qualitative elements, replacing the large-scale, costly and resource intensive surveys and be supplemented by outcome data reported in the National Diabetes Audit and QOF. It could also endeavour to provide a wider representation of primary care, podiatry and dietetics as key components of the services forming the multidisciplinary team and the experience of people with diabetes.

The process of the research has been both exciting and transformational in nature and required similar strengths shown by the specialist teams, such as being highly motivated and committed. The clinicians who have participated in the study have been passionate about their teams and the people with diabetes in their care and they have continued to be champions for high quality care which meets the needs of people with diabetes in their care.

9.5 Future work

Further studies could extend the range of this study by gathering the views of more stakeholders involved in diabetes service delivery including people with diabetes. This could be planned to cover a further decade and evaluate the current and any future phase of NHS reform.

In light of this the following could be considered:

- To use a mixed methods approach when exploring data on diabetes service delivery and other analogous services.

- Extend the conceptual framework to incorporate the primary and community diabetes services and diabetes networks as well as specialist services.
- Explore generating additional data which would link service delivery to outcomes.
- Explore the views of further professional groups in the multi-disciplinary team, people with diabetes, commissioners and others engaged in improving service delivery.
- Encourage research that considers the human and social aspects of working life to help adapt to change.
- To include a larger number of case study locations.
- To identify a network of services where changes and issues could be tracked over time, building on the knowledge and experience of those in service for a long time and able to reflect back to prior experience.
- To consider the use of these findings to inform peer review supporting clinicians through change and service improvement.
- To support individual clinician reflection on internal barriers and motivators, to support the challenge of leadership and their role in bringing out change.
- Encourage research which would evaluate the benefit of NHS reform in England compared to alternative systems experienced in Scotland, Wales and Northern Ireland.

Many of the issues which presented themselves in 2000, 2006 and 2011 still persist despite service redesign and the large ongoing NHS structural reforms. Indeed many of the same issues were present in the 1991 CASG report (173). These times of change have afforded the opportunity to examine roles, to work in new ways and define new structures. Within this, clinicians have demonstrated their ability to transform barriers into opportunities, their resilience and ability to innovate and to work differently.

However, support is needed to enable services to continue to weather successive changes. The methods used in this study offer an opportunity to review the complex nature of service delivery, the agents involved and explore why, despite successive changes, some issues continue to remain the same.

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Appendix A - Consultant questionnaire

Consultant Questionnaire

ABCD & Diabetes UK survey of specialist diabetes services 2006
Individual Consultants
1. If you would like identifying information to be kept confidential, please tick yes Y/N

Details about where you work:
2. Name of your acute NHS trust
3. Name of your network
4. Name of your hospital
5. Please write the number of commissioning bodies (i.e. PCTs in England, LHBs in Wales, Health Boards in Scotland and HSSBs in Northern Ireland) service by your Acute Trust?

Details about yourself
7. What is your age?
<31, 31-35, 36-40, 41-45, 46-50, 51-55, 56-60, >61
8. Are you male or female?
9. How many years have you been in a consultant post (or equivalent)
10. Have you previously occupied a consultant post (or equivalent) in a different trust? Y/N

Status of diabetes service
11. How many other consultants are there working on your Acute site in diabetes?

12. Please state the number of whole time equivalent (WTE) consultants per 100,000 of the catchment population
Greater than 1.5, 1.26-1.5, 1.1-1.25, 0.76-1.0, 0.51-0.75, 0.26-0.50, 0.1-0.25, no consultants

13. Please state the number of WTE hospital diabetes specialist nurses per 100,000 of the catchment population
Greater than 1.5, 1.26-1.5, 1.1-1.25, 0.76-1.0, 0.51-0.75, 0.26-0.50, 0.1-0.25, no DSNs

14. What WTE dietitian availability is there for the specialist diabetes service?

15. What WTE podiatrist availability is there for the specialist diabetes service?

16. Does the diabetes service have a diabetes register?

17. Is there a joint ante-natal diabetes service?

18. Is there a joint diabetes-ophthalmology clinic in the specialist diabetes service
19. Are there separate diabetes clinics for the elderly?
20. Is there a local vascular surgeon in your hospital?
21. Are lipids measured in your specialist diabetes service?
22. Is microalbuminurea available in your specialist diabetes service?
23. Is HDL measured in your specialist diabetes service?
24. Is there a specific service for erectile dysfunction?

25. Is there a joint paediatric and adult specialist diabetes service?
26. Are there guidelines to ensure comprehensive diabetes care in all settings?
27. Is structured education offered to people with diabetes?
28. Is education offered to medical staff?
29. Do patients have access to a psychologist?
30. Based on your answers to the above questions, do you feel your specialist diabetes service is well resourced?
Well resourced, Reasonably well resourced, Not well resourced
31. Comments

Working methods within your current hospital
32. Are you involved in general medicine? If no, please proceed to the next section Y/N
33. Is your current hospital?
Designated teaching, Associated teaching, District general
34. Do you have a medical admissions unit? Y/N
35. What is the average number of acute medical admissions per 24 hours?
36. Does your 'team' operate together for on-call or not? Y/N
37. If 'Yes', how often are they on-call?
1 in 4, 1 in 5, 1 in 6, 1 in 7, 1 in 8, 1 in 9. 1 in 10, other
38. Is the frequency of on-call different for consultants to other team members? Y/N
39. How frequently do you carry out on-call duties?
1 in 4, 1 in 5, 1 in 6, 1 in 7, 1 in 8, 1 in 9. 1 in 10, 1 in 11, 1 in 12, 1 in 13, 1 in 14, 1 in 15, >1 in 15
40. Do you participate in a physician of the week system? Y/N
41. If 'Yes' how long is the duty period?
Whole 7 day week, Blocks of days, Weekdays and weekends separated
42. Do you work a ward-based system? Y/N
43. Is general medicine fully integrated with care of the elderly? Y/N/Partially
44. Is there a designated ward for diabetes in-patients? Y/N

General and specialist duties
45. Have any of your physician colleagues opted out of the acute medical on call rota? Y/N
46. If 'Yes', what speciality/specialities?
Cardiology
Rheumatology
Thoracic
Elderly care
Diabetes and endocrinology
Respiratory
Neurology
Renal medicine
Gastroenterology
Other

47. If 'Other', please specify
48. If 'Yes', rough age(s) of colleagues who have opted out
29 and under, 30-39, 40-49, 50-59, 60 and over
49. If 'Yes', reason for colleague opting out (i.e. seniority)

Your contract and working patterns
50. What type is your current contract?
New NHS consultants contract
Old NHS consultants contract
Equivalent

University
Other contract

51. If on the ‘New NHS contract’, please write
How many programmed activities do you carry out?
How many are devoted to acute medicine/ general medicine
How many are devoted to diabetes out-patient activity (including admin)
How many are spent in community diabetes
How many to endocrine activity
How many sessions are devoted to in-patient activities

52. Which type of clinics do you participate in
General diabetes
Pump-intensive management
Joint paediatric
Transitional adolescent-adult clinics
Joint foot
Sport and diabetes
Liaison psychiatry diabetes
Other specialist clinics
Ante-natal
Diabetes renal
Joint adolescent
Joint Ophthalmology
Joint men’s health
HIV – diabetes
Community diabetes clinic

53. Do you participate in specialist endocrine clinics?
Reproductive
Paediatric-adolescent endocrine
Thyroid
Obesity
Metabolic bone-osteoporosis
Pituitary
Lipid clinics

54. Qualitative thoughts on impact of acute medicine on speciality workload?

55. Impact of commitments to acute medicine on speciality: does this lead to cancelled clinics for:
Consultants, registrar, SHO

56. How would you rate your current job satisfaction
Poor, moderate, good, excellent

Changing specialist diabetes services
57. Are you aware of practice based commissioning? Y/N/Not applicable in my nation
58. If Yes, how will this impact on specialist service provision
59. Are you aware of the DoH scheme in England and Wales for ‘Payment by Results’? Y/N
60. If ‘Yes’, how will it impact on specialist diabetes services?
61. Are you aware of proposed tariffs for specialist diabetes services? Y/N
62. If ‘Yes’, what is the recommended tariff for a new diabetes consultation?
63. If ‘Yes’, what is the recommended tariff for a follow up consultation?
64. Have you been involved in any discussions regarding these? Y/N

Best and worst issues of Consultant post and/or most pressing concerns regarding:
65. Acute medicine
66. Diabetes

67. Endocrinology

General strengths, weaknesses and issues within your specialist service?
68. Please offer 3 main strengths of your specialist service
69. Please offer 3 main weaknesses of your specialist service
70. Please offer 3 main threats of your specialist service

71. Any other comments

Thank you for filling in our survey

Appendix B - Psychological questionnaire

Psychological survey

National UK survey of psychological services for people with diabetes

Introduction

The ***pyramid of psychological problems***, shown below, is intended to be helpful as you complete this questionnaire. The focus of the questions is mainly upon services to help people with psychological and emotional problems at level 2.

Also, healthcare professionals are divided, for simplicity only, into two categories; '**Non-psychological'** (diabetologists, diabetes nurses, podiatrists, etc) and '**Psychological'** (counsellors, psychologists, liaison psychiatrists, etc). This is important because **the questionnaire is in two parts:**

Part 1

Psychological care provided from within the '**non-psychological'** elements of the diabetes team

Part 2

Specialist psychological services for people with diabetes, i.e. provided by '**psychological'** staff

About you and your team
Name:
Title:
Contact number:
Email address:
What is the name of your organisation:
And your postcode:

How many of the following do you have in or associated with your multidisciplinary team?

'Non-psychological'	**Number**
Consultant diabetologists	
Diabetes nurse specialists	
Consultant nurses	
SpRs	
SHOs	
PRHOs	
Dietitians	
Podiatrists	
Physiotherapists	
Other (specify__________)	

Which of the following do you have in or associated with your multidisciplinary team?
*(**Note:** "in or associated with" should be taken to mean that these individuals have allocated time available specifically for patients of the diabetes service)*

'Psychological'	**Name**	**Telephone no.**	**Email address**

Counsellor			
Psychologist			
Liaison psychiatrist			
Psychotherapist			
Other*			

(*Please describe)______________________________

It is VERY IMPORTANT that you fill in the name, telephone number and email address of at least one psychological member, if you have one, as we need to contact that person by email and telephone for the second part of the survey.

<u>Part 1) The questions in this part all refer to:</u>
Psychological care provided from within the 'non-psychological' elements of the diabetes team

1) For your diabetes patients do you have:
A telephone advice system providing psychological support?
Yes No Don't know

Protocols or guidelines for referral to psychological services for patients at level 2?
Yes No Don't know

Adequate referral route to psychiatric services for patients at level 3?
Yes No Don't know

2) Screening tools
Are any screening/assessment tools for psychological well-being used by your 'non-psychological' team members?
Yes No Don't know

3) Training in psychological problems
Has anyone in your 'non-psychological' team had any training in identifying and managing psychological problems?
Yes No Don't know

If yes do these include training in:

counselling	Yes	No	Don't know
motivational interviewing	Yes	No	Don't know
cognitive behavioural therapy	Yes	No	Don't know
psychodynamic psychotherapy	Yes	No	Don't know
group therapy	Yes	No	Don't know
family or couple therapy	Yes	No	Don't know
other *	Yes	No	Don't know

*Please list:
____

4) Guidelines

Do you have clinical management guidelines for the following?	IF YES, do they consider psychological issues?

a) Difficulties with self-management (e.g. persistently high HbA_{1c} >10%)	Yes	No	Yes	No
b) Recurrent DKA	Yes	No	Yes	No
c) Low BMI	Yes	No	Yes	No
d) Eating disorders (bingeing, Bulimia, Anorexia	Yes	No	Yes	No
e) Morbid obesity	Yes	No	Yes	No

5) Below is a list of psychological problems which may be faced by patients with diabetes. Please rate how well you think your 'non-psychological' team is able to deal with the following:

	Excellent	**Good**	**Moderate**	**Poor**
Problems with self-management of diabetes (adherence/compliance)	☐	☐	☐	☐
Depression	☐	☐	☐	☐
Needle phobia	☐	☐	☐	☐
Other anxiety disorders	☐	☐	☐	☐
Eating disorders/problems	☐	☐	☐	☐
Drug and alcohol problems	☐	☐	☐	☐
Psychotic illnesses	☐	☐	☐	☐
Psychosexual problems	☐	☐	☐	☐
Suicidal patients and self-harm	☐	☐	☐	☐

Service provision issues raised by the National Service Framework (NSF) for diabetes:

6) Standard 3 requires provision of 'person centred care' which includes counselling and behaviour change support skills

Do you agree that this is necessary? Yes No
Does your service currently provide this? Yes No
If not, are you currently taking steps to provide this? Yes No

7) Standard 12 requires 'regular surveillance for, and effective management of depression'

Do you agree that this is necessary? Yes No
Does your service currently provide this? Yes No
If not, are you currently taking steps to provide this? Yes No

Issues raised by recommendations within the NICE guidelines for diabetes:

8) ‘Multidisciplinary teams (MDTs) should be alert to the development or presence of clinical or subclinical depression and/or anxiety, especially if there are problems with self management’.

Do you agree that this is necessary? Yes No
Does your MDT currently provide for this adequately? Yes No Don’t know
If not, do you think more training of the MDT is required? Yes No Don’t know
Do you think more psychological staff are required? Yes No Don’t know

9) Diabetes professionals should be:

a. ‘Able to detect and basically manage non-severe (level 1) psychological disorders in people from **different cultural backgrounds**’.

Do you agree that this is necessary? Yes No
Can your diabetes professionals currently do this? Yes No Don’t know
If not, do you think more training of your staff is required to do this?
Yes No Don’t know

b. ‘Familiar with counselling techniques and drug therapy, while arranging prompt referral to specialists, especially if there is significant interference with well-being or diabetes self-management’.

Do you agree that this is necessary? Yes No
Can your diabetes professionals currently do this? Yes No Don’t know
If not, do you think more training of your staff is required to do this?
Yes No Don’t know

10) ‘Alert to eating disorders and insulin dose manipulation if there is either poor glucose control, low BMI or over concern with body shape and weight. Early, and occasionally urgent, referral to local eating disorders services should be considered’.

Do you agree that this is necessary? Yes No
Does your MDT currently provide for this adequately? Yes No Don’t know
If not, do you think more training of the MDT is required to do this?
Yes No Don’t know
Do you think more psychological staff are required? Yes No Don’t know

11) When dealing with psychological issues, how do the skills of the doctors in your team compare with those of an experienced GP?

Better Same Worse

Part 2 (telephone) structured interview/questionnaire

<u>Part 2) The questions in this part all refer to:</u>

Specialist psychological services for people with diabetes, i.e. provided by ‘Psychological’ staff

12) In your area, are specific psychological services provided for people with diabetes who have psychological problems at level 2 of the pyramid?

Yes No

13) If yes, please define the age groups that specialist psychological services are provided for (tick all that apply)

Ages 17-64 Age 65+ Both

14) What elements of psychological help are available for people with diabetes with level 2 psychological problems? (tick all that apply)

Counselling	☐
Motivational interviewing	☐
Cognitive behavioural therapy	☐
Psychodynamic therapy	☐
Group therapy	☐
Family or couple therapy	☐
Other (please specify):______________	☐

15) Who provides these services specifically for people with diabetes, and how many are there of each discipline?

	1	**2**	**3**	**3+**
Counsellors	☐	☐	☐	☐
Psychologists	☐	☐	☐	☐
Liaison psychiatrists	☐	☐	☐	☐
Psychotherapists	☐	☐	☐	☐
Other (please specify):_____	☐	☐	☐	☐

16) Of these services, how many sessions (half days) are available per week or, if less than one per week, how many per month?

	Per week	Per month
Counsellors		
Psychologists		
Liaison psychiatrists		
Psychotherapists		
Other (please specify):_____		

17) What level of experience do the people who provide these services have in treating 'people with diabetes' (PWD)?

	See PWD very occasionally	See PWD occasionally	See PWD on a fairly regular basis	See PWD frequently	Have been a member of a diabetes team or work with PWD for over a year
Counsellors					
Psychologists					
Liaison psychiatrists					
Psychotherapists					
Other (please specify):_____					

18) Do those providing the psychological service work with the diabetes services(s) as dedicated members of the team?
Yes No

19) Are these services dedicated for people with diabetes or are they simply local generic services, which can be referred to? (please tick one below)
Specific service for diabetes Local generic services

20) Do the psychology/psychiatry/counselling staff clinically treat* the patients referred to them? (* as distinct from providing advice, supervision, case discussion or other interventions which focus on supporting the 'non-psychological' members of the diabetes team in their work)
Yes No

21) Do the staff provide education/training for other healthcare professionals working with people with diabetes?
Yes No

22) Do they provide clinical supervision for other healthcare professionals working with people with diabetes?
Yes No

23) Where are these specialist psychological services provided? (tick all that apply)

GP practice(s)	☐
General hospital	☐
Mental health unit	☐
Other (Please specify below)	☐

24) Are services available for routine cases, urgent cases or both? (tick one box only)

Routine	☐
Urgent	☐
Both	☐

25) What is the average waiting time for routine referrals to these services? (tick one box only)

Up to one month	☐
1 to 2 months	☐
2 to 3 months	☐
More than 3 months	☐

26) Are urgent referrals seen straight away?
Yes No

27) Is there a limit as to how long the service and/or clinician can continue to provide treatment to each person they see?
Yes No
If yes, please specify how long in weeks __________weeks

28) What organisation provides these psychological services?

PCT	☐
Acute Trust	☐
Mental Health Trust	☐
Other (please specify)	☐

29) Finally, in your opinion what gaps are there in services for people with diabetes who have emotional, psychological or mental health problems?

End:
(Finish by thanking the person for taking part in this survey)

Appendix C - Retinal screening questionnaire

Retinopathy Screening England and Wales

ABCD & Diabetes UK survey of Specialist Diabetes Services 2006

Please complete this survey on behalf of the Diabetes team in each Acute site.

1.Name of (Acute) NHS Trust linked to retinal screening programme?

2. Name of your 'Network'

3. Name of Hospital(s):

4. Please write the number of commissioning bodies (i.e. PCT- England, LHBs – Wales) served by your (Acute) Trust:

5. Please write the name of each commissioning body served by the (Acute) Trust Please write each name separated by a comma

6. What is the role of the person completing the survey on behalf of retinal screening programme?

☐ Lead of the retinal screening programme
☐ Other

7. If other, please specify

8. Has the (Acute) Trust recently amalgamated/ or about to amalgamate?

☐ Yes – recently amalgamated
☐ Yes – about to amalgamate
☐ No

9. Has the Commissioning body (i.e. PCTs – England, LHBs-Wales) recently amalgamated/ or about to amalgamate?

☐ Yes – recently amalgamated
☐ Yes – about to amalgamate
☐ No

10. Is there a co-ordinated diabetic retinopathy screening programme in the locality?

Yes No

11. If 'No', how does retinal screening operate?

☐	Optometry based	☐	Digital photography
☐	Polaroid photography	☐	Opportunistic
☐	Structured	☐	Diabetes-Register based
☐	Individual practice-based	☐	Primary care provider-based
☐	Hospital-based	☐	Network-based

12. If 'Yes', how many primary care commissioning organisations are included in the programme?

13. Please state the names of the primary care commissioning organisations included in the programme

Please separate each name with a comma

14. Please tick all boxes that apply to whatever scheme operates in the locality:

☐	Optometry based	☐	Digital photography
☐	Polaroid photography	☐	Opportunistic
☐	Structured	☐	Diabetes-register based
☐	Individual Practice-based	☐	Mobile system
☐	Primary care provider-based	☐	Located in hospital
☐	Located in community	☐	Other

15. If ‘Other’, please briefly describe:

16. Is the programme operated from fixed sites, mobile sites or mixed?
☐ Fixed ☐ mobile ☐ mixed

17. Which recommendations are followed for retinopathy screening?
☐ NICE ☐ NSC ☐ Neither

18. Who is responsible for managing the scheme?
Tick all that apply

☐	Primary care commissioning organisation	☐	(Acute) Trust
☐	Joint Primary care/ (Acute) Trust	☐	Other

19. If optometry are involved – are only selected optometrists involved?
☐ Yes ☐ No ☐ Not applicable

20. If ‘Yes’, how are they selected/ accredited?

21. Are local optometrists part of a centralised system?
Yes No

22. Is a new retinal screening system being introduced to replace an old system?
Yes No

23. Is it known what percentage of the population have been offered screening in the last 12 months?
Yes No Don’t know

24. Is it known what percentage of the population have actually attended and been screened in the last 12 months?
Yes No Don’t know

25. If Yes, what percentage of the population:

	%
Are estimated to have been offered screening in the last 12 months	
In the last 12 months have actually attended and been screened	

26. What percentage of people with diabetes are screened with a digital camera?
Please write a per cent, for example, 57%

27. Has the service recruited new retinal screening personnel in the last two years?

Yes No Don’t know

28. Are retinal screeners enrolled in training schemes?
Yes No Don’t know

29. Is there an accreditation process for them?
Yes No Don’t know

30.Is there a service model whereby community based patients with active retinopathy can be transferred to specialist diabetes services for their ongoing diabetes management?
Yes No Don’t know

31.Is pupillary dilation mandatory for screening?
Yes No

32.Is visual acuity routinely recorded?
Yes No

33.If ‘Yes’, by pinhole?
Yes No

34.Who receives the results of the screening?
Tick all that apply

☐	Ophthalmologist	☐	GP
☐	Hospital diabetologist	☐	Patient

35.What computer system is used?

☐	Clinisys Systems (Sysmed Solutions Ltd)	☐	Orion Imaging
☐	Digital healthcare ltd	☐	Siemens plc
☐	Other		

Q36. If ‘Other’, please state:

Q.37. How is the scheme quality controlled?

Q38. Who is responsible for grading images?

☐	Retinal screener/ technician	☐	Ophthalmologist
☐	Optometrist	☐	Diabetologist
☐	Other		

Q39. If ‘Other’, please specify

Q40. What is the mechanism for dealing with ungradable images?
☐ Patient automatically seen at ophthalmology department
☐ Referred to optometrist
☐ Consultant review
☐ None
☐ Other

Q41. If “Other”, please specify

Q42. What is the current non attendance rate?

Q43. What register is used for call/recall?

☐ Central register

☐ Practice-based register

Q44. What mechanism is in place to deal with non-attendees?

☐	Letter reminder to patient
☐	GP informed
☐	Further appointment generated
☐	None
☐	Other

Q45. If "Other", please specify

Q46. Are people who are house-bound/unable to access screening services screened?

☐	Yes
☐	No

Q47. If "Yes", how are they screened?

Q48. Since the introduction of the NSF standards and delivery documents has the local retinal service improved?

☐	Yes
☐	No

Q49. Has a new retinal screening system been set up since 2000?

☐	Yes
☐	No

Q50. Has an established system that did not conform to National Screening Committee standards been withdrawn?

☐	Yes
☐	No

Q51. Is there waiting list for patients identified as needing treatment for retinopathy?

☐	Yes
☐	No

Q52. If "Yes", how long?

☐	Under 1 week
☐	1 to 4 weeks
☐	5 to 8 weeks
☐	Longer than 8 weeks

Q53. Any other issues/concerns:

Q54. How are patients screened for retinopathy?

☐	At specific annual review clinic
☐	On an annual basis according to check list

☐	Practice-based register call-up
☐	Opportunistically

Q55. How often are patients screened?

☐	Once a year
☐	Between 1 and 2 years
☐	Every 2 years
☐	More than 2 years
☐	Variable

Q56. Is there a mechanism to screen 6 monthly as advised by NICE for:

	Yes	No
Insulin conversions with retinopathy	☐	☐
Hypertension	☐	☐
Other clinical issues	☐	☐

Q57. If "Other", please specify

Q58. Given the suggested prevalence of retinopathy in newly diagnosed Type 2 diabetes, is there a fast tract mechanism to ensure early screening?

☐	Yes
☐	No

Q59. Does screening take place during hospital outpatient's clinics?

☐	Yes
☐	No

Q60. If yes, has opportunistic screening during hospital clinics been affected by new retinal screening programmes?

☐	Yes
☐	No

Q61. If yes, please describe how:

Q62. Are patients screened for cataracts?

☐	Yes
☐	No

Q63. Are patients screened for glaucoma?

☐	Yes
☐	No

Q64. Screening for pregnant women: how does the retinal screening programme screen pregnant women?

☐	With a digital camera
☐	Fundoscopy
☐	No screening

Q65. Is diabetic retinopathy care provided by a specified ophthalmologist?

☐	Yes
☐	No

Q66. Is there a joint clinic attended by both diabetes and ophthalmology personnel:

☐	Yes
☐	No

Q67. If ‘Yes’, how often does it run?

☐ Weekly
☐ Monthly
☐ Less often

Q68. Personnel involved:
State number, if zero, please write ‘0’

Consultant diabetologist	
Ophthalmologist	
Training registrar in ophthalmology	
Training registrar in diabetes	
Other	

Q69. Do patients have other aspects of diabetes care e.g. metabolic control, complications and foot care/ checks, covered at the same visit?

☐	Yes
☐	No

Q70. How soon are patients usually seen by the ophthalmologist following screening?

	Immediately/ within 1 week	Within 2 weeks	Within 1 month	Within 2 months	Within 4 months	According to clinical need
Patients with neovascularisation						
Patients with maculopathy						
Patients with reduced acuity						
Patients with unobtainable images						

Q71. Are there are any current problems/ issues with retinopathy screening locally?

Q72. If ‘Yes’, tick all that apply

☐	Funding	☐	Lack of proper organisation for scheme
☐	Disrupted old scheme	☐	IT support
☐	Other		

Q73. A meeting is planned for DR screening programme directors (clinical leads) and programme managers in September. In order for the correct people to be invited to this meeting, please would you provide the name and address of the following people:

	Name	Address
The diabetic retinopathy screening programme clinical lead in your area		
The diabetic retinopathy screening programme manager in your area		

Retinopathy Screening - Scotland

ABCD & Diabetes UK survey of Specialist Diabetes Services 2006

Please complete this survey on behalf of the Diabetes team in each Health Board.

1. Name of the Health Board Area linked to retinal screening programme?

2. Name of your related Managed Clinical Network

3. Please write the number of Community Health Partnerships within the Health Board Area:

4. Please write the name of each Community Health Partnerships within Health Board Area:
Please write each name separated by a comma

5. What is the role of the person completing the survey on behalf of retinal screening programme?
☐ Lead of the retinal screening programme
☐ Other

6. If other, please specify

7. Is there a co-ordinated diabetic retinopathy screening programme in the Board Area?

☐	Yes
☐	No

8. If 'No', how does retinal screening operate?

☐	Optometry based	☐	Digital photography
☐	Polaroid photography	☐	Opportunistic
☐	Structured	☐	Diabetes-Register based
☐	Individual practice-based	☐	Primary care provider-based
☐	Hospital-based	☐	Network-based

9. Please tick all boxes that apply to whatever scheme operates in the Board Area:

☐	Optometry based	☐	Digital photography
☐	Polaroid photography	☐	Opportunistic
☐	Structured	☐	Diabetes-register based
☐	Individual Practice-based	☐	Primary care provider based
☐	Hospital-based	☐	Networked based
☐	Other	☐	

10. If ‘Other’, please briefly describe:

11. Is the programme operated from fixed sites, mobile sites or mixed?
☐ Fixed ☐ mobile ☐ mixed

12. Which recommendations are followed for retinopathy screening?
☐ HTBS ☐ NICE ☐ NSC ☐ Neither
☐ Other

13. Who is responsible for managing the scheme?

14. If optometry are involved – are only selected optometrists involved?
☐ Yes ☐ No ☐ Not applicable

15. If ‘Yes’, how are they selected/ accredited?

16. Are local optometrists part of a centralised system?
Yes No

17. Is a new retinal screening system being introduced to replace an old system?
Yes No

18. Is it known what percentage of the population have been offered screening in the last 12 months?
Yes No Don’t know

19. Is it known what percentage of the population have actually attended and been screened in the last 12 months?
Yes No Don’t know

20. If Yes, what percentage of the population:

	%
Are estimated to have been offered screening in the last 12 months	
In the last 12 months have actually attended and been screened	

21. What percentage of people with diabetes are screened with a digital camera?
Please write a per cent, for example, 57%

22. Has the service recruited new retinal screening personnel in the last two years?
Yes No Don’t know

23. Are retinal screeners enrolled in training schemes?
Yes No Don’t know

24. Is there an accreditation process for them?
Yes No Don’t know

25. Is there a service model whereby community based patients with active retinopathy can be transferred to specialist diabetes services for their ongoing diabetes management?
Yes No Don’t know

26. Is pupillary dilation mandatory for screening?
Yes No

27. Is visual acuity routinely recorded?
Yes No

28. If 'Yes', by pinhole?
Yes No

29. Who receives the results of the screening?
Tick all that apply

☐	Ophthalmologist	☐	GP
☐	Hospital diabetologist	☐	Patient

30. What computer system is used?

☐	Clinisys Systems (Sysmed Solutions Ltd)	☐	Orion Imaging
☐	Digital healthcare ltd	☐	Siemens plc
☐	Other		

31. If 'Other', please state:

32. How is the scheme quality controlled?

33. Who is responsible for grading images?

☐	Retinal screener/ technician	☐	Ophthalmologist
☐	Optometrist	☐	Diabetologist
☐	Other		

34. If 'Other', please specify

35. What is the mechanism for dealing with ungradable images?
☐ Patient automatically seen at ophthalmology department
☐ Referred to optometrist
☐ Consultant review
☐ None
☐ Other

36. If "Other", please specify

37. What is the current non attendance rate?
Please write the per cent

38. What register is used for call/recall?
☐ Central register
☐ Practice-based register

39. What mechanism is in place to deal with non-attendees?
Tick all that apply

☐	Letter reminder to patient
☐	GP informed
☐	Further appointment generated
☐	None
☐	Other

40. If “Other”, please specify

41. Are people who are house-bound/unable to access screening services screened?
Yes No

42. If “Yes”, how are they screened?

43. Since the introduction of the NSF standards and delivery documents has the local retinal service improved?
Yes No

44. Has a new retinal screening system been set up since 2000?
Yes No

45. Has an established system that did not conform to National Screening Committee standards been withdrawn?
Yes No

46. Is there waiting list for patients identified as needing treatment for retinopathy?
Yes No

47. If “Yes”, how long?

☐	Under 1 week
☐	1 to 4 weeks
☐	5 to 8 weeks
☐	Longer than 8 weeks

48. Any other issues/concerns:

49. How are patients screened for retinopathy?

☐	At specific annual review clinic
☐	On an annual basis according to check list
☐	Practice-based register call-up
☐	Opportunistically

50. How often are patients screened?

☐	Once a year
☐	Between 1 and 2 years
☐	Every 2 years
☐	More than 2 years
☐	Variable

51. Is there a mechanism to screen 6 monthly as advised by HTBS/ NICE/ NSC for:

	Yes	No
Insulin conversions with retinopathy	☐	☐

Hypertension	☐	☐
Other clinical issues	☐	☐

52. If “Other”, please specify

53. Given the suggested prevalence of retinopathy in newly diagnosed Type 2 diabetes, is there a fast tract mechanism to ensure early screening?
Yes No

54. Does screening take place during hospital outpatient’s clinics?
Yes No

55. If yes, has opportunistic screening during hospital clinics been affected by new retinal screening programmes?
Yes No

56. If yes, please describe how:

57. Are patients screened for cataracts?
Yes No

58. Are patients screened for glaucoma?
Yes No

59. Screening for pregnant women: how does the retinal screening programme screen pregnant women?

☐	With a digital camera
☐	Fundoscopy
☐	No screening

60. Is diabetic retinopathy care provided by a specified ophthalmologist?
Yes No

61. Is there a joint clinic attended by both diabetes and ophthalmology personnel:
Yes No

62. If ‘Yes’, how often does it run?
☐ Weekly
☐ Monthly
☐ Less often

63. Personnel involved:
State number, if zero, please write ‘0’

Consultant diabetologist	
Ophthalmologist	
Training registrar in ophthalmology	
Training registrar in diabetes	
Other	

64. Do patients have other aspects of diabetes care e.g. metabolic control, complications and foot care/ checks, covered at the same visit?
Yes No

65. How soon are patients usually seen by the ophthalmologist following screening?

	Immediately/ within 1 week	Within 2 weeks	Within 1 month	Within 2 months	Within 4 months	According to clinical need
Patients with neovascularisation						
Patients with maculopathy						
Patients with reduced acuity						
Patients with unobtainable images						

66. Are there are any current problems/ issues with retinopathy screening locally?

67. If ‘Yes’, tick all that apply

☐	Funding	☐	Lack of proper organisation for scheme
☐	Disrupted old scheme	☐	IT support
☐	Other		

Q73. A meeting is planned for DR screening programme directors (clinical leads) and programme managers in September. In order for the correct people to be invited to this meeting, please would you provide the name and address of the following people:

	Name	Address
The diabetic retinopathy screening programme clinical lead in your Health Board		
The diabetic retinopathy screening programme manager in your Health Board		

Thank you for filling in our survey

Appendix D - DSN, Nurse Consultant and Community DSN questionnaire

DSN, Nurse Consultant and Community DSN

Please complete one survey per locality

We kindly request that the Lead DSN for this locality completes this questionnaire. If you are not the lead DSN, please forward to the appropriate person.

1.Is there an integrated primary and specialist service in this locality?
If no, please copy this survey and ask the community service to complete a questionnaire

Yes No

2.If the service is not integrated, please indicate if you are based in primary care or within specialist services

Primary care	☐
Specialist services	☐
Other	☐

3.If other, please specify

4.Name of Acute NHS Trust in this locality
If there is more than one, please separate with a comma

5.Name of the Network in this locality

6.Name of hospital(s) in this locality

7.Please write the number of commissioning bodies (i.e. PCTs – England, LHBs – Wales, Health Boards – Scotland and HSSBs – Northern Ireland) served by the Acute Trust

8.Please write the name of each commissioning body:
Please write each name separated by a comma

Employment

9. Who are the diabetes nurses employed by?

	Acute Trust	Primary care provider	GP	Other
Hospital DSN				
Nurse Consultant in diabetes				
Community DSN				
Diabetes healthcare assistant				

10. If ‘other’ please specify

Hospital DSN	
Nurse consultant in diabetes	
Community DSN	
Diabetes healthcare assistant	

11. Who are the diabetes nurses managed by?
Please write WTE

	Acute Trust	Primary care provider	GP	Other
Hospital DSN				
Nurse Consultant in diabetes				
Community DSN				
Diabetes healthcare assistant				

12. If ‘other’ please specify

Hospital DSN	
Nurse consultant in diabetes	
Community DSN	
Diabetes healthcare assistant	

13. How many of the following nurses are employed on short term contracts funded by external sources?
Please write the WTE

Hospital DSNs	
Community DSNs	

Work settings

14. Where do hospital DSNs work?

	Hospital ward	Hospital out-patients	Nurse led clinics in general practice	Primary care	Both hospital and primary care
Acute Trust employed DSNs					
Primary care provider employed DSNs					
GP employed DSNs					
Other					

15. Where do Nurse Consultants in diabetes work?
Please write WTE

	Hospital	Hospital	Nurse led	Primary	Both

	ward	out-patients	clinics in general practice	care	hospital and primary care
Acute Trust employed Nurse Consultants					
Primary care provider employed Nurse Consultants					
GP employed Nurse Consultants					
Other					

16. Where do Community DSNs work?
Please write the WTE

	Hospital ward	Hospital out-patients	Nurse led clinics in general practice	Primary care	Both hospital and primary care
Primary care provider employed Community DSNs					
GP employed Community DSNs					
Other					

17. Is there a service level agreement between the hospital or primary care provider to provide services in the community or hospital?
Yes No

18. Is there a named DSN nurse contact for each patient?

	Yes	No
Hospital DSN	☐	☐
Community DSN	☐	☐

19. Do nurses cover other roles, i.e. not solely in diabetes?
Yes No

20. If ‘Yes’, what other roles do they cover?

Hospital DSN	
Nurse Consultant in diabetes	
Community DSN	
Diabetes Healthcare Assistant	

21. Are there other hospital based nurses engaged in specialist diabetes service provision?
Yes No

22. If ‘Yes’, please tick all that apply

Diabetes nurse facilitator	□
Other	□

23. If ‘Other’, please state

24. Paediatric Diabetes Specialist Nurses (PDSN):

How many separate PDSNs are there?	
How many have a paediatric qualification	
What is the WTE of the PDSN(s)	
Number of children under 18 per PDSN	

25. Do any of the DSNs or Nurse Consultants have a formal role in diabetes research?
Yes No

26. If ‘Yes’, please give details

27. Have the diabetes nurses been banded?
Yes No

28. Please state the number of nurses in each band:
Please write the WTE

Band 5	
Band 6	
Band 7	
Band 8	
Band 9	

29. Please state the number of nurses who were in the old Grades:

Grade D	
Grade E	
Grade F	
Grade G	
Grade H	

30. What are their specific clinical roles?

	Hospital DSN	Nurse Consultant in diabetes	Community DSN	PDSN
Patient management				
Prescribing				
Does adjustment only				
Education for nursing staff				
Education for medical staff				
Education for other allied health professionals				
Education for patients				
Pump training				
Hypertension clinics				
Foot clinics				
Inpatient work				
Ante-natal				
CVD				
Renal clinics				
Non-medical prescribing				
Pre-assessment clinics prior to surgery				
Other				

31.If ‘other’ please specify

32.What do Support Nurses/ Diabetes Care Technicians/ Facilitators etc carry out at clinic?

	Yes	No
Visual acuity	☐	☐
Weight-Height-BMI	☐	☐
Waist	☐	☐
Urine check	☐	☐
BP	☐	☐
Foot screening	☐	☐

Pre-conception discussion	☐	☐
Medication review	☐	☐
Check injection sites	☐	☐
Smoking cessation advice	☐	☐
Exercise advice	☐	☐
Other	☐	☐

Q33. If ‘other’ please state:

Q34. Are there independent diabetes nurse-let clinics available?
Yes No

35. If ‘Yes’, how many nurse-led clinics are held each week?
☐ 0
☐ 1
☐ 2
☐ 3
☐ 4 and over

Q36. Nurse prescribing: How many nurses are…

	Number of nurse
On a course in nurse prescribing?	
Are qualified in nurse prescribing?	
Are putting prescribing into practise?	

37. If nurses are qualified and not using prescribing, please describe who not?

38. Is there any restriction on self-monitoring of blood glucose?
Yes No

39. If ‘Yes’, how has this operated?
☐ Guidance to patients from primary care organisation
☐ Guidance to patients from GP
☐ Guidance to patients from Acute Trust
☐ Informal

40. Do the hospital DSNs have a liaison role with Primary Care Practice Nurses?
Yes No

41. Any other comments (regarding work settings)?

In-patient Diabetes Care

42. Do all people with diabetes admitted to hospital have ready access to specialist diabetes team support?
Yes No

43. is there a designated ward for specific diabetes related in-patient admissions?
Yes No

44. Do bed managers routinely transfer diabetes-related hospital admissions to the designated diabetes ward?
Yes No

45. Is there a discharge follow-up pathway to primary care for ward discharges?
Yes No

46. Is there a discharge follow-up pathway from wards to diabetes out-patient specialist care?
Yes No

47. Is there a written job description for the role of hospital DSN?
Yes No

Hospital Diabetes Service – Clinic Facilities

48. Are interpreting services available?
Yes No

49. Are there out-of-hours diabetes sessions?
Yes No

50. If ‘yes’,

	Yes	No
At weekends	☐	☐
In the evenings	☐	☐

51. What in-house telephone helpline service is available?
☐ Universal
☐ Specialist patient group
☐ Pregnancy
☐ Paediatric telephone helpline
☐ None

52. When is the helpline available?
☐ Weekday office hours
☐ Weekend office hours
☐ Weekday evenings
☐ 24hrs – 7 days a week

53.Which members of staff operate the helpline?

- ☐ Hospital DSNs
- ☐ Secretaries
- ☐ Junior medical staff
- ☐ Education centre staff
- ☐ Consultant
- ☐ Members of Multi-disciplinary team
- ☐ Podiatrist
- ☐ Dietitian

54. Are general diabetic clinics (i.e. not sub-speciality clinics) operated?
Yes No

55. If ‘Yes’, is there an independent nurse-run clinic list?
Yes No

56. If ‘Yes’, is the independent nurse-run clinic list a costed activity?
Yes No

57. Who is generally available for diabetes support in diabetes clinics?

Consultants	
SpRs or equivalent	
Hospital DSNs	
Community DSNs	
Hospital Practitioner/ GPwSI/ Clinical assistant	
Podiatrist	
Orthotists	
Men’s Health Nurses	
Diabetes Health Care Assistant	
Senior House Officer	
Psychologists	
Dietitians	
Associate Specialist	
Other	

Q58. Is a patient held record used?
Yes No

Q59. If ‘Yes’, who fills it in?
Tick all that apply

Patient	☐	Doctor	☐
Hospital DSN	☐	Health Care professional/ Technician	☐

Q60. Are Care Plans developed with patients?
Yes No

Data collection

Q61. Are the following extra activities carried out by nurses recorded?

	Yes	No

Telephone advice	☐	☐
Informal patient drop in activity	☐	☐
Inpatient contact	☐	☐
Multidisciplinary team activity/ meetings	☐	☐

Q62. Which of these activities are measured on a monthly basis?

	Yes	No
Number of telephone contacts for advice	☐	☐
Number of informal patient drop-in visits	☐	☐
Number of inpatient contacts	☐	☐
Number of multi-disciplinary team activity/ meetings	☐	☐

Q63. Please estimate the percentage of time per month spent on each of these activities:

Telephone advice	
Informal patient drop in activity	
Inpatient contact	
Multidisciplinary team activity/ meetings	

Education, Structured Education and staff CPD

Q64. Are education sessions for patients and carers available?
Yes No

Q65. If Yes, where is education provided?
Tick all that apply
☐ in Primary Care
☐ in Acute Trust

Q66. Which topics are covered in education programmes

Nature of diabetes	☐	Why metabolic control is important	☐
Carbohydrate dose adjustment	☐	Impact of diet/ exercise	☐
Coping with diabetes during illness	☐	Footwear	☐
Contraception	☐	Driving	☐
Insurance	☐	Employment	☐
Injection technique	☐	Prescription charges	☐
Travel	☐	Pre-conception counselling	☐
Hypoglycaemia	☐	Erectile dysfunction	☐
Smoking	☐	Alternative intensive Mtg scheme	☐
Home blood monitoring	☐	Home urine monitoring	☐
Group initiation of insulin	☐	Other	☐

Q67. If ‘other’ please specify

Q68. How is education provide?

	New Type 1 diabetes	New Type 2 diabetes	Ongoing Type 1 diabetes	Ongoing Type 2 diabetes
One to one	☐	☐	☐	☐
In a group	☐	☐	☐	☐
Information provision	☐	☐	☐	☐
E-learning	☐	☐	☐	☐

Q69. Who plans and delivers education sessions?
Tick all that apply

	Plans education sessions	Delivers education sessions
Hospital DSN	☐	☐
Medical Staff	☐	☐
Podiatrists	☐	☐
Dietitians	☐	☐
Pharmacists	☐	☐
Diabetes nurse educator	☐	☐
Other	☐	☐

Q70. If ‘Other’, please specify

Q71. When are education sessions held?

☐	Weekdays	☐	Weekends
☐	Evenings	☐	Other

Q72. How often are education sessions held?

☐	Twice a week	☐	Once a week
☐	Every two weeks	☐	Once a month
☐	Less frequently than once a month		

Q73. Is structured education provided (as per NICE guidance)?
Yes No

Q74. If ‘Yes’, what is the name of the structured education programme provided?

Q75. How is the course being quality assured?

Q76.
Is the NDST and Diabetes UK self assessment tool being used?

Q77. How is the course peer reviewed?

Q78. Education courses are provided for which of the following groups?
Tick all that apply

☐	Type 1 newly diagnosed	☐	Type 1 ongoing
☐	Type 2 newly diagnosed	☐	Type 2 ongoing
☐	People with severe mental illness	☐	Disability
☐	Children and parents	☐	Older people
☐	Refugees and asylum seekers	☐	Homeless
☐	Prisoners with diabetes	☐	Travelling community
☐	People with language barriers	☐	Black and minority ethnic groups
☐	Young adults/ teenagers	☐	Other
☐	None of these		

Q79. Do staff have protected time for continuing professional development
Yes No

Q80. Is there a protected budget for diabetes continuing professional development?
Yes No

Appendix E - Diabetes UK / NHS Diabetes National Survey of Diabetes Specialist Nurses 2009

Diabetes UK / NHS Diabetes National Survey of Diabetes Specialist Nurses 2009

Surname:		**NMC number**	
Forename:		**DOB:**	
Email address:			
Current job title:			

Charlotte Gosden
Diabetes UK
Freepost RLXE-CRYS-HBXB
London NW1 7AA

This address is placed here to help return in a window envelope if required BY 27th November 2009:
Alternatively you can fax 020-7424-1001
OR email: charlotte.gosden@diabetes.org.uk

Employing Trust or other	
Base Address	

Question 1: Post basic qualifications (please tick if held):

	Yes		**Yes**
Diabetes Diploma / Certificate	☐	Diabetes counselling course	☐
Diabetes related degree (completed)	☐	Non-medical Prescribing course	☐
Diabetes related Masters (completed)	☐	PhD completed or undertaking	☐
Ad hoc modules Degree	☐	Other	☐
Ad hoc modules Masters	☐	If Other, please specify	

2. Years of DSN experience		**5. Current banding:**	
3. Anticipated Retirement date (eg 2020)		**6. Top of band** (please circle):	Yes / No
4. Hours worked per week in current diabetes post		**7. Present appointment type** (please circle one)	NHS University Pharmaceutical Other

8. In what setting(s) do you currently work?

	Hospital	**Community**	**Other, please specify**
Hours / week			Hours……………………………………………….. Setting……………………………………………….

9. How many hours per week is spent working on each of these:?

	General Adult	**Paediatric**	**Inpatient**	**Research**	**Other, please specify**
Hours / week					Hours…………….. ROLE………………

10. Is there a clinical lead for your service? Please circle correct answer	Yes No	**11. If Yes, is this either** Please circle correct answer	Consultant GPwSI Other
		If other, please specify	

12. If you are the LEAD NURSE, please complete this section around your local service:

	Posts Vacant/ Frozen / unfilled after advert	**Reason**	**WTE**	**Band**
1				
2				
3				
4				
5				

Comments: Thank you very much

Appendix F - Paediatric and Adolescent services for Diabetes in the UK 2008

Paediatric and Adolescent services for Diabetes in the UK 2008

Question 1. How would you describe yourself?
General paediatrician
Paediatrician with special interest in diabetes
Paediatrician with special interest in diabetes and endocrinology
Paediatric diabetologist or endocrinologist

Question 2. Where do you see children with diabetes?
General paediatric service
Paediatric diabetes service
General diabetes service

Question 3. If other, please specify – see above

Question 4. Does the service have clinics at more than one location? Yes/ No

Question 5. If yes, please name the geographical location of each clinic

Question 6. Please write the name of each commissioning body served by the paediatric diabetes service

Question 7. How many consultants are involved in the service?

Question 8. How many programmed activities are dedicated to diabetes per consultant?

Question 9. If known, how many programmed activities are dedicated to diabetes per consultant?

Question 10. How many children and young people with diabetes are looked after by the service?
By Service

By Clinic

Question 11. Did the service contribute to the National Paediatric Diabetes Audit in 2006? Yes/No

Question 12. Does the service have local protocols for children and young people with diabetes in the following situations?

BSPED protocol for diabetic ketoacidosis Yes/No
Hypoglycaemia
Surgery
Sick day rules

Question 13. Does the service run local 'fun days' or holidays for children and young people with diabetes?

Fun day Yes /No
Weekend camp
Week away

Staffing levels

Question 14. Does the service provide training in diabetes for paediatric trainees? Yes/No

Question 15. If yes, how much time do trainees spend in the paediatric endocrinology and diabetes service?

Question 16. Do PDSNs attend the service? Yes/No

Question 17. What is the whole time equivalent of PDSNs for the service?

Question 18. What is the WTE of adult trained DSNs who support the paediatric service?

Question 19. If the service is supported by a PDSN, do they work solely in paediatric diabetes? Yes/No/ N/A

Question 20. If the service is supported by a PDSN, do they work in both community and hospital clinics? Yes/No/ N/A

Question 21. Are children and young people with Type 1 diabetes offered appropriate dietetic support to help optimise body weight and glycaemic control?
Yes/ No

Question 22. If yes, how many dietitian sessions are available to the service? Analyse by clinic

Diagnosis and initial management

Question 23. Does the service have a diabetes register?
Yes, an electronic register
Yes, a paper based register
No register available
Both electronic and paper register

Management from diagnosis

Question 24. Does the service offer children and young people with Type 1 diabetes and their family's 24-hr access to advice from the diabetes care team?
Yes/no

Question 25. Does the service involve children and young people with Type 1 diabetes and their families in making decisions about the package of care provided by the diabetes team?

Yes, through a written care plan
Yes, but not written

No

Question 26. Where are the majority of children managed at time of diagnosis if they are well at presentation?

At home	Yes/No
As an inpatient	Yes/ No

Question 27. Are children and young people newly diagnosed with Type 1 offered a structured education programme? Yes/No

Ongoing management – education

Question 28. Are children and young people offered timely and ongoing opportunities to access information about the development, management and effects of Type 1 diabetes?
Yes/ No

Question 29. Are young people who drink alcohol…?
Offered an alcohol education programme? Yes/ No
Advised to eat food containing carbohydrate before and after drinking? Yes/ no
Advised to monitor blood glucose levels regularly? Yes/ no

Question 30. Are children and young people…
Informed about general health problems associated with smoking? Yes/ No

Offered smoking cessation programmes?	Yes/ no
Advised about driving?	Yes/ No
Given contraceptive advice?	Yes/ no

Question 31. Comments on education

Insulin regimens

Question 32. Does the service offer the following insulin regimens?
Twice a day insulin injections
Three times a day insulin injections
Multiple daily injection regime
Continuous subcutaneous insulin infusion

Question 33. Is there a trained specialist team available to initiate insulin pump therapy? Yes/ No

Trained specialist team to initiate pump therapy? Yes/No

Question 34. How many children and young people in the service are using a pump?

Monitoring glycaemic control

Question 35. What is the mean annual HbA_{1c} **for children and young people under 16 years old?**

Question 36. Are children and young people informed that the target for long-term glycaemic control is an HbA_{1c} **level of less than 7.5%?** Yes/ No

Question 37. What target HbA_{1c} **does the service aim for?**

0-5yrs HbA_{1c} **target**
6-11 HbA_{1c} **target**
12 and older HbA_{1c} **target**

Question 38. How often does the service recommend children and young people test their blood glucose level?

	Testing for twice a day injections	Testing for three times a day injections	Testing for multiple daily injections	Testing for cont sub insulin infusion
2-3 times				
3-4 times				
>4 times				

Question 39. Are HbA_{1c} **measurements available at the time of the outpatient clinic?**
Yes always
Yes sometimes
No never

Question 40. Are children and young people with HbA_{1c} **levels consistently above 9.5% offered additional support?** Yes/ No

Question 41. Does the service follow NICE guidance for optimal targets for short-term glycaemic control (pre-prandial 4.8mmol/litre and post-prandial less than 10 mmol/litre)?

0-5yrs	Yes/No
6-11 yrs	Yes/No
12yrs and over	Yes/No

Question 42. Do children and young people have access to continuous glucose monitoring systems for persistent hypoglycaemia unawareness, repeated hypoglycaemia or hyperglycaemia?
Yes/ No

<u>Screening for complications and associated complications</u>

Question 43. Do children and young people have screening for:
Coeliac disease at diagnosis
Coeliac every 3 years until transfer
Thyroid disease at diagnosis
Thyroid annually after diagnosis
Retinopathy annually from 12 years
Microalbuminuria annually from 12 yrs
BP annually from 12 yrs

Question 44. If the thyroid function is not tested annually, what is the current modus? Please tick as appropriate

- Ad hoc
- Every 3 years
- Based on thyroid Ab detection
- Other

Question 45. Are children and young people offered?
Annual foot care review Yes/ No
Investigation of the state of injection sites at each clinic visit Yes/ No

Question 46. Is the national retinal digital photographic programme available for all young people over the age of 12yrs in your service? Yes/ No

Question 47. If no, when will this be available? Please tick as appropriate
By December 2008
By 2009 or later

Question 48. If no, what methods are used to carry out retinopathy screening? Please tick all that apply

	Tick
Retinal photography	
Non dilated fundoscopy	
Dilated fundoscopy by paediatrician	
Dilated fundoscopy by ophthalmologist	
Other, please specify	

Question 49. If other, please specify

Question 50. If yes, what is the uptake by children and young people with diabetes for screening?

Question 51. If yes, what are the factors that have influenced the uptake?

<u>Psychological support</u>

Question 52. Does the service have a psychological professional who works as an integrated member of the diabetes team? Yes/ No

Question 53. If yes, what is the WTE of a psychological professional available to the diabetes service?

Question 54. If there is no dedicated psychological professional as part of the service, to who are referrals made? Please tick all that apply

By service

	Tick
Clinical psychologist	
Health psychologist	
Psychotherapist	
Psychiatrist	
Counsellor	
Nurse therapist	
Social worker	
Family therapist Other	

Question 55. What is the average waiting time for an appointment?

Question 56. Do you refer to psychological services for the following?

	Yes	No	Would do if service available
Problems with self-management			
Recurrent DKA			
Low BMI			
Eating disorders (bingeing, bulimia, anorexia)			
Disordered eating (eg skipping meals)			
Morbid obesity			
Depression			
Needle phobia			
Anxiety			
Drug and alcohol problems			
Psychotic illnesses			
Psychosexual problems			
Domestic violence and sexual abuse			
Suicidal patients and self harm			
Family difficulties			
Communication problems with the family /team			

Question 57. Do children and young people with Type 1 diabetes who have frequent hypo's and/or recurrent seizures have access to neuro-psychological assessments?
Yes/ No/ Would if service was available

Question 58. Does your service have a psycho-educational programme (e.g. one that is structured, group based, and covers all aspects of diabetes care and management in relation to the family)?
Yes/ No

<u>Continuity of care</u>
Question 59. Are children and young people offered information and contact details of local diabetes support groups and organisations? Yes/ No

Question 60. Does the diabetes team liaise regularly with school staff who supervise children and young people to offer diabetes education and information? Yes/ No

Question 61. Are children and young people advised how to obtain information about disability benefits? Yes/ No

Transfer from paediatric to adult services

Question 62. Are there specific local protocols agreed for transferring young people with Type 1 diabetes from paediatric to adult services? Yes/ No

Question 63. Does the paediatric care team organise age-banded clinics? Yes/ No

Question 64. Are young people with Type 1 given sufficient time to familiarise themselves with the practicalities of transition from paediatric to adult services?
Yes/ No

Question 65. Which of the following models of transition does the service use

- Repeated joint clinic with adult colleague, then gradual transfer
- One-off joint clinic with adult colleague, then transfer
  Adult diabetologist in paediatric clinic, then transfer
- Paediatrician attends adult clinic with patient for handover
- Paediatrician runs separate transition clinic in adult diabetes centres
- Transfer only between consultants by letter
- Adult nurses meet patient before transfer
- Transfer to GP care only
- Other

Question 66. If other, please specify

Question 67. At what age does the transition process approximately start and finish
Analyse by clinic
Start:
Finish:

Schools

Q68. To what extent have staff from the service found arranging for children to do their own BG testing at school?

Primary school
Very easy Easy Neither easy or difficult Difficult Very difficult

Secondary school
Very easy Easy Neither easy or difficult Difficult Very difficult

Question 69. To what extent have staff from the service found arranging for children and young people to give their own insulin injections at school?

Primary School
Very easy Easy Neither easy or difficult Difficult Very difficult

Secondary school
Very easy Easy Neither easy or difficult Difficult Very difficult

Question 70. To what extent have staff from the service found arranging someone at the primary school who is willing to carry out BG testing?
Very easy Easy Neither easy or difficult Difficult Very difficult

Question 71. To what extent have staff from the service found arranging someone to perform insulin injections in primary schools?
Very easy Easy Neither easy or difficult Difficult Very difficult

Question 72. If the child is not able to inject themselves, who currently provides this support in school if necessary?

- Parent
- School nurse
- Teacher
- First aider
- Relative
- Other school staff

Comments

Question 73. If you would like to provide any other comments about the paediatric service, please state them below?

Appendix G - Well-resourced score update questionnaire 2011

Well resourced score update questionnaire

Name of Trust: ________________

	Name	Telephone no	Email address
Consultant Diabetologist			
Lead DSN			`

1. What is the catchment population for the specialist diabetes service?
2. Please state the number of whole time equivalent (WTE) consultants
3. Please state the number of WTE hospital diabetes specialist nurses
   Community DSNs – 3.8 transferred
4. What WTE dietitian availability is there for the specialist diabetes service?
5. What WTE podiatrist availability is there for the specialist diabetes service?
6. Does the diabetes service have a diabetes register? Yes/No
7. Is there a joint ante-natal diabetes service? Yes/No
8. Is there a joint diabetes-ophthalmology clinic in the specialist diabetes service? Yes/No
9. Are there separate diabetes clinics for the elderly? Yes/No
10. Is there a local vascular surgeon in your hospital? Yes/No
11. Are lipids measured in your specialist diabetes service? Yes/No
12. Is microalbuminuria available in your specialist diabetes service? Yes/No
13. Is HDL measured in your specialist diabetes service? Yes/No
14. Is there a specific service for erectile dysfunction? Yes/No
15. Is there a joint paediatric and adult specialist diabetes service? Yes/No
16. Are there guidelines to ensure comprehensive diabetes care in all settings? Yes/No

17 .Is structured education offered to people with diabetes? Yes/No

18. Based on these questions, how well resourced do you feel your specialist diabetes service to be?

Well resourced   Reasonably well resourced   Not well resourced

19. Do patients have access to emotional and psychological support? Yes/No
20. Is the specialist service engaged in commissioning through the local diabetes network? Yes/No

Thank you for taking the time to complete the questionnaire

Please return in the self-addressed envelope by 13th May 2011 to:

Charlotte Gosden, The Lodge, Hyde Street, Upper Beeding, West Sussex, BN44 3TG.

Appendix H - An update of diabetes specialist services 2011 topic guide

An update of diabetes specialist services 2011

Part 2
Semi-structured telephone interview

Introduction

Thank you for taking the time to talk to me today about your diabetes service. I hope you received the email with the questions that I am hoping we can cover in today's conversation and I am anticipating that this will take up to 30 minutes.

I am aiming to speak to four other services in England and write up the findings as case studies for my doctoral thesis, which is being supervised by Professor Richard Holt and Professor Rhys Williams, and also as a report for Diabetes UK. The results will also be published in an academic journal and submitted for presentation at the Diabetes UK Annual Professional Conference. Your location and identity will be anonymised and remain confidential in any report I write on the issues raised in our discussion.

For the purpose of our records and analysis, I will be making notes during the interview and will record the conversation to make sure that I do not miss any important points .

Background information

Name of Consultant/ DSN

Duration of employment at the diabetes service/ if Consultant or DSN was not working at the same Trust when the 2006 survey took place, where was the Consultant working at that time.

Description of the Trust/ PCTs that use the Trust

Interview with the Diabetes Consultant

Status of the diabetes service

When considering the status of your diabetes service, what in your view, are the most pressing issues today?

Probe:
Specific diabetes services poorly/well supported
Effect of restructuring
Job security/ Staffing levels/ pressures of acute medicine
Increased/ decreased workload
IT
Links with primary care/ integrated service
Services under threat due to commissioning
Variable service quality

Strengths/ weaknesses and issues within the specialist service

What do you think are the main strengths, weaknesses, threats and opportunities and issues within your specialist service?

For example, in 2006 services identified expert, motivated staff, good links with primary care and comprehensive well organised services as strengths and in your location, XXX were identified.

Please offer three main strengths of your specialist service	
1	
2	
3	
Please offer three main weaknesses of your specialist service	
1	
2	
3	
Please offer three main threats of your specialist service?	
1	
2	
3	
Please offer three main opportunities of your specialist service?	
1	
2	
3	

Retinal screening

With regards to retinal screening, what if any, are the current problems/ issues with retinopathy screening locally?

For example, in 2006:

lack of funding, lack of proper organisation, disruption of an old scheme, IT support were seen as issues? Are these still current today? What else would they be?

Emotional and psychological support

In your opinion, what gaps are the in services for people with diabetes who have emotional, psychological or mental health problems?

In 2007 the issues identified included:
Only 2.6% complied with all 6 NSF/ NICE guidance recommendations
Diabetes MDT wanted expert psychological input
Often access to support was only in form of generic services
Often no access to telephone advice/ to screening and assessment tools or protocols or guidelines
Long waiting times from referral

NHS restructuring
What in your view will be the impact of the current changes to GP consortia commissioning on diabetes specialist services if these suggested changes should go ahead?

How do you think that the issues facing your specialist diabetes service have changed in the last five years?

Probe: aspects of diabetes service such as: care processes, emotional and psychological support and care, retinal screening, dietetic and podiatry support,

In 2006, many services expressed concern over the fragmentation of diabetes services, how would you describe the integration of care and joint working with primary care in your service?

What in your view are the prospects of delivering the NSF in 2013 at the current time within your diabetes service?

Close
Thank you very much for your time today, I will be writing up the notes from today and may be in touch again to verify some of the data to ensure I have accurately noted down our conversation. If you have any questions in the meantime or wish to make any changes, please do not hesitate to contact me. If you would like a report of the findings overall, I will be happy to post this to you in due course.

Diabetes Specialist Nurse
In addition
What in your view are the best and worst issues of DSN post and/or most pressing concerns?

Please offer three main strengths of your specialist service	
1	
2	

3	
Please offer three main weaknesses of your specialist service	
1	
2	
3	
Please offer three main threats of your specialist service?	
1	
2	
3	
Please offer three main opportunities of your specialist service?	
1	
2	
3	

Probe:
Changing clinical role
Training/ Qualifications/ Standards required to be a DSN
Prescribing/ ability to carry out prescribing
Opportunities for cross-working with primary care
Access and funding for CPD

Close
Thank you very much for your time today, I will be writing up the notes from today and will be in touch again to verify some of the data to ensure I have accurately noted down our conversation. If you have any questions in the meantime or wish to make any changes, please do not hesitate to contact me. If you would like a report of the findings overall, I will be happy to post this to you in due course.

Appendix I - Index for coding interviews

Index used for coding interviews, data from 2000 surveys and re-code 2006 data		
Theme 1		
Service redesign and experience of change	**Numbers**	**Code**
	3.1	Fragmentation of diabetes service
	3.2	Shift to primary care
	3.3	Lack of PCT interest in specialist diabetes services
	3.4	Restructure of diabetes service
	3.5	Working in new teams
	3.6	Working in new locations
	3.7	Relationships with key personnel
	3.8	Working differently
	3.9	New models of care
	3.10	Adaptable teams
	3.11	Service and personnel cuts
	3.12	Demonstrate value/ relationships to money
	3.13	Working relationship with primary care
	5.1	GP consortia commissioning
	5.2	Degree of change in issues
	5.3	Pace of change
	5.4	Circle of changes
	5.5	Stimulus to change
	5.6	Place in the process of change (start, middle)
	5.7	Cultural change and boundaries demolished
	5.8	Change in philosophy
	5.9	Change in priorities
	5.10	Destructive force
	5.11	Proactive
Theme 2		
Team dynamics		
	1.7	National political presence
	1.8	Clinical competency
	1.9	Non multidisciplinary knowledge of diabetes
	1.10	Upskilling non multidisciplinary healthcare professionals
	1.11	Issues relating to teams
	1.13	Attitudes to change (reluctance)
	1.14	Perceptions defining team strengths/ weaknesses
	1.15	How we position ourselves for future (savvy)
	1.16	Team ethos
	1.17	Multidisciplinary staffing levels
	1.18	Gaps in workforce
	1.26	Team morale
	1.27	Workforce planning
	1.28	Professional pride
	1.42	Lack of knowledge
Theme 3		
Ability to do my job		
	1.1	Pressure from increased numbers of patients
	1.2	Pressures on workload

	1.3	Job function
	1.4	Managerial pressure
	1.5	Leadership capabilities
	1.6	Relationship with research
	1.12	Impact of new technology
	1.19	Care of person with diabetes
	1.20	Patients slipping through the net
	1.21	Lack of IT support
	1.22	Shared electronic access to data
	1.23	Specific diabetes services
	1.24	Effect of local demographics
	1.25	Postcode lottery/ service inequalities
	2.1	Integration with primary care
	2.2	New provider competitors
	2.3	Commissioner demands and expectations
	2.4	Trivialisation of diabetes and specialist services
	2.5	Lack of financial resources
	2.6	Incentives
	2.7	Uncosted activities
	2.8	Lack of workforce planning
	2.9	Organisational infrastructure
	2.10	Diabetes prioritised
	4.1	Delivery of standards
	4.2	Impact of government policy changes
	4.3	Use of performance management tools
	4.4	Quality of care
Theme 4		
Emotion		
	1.29	Anxiety
	1.30	Frustration
	1.31	Goodwill
	1.32	Power
	1.33	Confrontation
	1.34	Committed and motivated staff
	1.35	Group effort/ team work/ close relationships
	1.36	Negotiation
	1.37	Suspicion, a bit like poker/ sceptical
	1.38	Seeing the benefit
	1.39	Positive way forward
	1.40	Higher aspiration to provide more services to before/ strive
	1.41	Taking more responsibility (for patients in service redesign)
	1.43	Protective
	1.44	Disappointment
	1.45	Uncertainty
	1.46	Expectations
	1.47	Negative impact of retirement/maternity leave/holidays

Appendix J – Comparison of strengths, weaknesses, opportunities and threats identified in 2000, 2006 and 2011

Strengths			
	2000	**2006**	**2011**
Leicester Royal Infirmary 2000 ID 99 2006 ID 502	No response	1.16 team ethos and team work (teamwork across the patch) 2.1 Integration with primary care (consultant clinics in community hospitals) 1.23 specific diabetes services (guidelines on website)	1.34 committed and motivated workforce 1.8 clinical competency 4.4 quality of care 1.6 relationship with research 3.10 adaptable team
Pinderfields 2000 ID 296 2006 ID 228	2.1 Integration with primary care (co-ordinated, good links with primary care; good LDSAG) 1.23 specific diabetes services (continuous education, good education, diabetes register) 1.19 care of person with diabetes (patients like the services)	3.7 relationships with key personnel (managed network) 1.23 specific diabetes services (diabetes register) 1.16 team ethos and team work (excellent team work)	2.1 Integration with primary care (making strides through team without walls) 1.23 specific diabetes services (comprehensive set of services especially structure education) 1.16 team ethos and team work (excellent workforce)
Wythenshawe hospital 2000 ID 359 2006 ID 386	1.34 committed and motivated (excellent dedicated staff) 1.23 specific diabetes services (good register) 2.9 organisational infrastructure (diabetes centre for patient education) 1.23 specific diabetes services 9interesting subspeciality mix with cardiovascular medicine and CF related diabetes)	1.34 committed and motivated workforce (motivated) 1.23 specific diabetes services (good education) 1.8 clinical competency (highly skilled teams)	1.34 committed and motivated workforce 1.23 specific diabetes services (good education) 1.8 clinical competency
Heart of England 2000 ID 25 2006 ID 158	1.23 specific diabetes services (Service well developed, fulfilling most of the recommendations from the various professional bodies)	1.35 Group effort, team work , close relationships (multiprofessional team; joint working with other specialities)	5.2 degree of change in issues, (still top three same as before) 1.35 Group effort, team work , close relatonships (multiprofessional team; aspiring to do more) 1.16 team ethos (Multidisciplinary approach) 1.14 perceptions defining team strengths/ weaknesses (able to do more now) 1.23 specific diabetes services (able to do more) Joint working with other specialities 1.6 relationship with research (academic side, plus get referrals, they use the profile of the department, 1.7 national presence (we are seen as leaders)

		1.6 relationship with research (academic side)	1.38 seeing the benefit (about to be involved in diabetes education locally and nationally)
Hull **2000 ID 428** **2006 ID 178**	1.23 specific diabetes services (we have a virtually full range of services)	3.7 relationships with key personnel (good manager who has joint secondary and primary care links) 1.34 committed and motivated workforce (good morale considering context) 1.23 specific diabetes services (focus on structured education)	1.34 committed and motivated workforce 1.23 specific diabetes services 3.9 new models of care 4.4 quality of care 1.38 seeing the benefit

Weaknesses			
	2000	**2006**	**2011**
Leicester Royal Infirmary 2000 ID 99 2006 ID 502	2.9 Organisational infrastructure (no dedicated centre; poor outpatient facilities)	1.23 specific diabetes services (psychology support – none; telephone helpline ; inpatient diabetes)	1.23 specific diabetes services (psychology) 1.22 shared primary and secondary electronic access to data
Pinderfields 2000 ID 296 2006 ID 228	1.23 specific diabetes services (variable retinal screening; no psychology input; education could be better) 2.5 lack of resources (little support for expansion) 1.18 gaps in the workforce (DSN services bursting to its capacity)	1.23 specific diabetes services (lack of psychological service; patient education could be better) 1.2 Pressures on workload (workload)	1.23 specific diabetes service (inpatient service; skeleton psychological service) 4.3 use of performance management tools/ 4.2 impact of government policy changes (lack of available information on outcomes, patient episodes)
Wythenshawe hospital 2000 ID 359 2006 ID 386	3.7 relationships with key personnel (poor communication between primary and specialist care; poor co-operation with some specialities) 2.5 lack of resources (poorly funded - very high demand from tertiary referral services elsewhere in the trust ie cardiothoracic medicine and surgery, transplant and CF unit) 1.2 pressures on workload (heavy demands for general medical service - not enough consultant time) 1.21 Lack of IT support (outdated computer system)	4.2 impact of Government policy changes (political footballs) 3.7 relationships with key personnel (poor communications) 3.3 Lack of PCT interest in specialist diabetes services (not valued)	3.1 fragmentation of diabetes services 3.7 relationships with key personnel (poor communications) 3.5 working in new teams (how overcoming the weakness) 3.3 Lack of PCT interest in specialist diabetes services (not valued) 1.30 frustration
Heart of England 2000 ID 25 2006 ID 158	1.2 Pressures on workload (DSN service particularly finding difficulty coping with increasing activity and expectations)	1.27 workforce planning (not enough nurses, not enough secretarial support) 3.4 restructure of diabetes services (integration of services with one of our PCTs)	5.2 degree of change in issues (weaknesses are still relevant but changed slightly) 3.9 new models of care 1.18 gaps in workforce (not enough secretarial support; deficiencies in auxiliary nursing services) 1.21 lack of IT support (lack of database of patients) 1.24 effect of local demographics (reaching out to South Asian population, services could be tailored to local population, only one Asian link worker) 1.30 Frustration (lack of database is big weakness)
Hull 2000 ID 428 2006 ID 178	2.5 Lack of financial resources (because of service pressures, patient education is suffering and getting worse rather than better; need to have investment if retinopathy screening to cover all of population at risk)	1.23 specific diabetes services (under-resourced psychology service; reaching patients on other wards in trust)	1.25 postcode lottery and service inequalities (depending on who commissions what services) 2.3 commissioner demands and expectations (PCT lagging behind in tackling commissioning issues) 1.2 pressures on workload (acute medicine) 1.30 frustration

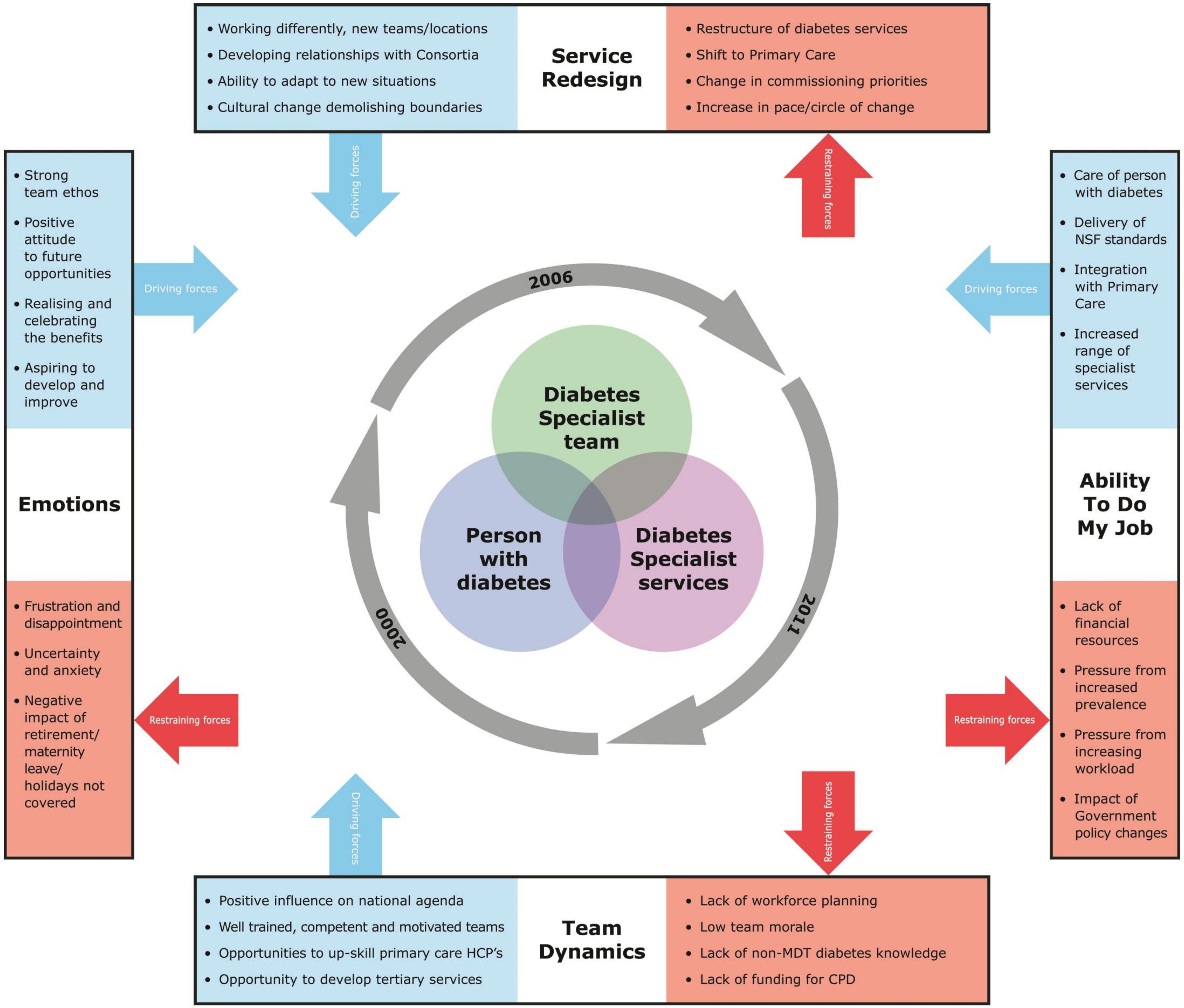
Opportunities			
	2000	**2006**	**2011**
Leicester Royal Infirmary 2000 ID 99 2006 ID 502	Not identified	Not identified	5.1 GP consortia commissioning (Commissioning clinical services) 1.7 national political presence (staff development, new modules and training influence national agenda) 1.10 upskilling non mdt HCPs (training packages for primary care to be appropriately skilled) 3.6 working in new locations (I see our role in primary care, doing a clinic) 3.9 new models of care (nurse led clinics in primary care and consultants, successful pilot)
Pinderfields 2000 ID 296 2006 ID 228	1.15 how we position ourselves for the future (need to think about how diabetes services will links with PCG's; how best to evolve the role of DSNs into a major education resource for Primary Care; outcome based practice)	Not identified	2.1 Integration with primary care (building on the links with primary care) 1.10 Upskilling non-MDT HCPs (opportunities for education, training, upskilling practice nurses and GPs) 1.1 pressure from increased numbers of patient (new model of upskilling to deal with this) 3.9 new models of care (possibility of sub-specialisation) 3.10 adaptable teams (look at different ways of linking up specialist with community service) 1.39 seeing the positive way forward (always with reorganisation, there are opportunities)
Wythenshawe hospital 2000 ID 359 2006 ID 386	3.9 new models of care (starting up new specialist clinics) 3.13 working relationships with primary care (developing links with primary care)	5.11 proactive working (lots of changes and developments)	3.8 working differently (biggest opportunity working closely in community) 1.46 expectations (working slightly differently is the opportunity) 2.1 integration with primary care (reunited as one team this year) 1.17 MDT staffing levels (manpower increased) 3.4 restructure of diabetes service (reconfigure across primary and secondary care) 1.11 issues relating to teams (important patients seen by right person with

			right skills immaterial of location)
Heart of England **2000 ID 25** **2006 ID 158**	Not identified	Not identified	5.2 degree of change in issues (threats are opportunities turned around) 3.10 adaptable teams (reinvent ourselves, look in a different way) 3.8 working differently (opportunity to develop and free up some time develop highly specialist tertiary centre – having the academic interest) 3.9 new models of care (look beyond traditional diabetes centre, great challenge and opportunity to develop; be owned by the GP, everyone be part of the same organisation) 1.40 higher aspiration to offer more services than before. 1.39 positive way forward (tertiary services)
Hull **2000 ID 428** **2006 ID 178**	Not identified	3.9 new models of care (forward looking models of care)	3.7 relationships with key personnel (cement relationships with GPs 3.8 working differently (cluster level commissioning) 1.36 negotiation (important to agree on psychology, gets missed out) 3.4 restructure of diabetes service (provide guidance to individual commissioning groups)

Threats			
	2000	**2006**	**2011**
Leicester Royal Infirmary 2000 ID 99 2006 ID 502	Not identified	4.2 impact of government changes (payment by results; commissioning) 2.5 lack of financial resources Money (lack of)	5.1 GP consortia commissioning (opportunity and a threat; don't know which way it will go, disinvestment or be commissioned) 5.6 place in the process of change (don't know which way it will go) 3.1 fragmentation of diabetes services (3 consortias, may do different things) 2.5 lack of financial resources 3.11 service and personnel cuts (specialist nurses under review) 1.45 uncertainty
Pinderfields 2000 ID 296 2006 ID 228	3.3 lack of PCT interest in specialist diabetes services (little support for expansion)	4.2 impact of government changes (payment by results) 2.2 new provider competitors (private services) 5.4 circle of changes (repeated reorganisations in primary care)	5.2 degree of change in issues (old threats don't exist anymore) 2.10 diabetes prioritised (diabetes is top priority) 1.2 pressures on workload (acute medicine) 2.5 lack of financial resources 3.2 shift to primary care (possible commissioners will change their mind from what we have agreed) 1.45 uncertainty (can never be sure if agreements will hold)
Wythenshawe hospital 2000 ID 359 2006 ID 386	Not identified	4.2 impact of government changes (politics) 2.5 lack of financial resources (money) 2.4 trivilisation of diabetes and specialist services (not valued) 1.44 disappointment (disillusionment)	2.5 lack of financial resources 1.21 lack of IT infrastructure (to work across hospital and community) 1.30 Frustration (difficult to work in new ways with lack of IT)
Heart of England 2000 ID 25 2006 ID 158	1.1 Pressures from increasing number of patients (number of referrals increasing year on year; average 10% pa increase in activity) 2.5 lack of financial resources (difficult to get in enough resources to cope with increased demand). 3.3 lack of PCT interest in specialist diabetes services (increasing reluctance of purchasers to put extra resource into secondary care service) 1.18 Gaps in workforce (difficulty finding suitable staff at clinical assistant/hospital practitioner grade)	4.2 impact of government changes (payment by results; Government Diktat) 3.3 lack of PCT interest in specialist diabetes service (secondary care not priority for PCTs)	3.12 Demonstrate value / relationships to money 2.3 commissioner demands and expectations (constant threat from commissioners to commission services they want, restricts our innovation and development) 5.10 destructive force (not just hitting the targets, good diabetes management is much more complex) 2.7 uncosted activities (innovations fail if not valued by commissioners) 2.4 trivialisation of diabetes and specialist services (perception that diabetes can be managed by anyone anywhere)

			5.8 change in philosophy (all diabetes should be managed in primary care making a mockery of specialist care) 5.2 degree of change in issues 1.43 Protective 1.30 Frustration 1.27 workforce planning (retirement, not being replaced 1.47 negative impact of retirement, maternity leave, holidays (reduced numbers, difficult to maintain service) 1.8 clinical competency (lack of funding for CPD) 1.36 negotiation (driven by management to make staff do more, but need to care for staff)
Hull 2000 ID 428 2006 ID 178	1.2 Pressures on workload (however we have a major problem with the volume of referral provoked by the lack of primary care diabetes services especially in urban X)	4.2 impact of government changes (payment by results) 1.4 managerial pressure (change in management) 3.3 lack of PCT interest in specialist diabetes service (PCT view diabetes as a low priority) 2.5 lack of resources (Trust and finances) 2.2 new provider competitors (future development of alternative care providers, PFI hospital) 1.27 workforce planning (changes to DSN role difficulties)	2.5 lack of financial resources (expect to get worse) 1.2 pressures on workload (pressures from acute medicine) 2.2 new provider competitors (providers entering market may not have expertise) 1.46 expectations 1.45 uncertainty (destroy good relations overnight taken years to build)

Appendix K - Conceptual framework



Service Redesign

- Working differently, new teams/locations
- Developing relationships with Consortia
- Ability to adapt to new situations
- Cultural change demolishing boundaries

- Restructure of diabetes services
- Shift to Primary Care
- Change in commissioning priorities
- Increase in pace/circle of change

Emotions

- Strong team ethos
- Positive attitude to future opportunities
- Realising and celebrating the benefits
- Aspiring to develop and improve

- Frustration and disappointment
- Uncertainty and anxiety
- Negative impact of retirement/ maternity leave/ holidays not covered

Ability To Do My Job

- Care of person with diabetes
- Delivery of NSF standards
- Integration with Primary Care
- Increased range of specialist services

- Lack of financial resources
- Pressure from increased prevalence
- Pressure from increasing workload
- Impact of Government policy changes

Team Dynamics

- Positive influence on national agenda
- Well trained, competent and motivated teams
- Opportunities to up-skill primary care HCP's
- Opportunity to develop tertiary services

- Lack of workforce planning
- Low team morale
- Lack of non-MDT diabetes knowledge
- Lack of funding for CPD

Appendix L - List of papers, reports and conferences attended

Reports:
Diabetes UK: Minding the gap. The provision of psychological support and care for people with diabetes in the UK, Diabetes UK, London, 2008

Diabetes UK and NHS Diabetes: The Diabetes UK and NHS diabetes workforce database of United Kingdom Diabetes Specialist Nurses and Nurse Consultants factsheet, DSNs: employment trends and workforce planning. NHS Diabetes, February 2010.

Conferences attended:
Speaker:
Gosden C, NDIS Diabetes Information for All: **'**Information for people with diabetes' Diabetes UK Annual Professional Conference, Liverpool 2010.

Oral presentation
Nicholson, T. 'A survey of psychological services for adults with Diabetes in the U.K. Are we meeting National guidance?' Diabetes UK Annual Professional Conference, Glasgow, 2008.

Gosden C, James J, Winocour P, Walton C, Nagi D, Turner B, Williams R, Holt R. 'Diabetes Specialist Nurses, Nurse Consultants and Community DSNs: Roles and Responsibilities', Diabetes UK Annual Professional Conference, Glasgow, 2009

Posters:
Gosden, C, Tinati T, Barnard K, Williams DRR, Holt RIG. 'A decade in diabetes specialist services 2000 to 2011: the views of consultant diabetologists and diabetes specialist nurses amidst continual healthcare delivery change' Diabetes UK Annual Professional Conference, Liverpool, 2014.

Gosden C, James J, Anderson U and Morris N. "Diabetes Specialist Nurses, Employment Trends and Workforce Planning 2009," FEND Federation of European Nurses in Diabetes, 15th Annual Conference, Stockholm Sweden, 2010.

Gosden C, Holt R, Edge J, James J, Turner B, Winocour P, Walton C, Nagi D, Williams R, Matkya K. 'Paediatric diabetes services in the UK. Diabetes UK, Association of Children's Diabetes Clinicians (ACDC), British Society of Paediatric Endocrinologists and Diabetologists (BSPED) and Association of British Clinical Diabetologists (ABCD) survey of Specialist Diabetes Services 2008'. ISPAD Conference, Ljubljana, Slovenia, 2009.

Gosden C, Winocour P, Holt RIG, Turner B, James J, Walton C, Nagi D, Williams DRR 'Diabetologists' perspectives of specialist diabetes services provision and progress since 2000'. Diabetes UK Annual Professional Conference, Glasgow, 2008.

Nagi D, Walton C , Gosden C, Winocour P, Turner B, James J, Holt RIG. 'Action on eyes – progress on the current state of screening services for diabetic retinopathy in England, Wales and Scotland' Diabetes UK Annual Professional Conference, Glasgow, 2008.

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Special Article

Association of British Clinical Diabetologists (ABCD) and Diabetes-UK survey of specialist diabetes services in the UK, 2006. 1. The consultant physician perspective

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Abstract

Aims To identify the views and working practices of consultant diabetologists in the UK in 2006–2007, the current provision of specialist services, and to examine changes since 2000.

Methods All 592 UK consultant diabetologists were invited to participate in an on-line survey. Quantitative and qualitative analyses of responses were undertaken. A composite 'well-resourced service score' was calculated. In addition to an analysis of all respondents, a sub-analysis was undertaken, comparing localities represented both in 2006/2007 and in 2000.

Results In 2006/2007, a 49% response rate was achieved, representing 50% of acute National Health Service Trusts. Staffing levels had improved, but remained below recommendations made in 2000. Ten percent of specialist services were still provided by single-handed consultants, especially in Northern Ireland (in 50% of responses, $P = 0.001$ vs. other nations). Antenatal, joint adult–paediatric and ophthalmology sub-specialist diabetes services and availability of biochemical tests had improved since 2000, but access to psychology services had declined. Almost 90% of consultants had no clinical engagement in providing community diabetes services. The 'well-resourced service score' had not improved since 2000. There was continued evidence of disparity in resources between the nations (lowest in Wales and Northern Ireland, $P = 0.007$), between regions in England (lowest in the East Midlands and the Eastern regions, $P = 0.028$), and in centres with a single-handed consultant service ($P = 0.001$). Job satisfaction correlated with well-resourced service score ($P = 0.001$). The main concerns and threats to specialist services were deficiencies in psychology access, inadequate staffing, lack of progress in commissioning, and the detrimental impact of central policy on specialist services.

Conclusions There are continued disparities in specialist service provision. Without effective commissioning and adequate specialist team staffing, integrated diabetes care will remain unattainable in many regions, regardless of reconfigurations and alternative service models.

Diabet. Med. 25, 643–650 (2008)

Keywords

Abbreviations ABCD, Association of British Clinical Diabetologists; DSN, diabetes specialist nurse; GP, general practitioner; NHS, National Health Service; NSF, National Service Framework; RCP, Royal College of Physicians; WTE, whole time equivalent

Introduction

The provision of services for people living with diabetes in the UK has been the focus of attention since the publication, in England, of the Diabetes National Service Framework (NSF) Standards and Delivery strategy documents in 2001 and 2002

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[1,2], the NSF for Diabetes in Wales [3], the Scottish Diabetes Framework [4] and the Blueprint for Diabetes Care in Northern Ireland [5]. A series of documents in support of commissioning and provision of diabetes services has since been published by the National Diabetes Support Team at the Department of Health [6–8], while at the same time a major shift in service provision from hospital to community care has been an explicit government policy objective [9,10].

Reconfiguration of diabetes care was underpinned by key standards, with implications for both specialist and primary care diabetes services. The introduction of the General Medical Services contract for general practitioners (GPs), with recording of process and surrogate outcome measures of diabetes care through the Quality Outcomes Framework, is reported to have enhanced care for those living with diabetes [11]. Integration of diabetes services across the primary care–specialist interface was another objective of service reconfiguration, along with appropriate resource allocation, staffing and skill mix [1–7].

Just prior to the introduction of the NSF in 2001, the Association of British Clinical Diabetologists (ABCD) undertook an extensive survey of secondary care services for diabetes in the UK [12–15]. The key findings were that over one-third of specialist services were provided by a single-handed consultant physician; that support from diabetes specialist nurses, podiatrists and dieticians was considerably less than had been recommended [16], that retinal screening programmes were not operating in at least 25% of centres, and access to key biochemical testing was far from comprehensive. Another important finding, which the NSF sought to eradicate, was clear evidence of regional variation in key personnel, facilities and specialist diabetes services. There were frequent reports of failed bids for service improvements, especially for dietetic and podiatry support.

In 2004–2005, 89 consultant diabetologists in England were interviewed in a review of the roles, responsibilities, working practices and job satisfaction of consultant diabetologists [17]. This, however, was prior to the impact of the White Paper on 'Shifting the Balance of Power' to the community and the acute financial shortfall for health economies in the UK in 2006 [18]. Challenges were recognized, but job satisfaction was generally high, and there was a clear understanding of the multifaceted roles of consultant diabetologists best met by a pool of specialists working collaboratively. There was a clear desire to engage in service reconfiguration, but frustration that this was impeded by the organizational structures and the ethos of plurality of provision that had been introduced into healthcare.

In 2006, Diabetes UK subsequently undertook a patient survey of its members and a progress survey of commissioning organizations [19]. This revealed high patient satisfaction, but recognition of deficient specialist psychologist support, inadequate retinal screening services, and outstanding issues regarding paediatric and transitional care of young adults with diabetes. There was continued concern that a 'post-code lottery' operated in accessing new therapies and services. Commissioning organizations concurred with the findings regarding psychology support and services for young people and identified a shortfall in resources for patient education. Several challenges that had hindered implementation of the Diabetes NSF were identified, e.g. reductions in funding, organizational change, 'practice-based commissioning' and 'payment by results'.

Given the rapid pace of change in the National Health Service (NHS) and the issues raised by these reports, it was considered vital to establish independently the views of specialists involved in service provision. In late 2005, ABCD, in collaboration with Diabetes UK, developed a series of surveys to review specialist diabetes services throughout the UK. The objectives were to identify existing provision in services and changes since the earlier ABCD survey of 2000. The independent Health Care Commission conducted a review amongst Primary Care Trusts in England during the same time period as our current survey, and reported variable provision of basic needs for people with diabetes, a shortfall in patient exposure to education programmes, and a need to engage all clinical stakeholders in the commissioning of diabetes services [20].

This current survey examined core specialist diabetes services, and focused on the views and working practices of consultant diabetologists throughout the UK, complementing the interviews with consultants in England conducted 12–18 months previously [17] and the report from the Health Care Commission [20].

Methods

An on-line survey was undertaken between May 2006 and February 2007 using the Opinion taker website. The survey was designed by the authors and included both closed and open questions about the provision of acute–general internal medicine and diabetes services. Consultants were asked to respond to three open questions, which in turn gave the opportunity for up to three responses. We ascertained what consultants considered were the main strengths and weaknesses of their specialist service, and the issues that they perceived most threatened the specialist service.

The questionnaire was piloted by the professional committees of ABCD and Diabetes UK. Consultants ($n = 693$) involved in the provision of specialist diabetes and endocrinology services in the UK were identified through the databases of ABCD, Diabetes UK and the Royal College of Physicians (RCP) Manpower Survey. E-mail addresses were obtained from the directories of ABCD, Diabetes UK and other sources available to these associations, and an invitation to complete the on-line survey was sent in May 2006. A reminder was sent in September 2006, with the option of completing a mailed hard copy, and non-responders were contacted by telephone. The survey was publicised through the ABCD and Diabetes UK websites and mail shots.

One hundred and one physicians were excluded (33 provided endocrine services only; 21 had retired; 19 did not provide diabetes services; nine were not consultants; nine had recently moved posts and three were between jobs; two were unknown at that address; two provided paediatric care; one was deceased; one was a duplicate; and one was a GP), leaving a total of 592 consultants actively involved in diabetes care. Localities which had provided responses to both the 2006/2007 and 2000 surveys were identified to compare trends in service provision between this subsample and the complete sample of respondents in both surveys.

Statistical analysis

The results were analysed using Excel and the Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA) using parametric and non-parametric tests according to the distribution of the data. Association and correlation between variables were measured by Pearson's r or Spearman's ρ and χ^2 tests. ANOVA was used to assess variance between means and an on-line statistical calculator (http://survey.pearsonncs.com/significant-calc.htm) tested significant differences between survey results in 2000 and 2006. $P < 0.05$ was considered to be statistically significant. Data are presented as frequencies, medians and ranges. Open-ended questions were systematically coded by one of us (C.G.), using an approach based on the framework method. Each response was read and assigned a code and grouped into themes that emerged from the data. To validate the interpretation, three consultant physicians (P.H.W., R.I.G.H. and C.W.) checked the interpretation of responses into codes and themes, and adjustments were made as required. Codes and themes were counted and ranked in order of frequency to represent the strength of respondent views.

As in the ABCD 2000 survey, a 'well-resourced service score' was used to describe variability in specialist service provision. This was based on levels of staffing, diabetes care services, and other core measures (Table 1). The same methodology was employed as in 2000 [12], with the exclusion of coding for retinal screening schemes, as this has been the focus of a separate survey. With a possible maximum score of 25 points, responses were graded as A* (24–25), A (21–23), B (18–20), C (15–17), D (12–14) or E (< 12 points).

Results

Two hundred and eighty-nine responses were received, representing a 49% response rate and covering 50% of acute NHS Trusts in the UK. The Trust responses by nation were England 51%, Northern Ireland 50%, Scotland 44% and Wales 33%. As reported elsewhere [21], the age and gender breakdown of the responding consultants were closely comparable to those in the RCP Census of Consultant Physicians in the UK with respect to Diabetes and Endocrinology [22,23], and matched the demographic characteristics of consultants interviewed in the earlier survey in England [17]. Data for 123 localities were obtained in both the 2000 and 2006/2007 surveys. Overall responders were comparable to non-responders in respect of region/country of response, age, gender, or time of response.

Table 1 Score components of a well-resourced service [with the same weightings (in parentheses) as used in the ABCD 2000 survey]

Consultants in diabetes (4)	Local vascular surgeon (1)
Diabetes specialist nurses (3)	Lipids measured (1)
Dietician (2)	High-density lipoprotein measured (1)
Podiatrist (2)	Microalbuminuria available (1)
Diabetes register (2)	Specific service for erectile dysfunction (1)
Joint antenatal diabetes service (1)	Joint paediatric clinic (1)
Joint ophthalmology diabetes service (1)	Clinic guidelines (1)
Separate clinics for the elderly (1)	Education (1)
	Access to psychologist (1)

Table 2 Whole-time equivalent (WTE) consultant numbers in 2000 and 2006

WTE of Consultants per 100 000	2000	2006
> 1.5	6.2%	8.8%
1.26–1.50	3.4%	5.5%
1.1–1.25	2.8%	21.0%
0.76–1.0	26.4%	32.4%
0.51–0.75	28.7%	16.5%
0.26–0.50	31.5%	14.0%
0.1–0.25	1.1%	1.8%

Key personnel

The number of consultant physicians providing specialist diabetes services had increased from 2000 from 456 to 592. Services were still provided by single-handed consultants in 10% of responses, but median whole time equivalent (WTE) consultant activity had risen from 0.67 per 100 000 population in 2000 to a range of 0.76–1.0 in the current survey (Table 2). Single-handed consultants were more frequently reported in Northern Ireland (50% of responses) than in the other nations (England 7.7%, Wales 14.3%, and Scotland 4.2%, $P < 0.001$).

The estimated provision of diabetes specialist nurses (DSNs) was ≥ 1 per 100 000 population in 60% of responses. This did not vary significantly by nation. Although the unit of measurement differed from the estimation of DSNs in the earlier 2000 survey, the median provision had increased from 1.0 to 1.1–1.25 per 100 000. The mode of enquiry regarding podiatric and dietetic staff also differed between the 2000 and the current survey, where median WTE dietician availability was 1 per 100 000 population without any variation by nation. There was fewer than one WTE dietician for the specialist diabetes service in > 72% of responses in the 2000 survey, suggesting increased dietetic service provision over the 6 years. The median WTE podiatrist availability was also one, and did not vary significantly by nation, whereas in the 2000 survey almost 97% of responses stated that WTE podiatric availability was < 1 WTE, again indicating an improvement in podiatric sessional input.

Table 3 Specialist diabetes services in 2006 compared with 2000

Specialist service	Status in 2000	Status in 2006
Diabetes register	73%	66%
Guidelines to ensure comprehensive care in all settings	85%	82%
Structured education for patients	77%	87%
Access to a psychologist*	45%	41%
Local vascular surgeon in the hospital	88%	86%
Joint antenatal*	85%	93%
Joint diabetes ophthalmology	15%	21%
Joint paediatric–adolescent*	60%	75%
Separate diabetes clinics for the elderly	13%	9%
Specific service for erectile dysfunction	60%	61%
Microalbuminuria*	93%	99%
High-density lipoprotein-cholesterol measured*	85%	96%
Lipids measured	99%	100%

*Difference is significantly different from 2000.

Table 4 Frequency of individual consultant involvement in subspecialist diabetes services

Type of service	% of respondents
General diabetes	99%
Antenatal	48%
Transitional adolescent–adult clinics	42%
Joint adolescent	21%
Joint paediatric	9%
Joint foot	38%
Diabetes renal	22%
Joint ophthalmology	5%
Pump-intensive management	26%
Liaison psychiatry diabetes	2%
Joint men's health	1%
Community diabetes clinics	13%
HIV-diabetes	1%
Sports and diabetes	1%
Other specialist clinics	16%

Specialist services and resources

The characteristics of specialist services in the current and 2000 surveys are presented in Table 3. Hospital diabetes registers, psychology access, and separate diabetes services for the elderly were less common than in 2000. Provision of joint antenatal, paediatric/adult and ophthalmology diabetes services had improved, as had laboratory access to high-density lipoprotein-cholesterol and microalbuminuria measurements, and training and resources for patient education. Other service provision had not changed appreciably. Changes in staffing levels and specialist services amongst the 123 acute trusts represented both in 2000 and 2006 were comparable to the complete samples (data not shown).

Table 5 Well-resourced service scores by nation and regions of England

Nations	Good	Average	Poor
England	23%	58%	20%
Wales	7%	73%	20%
Scotland	21%	75%	4%
Northern Ireland	8%	33%	58%

English Regions*

Regions	Good	Average	Poor
North	32%	52%	16%
Midlands and South	18%	61%	21%

Good (A*/A well-resourced score).
Average (B/C well-resourced score).
Poor (D/E well-resourced score).

Individuals were asked about the nature of services in which they were personally involved, reflecting sub-specialist interests amongst consultant diabetologists (Table 4). Whereas around 40% participated in clinic services with other disciplines such as obstetrics, paediatrics and podiatrists, only 13% were involved in community diabetes clinics.

'Well-resourced service score' and perceptions of service

There was considerable variation in the 'well-resourced service score'. The maximum score (A*) was recorded in only one response, with just over 25% of responses demonstrating a high score (A* or A). The mean score was 17.3 (graded C), with 15.7% of responses scoring D or E, reflecting considerable deficiencies in service provision (Table 5). There was significant variation in the score with geographical heterogeneity across England (by Strategic Health Authority, $P = 0.029$), with the highest scores in the North of England and the lowest in the East Midlands and the Eastern regions. There was also a difference between the nations, with the highest scores observed in England and Scotland, in comparison with Wales and Northern Ireland ($P = 0.007$). Services graded D/E were found in 4.2% of responses from Scotland, compared with 58.3% in Northern Ireland. Varying the weighting of the components of the scores did not appreciably alter these findings.

After adjusting for the number of consultants in each service, as was found in the 2000 survey, those services with fewer consultants had a lower score ($P = 0.0001$). Designated teaching hospitals tended to have better scores, but this was not significant ($P = 0.098$).

There was no significant interaction between the score and the age of respondents, or whether or not consultant colleagues had opted out of acute–general internal medicine. After removal of the component for a retinal screening programme, the mean well-resourced score (17.3) was comparable to 2000 (18.1). There was a significant relationship ($P = 0.001$) between the perception of those consultants that their service was well

Table 6 Strengths of specialist diabetes services—main themes

	Main themes	Frequency of reporting
1	Expert, committed and motivated specialist staff	166
2	Excellent multidisciplinary team working	118
3	Good links with primary care, effective networks and integrated community focused services	88
4	Comprehensive, well-organized service with a good range of speciality and sub-specialist clinics	154
5	Patient focused, innovative and high-quality service	78
6	Excellent education for patients and healthcare professionals	28
7	Good facilities and IT systems in place	37

Table 7 Weaknesses of specialist services—main themes

	Themes	Frequency of reporting
1	Under-resourced specialist services, in particular psychology (33), dietetics (35), education (23), podiatry (22), paediatric and adolescent clinics (13)	169
2	Lack of staff	99
3	Organization of service	73
4	Poor facilities, also includes split site working	42
5	Funding and finance cuts and higher prevalence	41
6	Lack of strategy and leadership	32
7	Poor links with community and/or primary care	32
8	Poor IT	29

Table 8 Threats to specialist services—major themes

	Themes	Frequency of reporting
1	Commissioning and negative impact of central government policy on diabetes care	176
2	Lack of understanding of complexity of diabetes and shift to primary care	106
3	Staffing and training cuts	93
4	NHS funding/finances/deficits	88
5	Service reconfiguration and fragmentation of care provision	51
6	Diabetes not prioritized, poorly valued and reduced investment to specific services	46
7	Pressures from acute medicine or general medicine	19
8	Poor communication and collaboration primary care, Primary Care Trusts and specialist services	16

resourced and the calculated score. The service was not regarded as well resourced in 36% of responses, and overall 20% of scores were D–E. Fifty-two percent of consultants reported their job satisfaction to be moderate or poor. Job satisfaction was strongly correlated with individual service scores ($P = 0.001$).

Strengths, weaknesses and threats to the specialist service

In the qualitative analysis of strengths, weaknesses and threats to the specialist service, more negative comments (232) were reported than positive comments [23]. These are recorded in Tables 6–8. The dominant themes that emerged as major threats to the specialist service were ineffective commissioning and the negative impact of central policy on specialist diabetes care, a belief that commissioners lacked understanding of the complexity of diabetes leading to a precipitate shift to primary care, staffing and training cuts, related financial deficits/funding issues, service reconfiguration and service fragmentation, and a perception that commissioners and acute trusts undervalued diabetes and saw it as a low priority.

Understanding of and engagement in commissioning diabetes services

In England, virtually all respondents were aware of 'payment by results' (99%) and 'practice-based commissioning' (100%), but there was misunderstanding about the exact tariff for new and follow-up diabetes specialist out-patient consultations. Only 50–65% estimated these correctly or to within 10% of these costs (tariff for new patient £247, estimated cost range £80–388; follow-up tariff £90, estimated cost range £30–180). It is notable that only 16% had been involved in discussions regarding these, particularly as lack of engagement of specialists in commissioning diabetes services was a recurrent negative theme in the qualitative analyses.

Discussion

This Internet-based survey attracted a response from approximately 50% of consultant physicians with a diabetes interest working in the UK. This response is less than the 77% achieved in the ABCD survey in 2000 [12]. Although the representativeness of the survey could be called into question, a lack of significant non-response bias is suggested by three features of the results. The respondents to this survey were broadly comparable to the general body of consultants identified in the RCP manpower survey [22,23] and the National Diabetes Support Team interviews of consultants in England [17]. The changes in service provision between 2000 and 2006/2007 in the analyses of the complete sample were mirrored in the comparison of the 123 localities that featured in both surveys, and there was no discernable trend in the responses to questions in relation to the time of receipt of response (data not shown). The latter index was used in the 2000 survey as an indicator of the possible extent of non-response bias [12]. The regional differences in the current survey are also unlikely to have been due to any important geographical non-response bias.

One important observation has been the demonstration of improvements in medical, nursing, dietetic and podiatric staffing levels since the ABCD survey in 2000. This would have been expected as a consequence of the Diabetes NSF and a national commitment to enhancing specialist diabetes services. It is important, however, to put these improvements in context of the more recent reductions in specialist staffing, which coincided with the latter stages of this current survey [24]. Although the number of consultants has increased, there are still 10% of services run single-handled, and the number of consultant physicians providing diabetes services remains considerably lower than recommended by the RCP and specialist organizations [22,23], and almost 300 fewer than suggested by the Department of Health in the Delivery Strategy document of the NSF [2]. The number of posts must also take account of an increase in consultants working part time (13% overall in the most recent RCP manpower survey) [23] and the impact of acute–general internal medicine. The ABCD–Diabetes UK survey has reported elsewhere the increasing commitment of specialist diabetologists to acute–general internal medicine as other core medical specialities have opted out, which in turn is impeding the contribution of the increased consultant numbers to diabetes service development [21].

The increased number of DSNs since 2000 is reassuring, but is still below that recommended at the time of the initial ABCD survey in 2000 [13]. Furthermore, the increase since 2000 has been superseded by more recent reports of cuts in specialist nurse posts in the wake of acute trusts financial deficits [24]. The increasing incidence of diabetes and staffing requirements for in-patient diabetes care will place further demands on the hospital-based DSNs. The relocation of some DSN services from acute trusts to the community makes this situation difficult to appraise. A detailed survey of DSNs in different health sectors will be the subject of a separate report. Similarly, although dietetic and podiatric support had also improved, numbers remain below recommendations made over 6 years ago [14–16].

Basic core components for a specialist diabetes service are, therefore, still not in place in many areas. Whereas educational input and joint antenatal specialist diabetes services have improved in the last 6 years, there remain a significant number of areas of concern identified in 2000 that have not been rectified. Adequate integrated information systems, collaborative working with ophthalmology and paediatrics, and services for the elderly and those with erectile dysfunction need further development. The lack of access to psychology support has been repeatedly highlighted in a succession of reports from different bodies and appears worse than in 2000 [12,19,20], despite explicit recognition as a core standard service in the Diabetes NSF [1]. Clinical psychology services are recognized to be generally under-resourced, and the contribution to diabetes services may be further impeded by the competing demands of Mental Health Trust provider units. The lack of ring-fenced funding for the Diabetes NSF has meant that, with the exception of retinal screening and GP-based registers, many specialist services that were in need of additional resources in 2000 did not develop before yet another major change in health service provision intervened and left them under-resourced. Consequently, the 'well-resourced service score' had not improved, despite improvements in some staffing levels.

Consultants were concerned that where progress had been made, this was under threat and might not be maintained due to loss of staff through lack of funding and fragmentation of the multidisciplinary specialist team. It was also felt that the unplanned shift of complex cases into the community without specialist involvement in service reconfiguration would jeopardize patient care. Despite aspirations to bring specialist care closer to patients' homes, very few consultants were engaged in providing community diabetes sessions.

We are unaware of comparable international research where such major reconfiguration of public healthcare systems may have impacted on diabetes services, although some moves toward greater partnership between primary and specialist diabetes services has been developed in parts of Canada [25], where the emphasis was on education of patients and non-expert healthcare professionals, and better utilization of community-based services with multidisciplinary teams, with a particular focus on more remote Aboriginal communities. Our current study highlights many issues that need consideration if other nations are planning to change diabetes service models and shift specialist care out of secondary care settings.

The drive and enthusiasm of consultants in diabetes in the UK exemplified in the earlier survey of English consultants [17] is still apparent. However, the intervening 12–18 months between the two surveys may have impacted on the broad perceptions of consultants. The level of job satisfaction appears to have fallen, as 34% expressed moderate or poor job satisfaction in the earlier survey [17], in comparison with > 50% who held such views in the current study. This may reflect the frustration in being unable to play a more active role in service reconfiguration and commissioning that was evident in the qualitative analyses.

The ABCD survey in 2000 revealed national and regional variation in services. Established services that were well resourced had received enhanced regional funding, leading to the perception that 'success bred success' [12]. The current survey has confirmed that regional disparities in service persist. Suboptimal service provision again appeared more likely in the Eastern region of England that had scored poorly in 2000, and in single-handed consultant-led services. Diabetes services and consultant staffing levels in Northern Ireland were notably under-resourced. The differences between the nations may in part reflect different stages of health service reform. 'Practice-based commissioning' is unique to England, whereas devolution had not taken place in Northern Ireland at the time of the survey. A more detailed analysis of this variation is in preparation.

The prevalence of diabetes is increasing, and to ensure the standards for care set out in the NSF are met, specialists have a vital role to play working in collaboration with primary care colleagues in the design and commissioning of diabetes services. Without the engagement of specialist staff, services will lack the leadership and expertise required to provide care for people with complex healthcare needs, and specialist training may be compromised. The Diabetes Commissioning Toolkit [6] in England has provided a blueprint to enable purchasers to commission an integrated diabetes service. Collaboration between all healthcare professionals involved in diabetes care in effective networks is essential to establish current service provision, enable workforce planning and thereafter commission a high-quality integrated diabetes service that is ready to meet the challenges of the diabetes epidemic [26].

Competing interests

None to declare.

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The conflict between specialist diabetes services and acute-general internal medicine for consultant diabetologists in the UK in 2006

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ABSTRACT —An online survey of consultant diabetologists in the UK examined the interface between specialist services and acute-general internal medicine (acute-GIM). Out of 592 consultants, 289 (49%) responded. Of these, 94% contributed to acute-GIM, devoting equivalent time to acute-GIM and specialist diabetes services. Of the respondents, 10% provided a single-handed specialist service and 78% provided endocrine services. The survey found the input to acute-GIM was increasing, partly because other specialties were opting out. The increased commitment to acute-GIM compromised specialist diabetes activity through reduced consultant and training-grade time for outpatient activity and service development. The shift to primary care of chronic disease led to further conflict between acute-GIM and delivery of a specialist service, given the current systems for provision of consultant-led care. The large number of specialist trainees in diabetes and endocrinology will require innovative commissioning mechanisms that reflect the need to sustain and develop specialist diabetes and endocrine care in the appropriate settings as well as the continued input in acute trusts for acute-GIM.

KEY WORDS: acute-general internal medicine, community shift, consultant physicians, diabetes, endocrinology, specialist training

Introduction

There has been a rapid pace of change in the NHS over the past five years. The magnitude and range of reforms has been likened to a process of creative destruction.[1] Uncertainty about the changing roles for healthcare professionals working in such an environment has led to a lack of clarity about the most effective means of service delivery and development.

Consultant physicians have been affected by these changes, and although their role in providing services to acute general hospitals is an established part of the UK healthcare structure, it is rapidly evolving. In the 2005 census of consultant physicians, the central role of key specialties providing support to acute-general internal medicine (GIM) was emphasised alongside their responsibility to their particular specialty.[2] The development of acute physician posts has been actively supported by the Royal Colleges of Physicians (RCP), although the commitment to acute-GIM from consultant physicians with specialist interests will continue to be encouraged.[3]

Currently consultants with a special interest in diabetes and endocrinology are the highest contributors to acute-GIM and therefore most likely to be affected by the changes.[2] Alongside developments in acute-GIM, there are profound reforms in the delivery of diabetes services. Government initiatives have moved towards an increasingly primary care-based delivery of chronic diseases including diabetes.[4,5] Consultant diabetologists may be working increasingly outside acute hospital settings and therefore a conflict between the delivery of acute-GIM and specialist services has arisen.

As the impact of service reforms on consultant diabetologists and the service they provide are largely unknown, the Association of British Clinical Diabetologists (ABCD) and Diabetes UK carried out a web-based survey of current working practices of UK consultant diabetologists in 2006. This survey was part of a larger body of work addressing other aspects of specialist diabetes services. These surveys were designed to identify current provision in specialist services and enable comparison with the 2000 survey.[6]

This report describes the role of the consultant diabetologist in the provision of acute-GIM and its impact on specialist diabetes services. Consultant attitudes towards the relationship between acute-GIM and diabetes services were also assessed.

Methods

An online survey was undertaken between May 2006 and February 2007 using the Opinion taker website. The survey was designed by the authors and included closed and open questions about the provision of

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acute-GIM and diabetes services. The questionnaire was piloted by the professional committees of ABCD and Diabetes UK prior to general circulation.

In total, 693 UK consultants involved in the provision of specialist diabetes and endocrinology services in the UK were identified through the databases of ABCD, Diabetes UK and the RCP Manpower survey. Their email addresses were obtained from the directories of ABCD, Diabetes UK and other sources available to these associations. An e-invitation was sent to complete the online survey in May 2006. A reminder was sent in September 2006 with the option of completing a hard-copy survey and non-responders were contacted by telephone. The survey was publicised through the ABCD and Diabetes UK websites and mail shots.

Of the 693 physicians 101 were excluded (34 only provided endocrine services, 23 had retired, 20 did not provide diabetes services, 10 were not consultants, 9 had moved post, 3 were duplicated or unknown at the address selected, 2 provided paediatric care, and 1 was deceased), leaving a total of 592 consultants actively involved in diabetes care.

Statistical analysis

The results were analysed using excel and SPSS using parametric and non-parametric tests according to the distribution of the data. Association and correlation between variables were measured by Pearson s r or Spearman s r and chi-square tests. ANOVA was used to assess variance between means and an online statistical calculator (http://survey.pearsonncs.com/significant-calc.htm) tested significant differences between survey results in 2000 to 2006. A p value of <0.05 was considered statistically significant. Data has been presented as frequencies, medians and ranges. Open-ended questions were systematically coded by CG, using an approach based on the framework method. Each response was read, assigned a code and grouped into themes that emerged from the data. To validate the interpretation, three consultant physicians (PHW, RIGH and CW) checked the interpretation of responses into codes and themes and adjustments were made as required. Codes and themes were counted and ranked in order of frequency to represent the strength of respondent views.

Results

In total, 289 (49%) responses covering 48% of UK acute NHS trusts were received and analysed. An analysis of the 303 non-responders by gender and locality revealed no significant differences compared to responders. The response rate, and age and gender breakdown was similar to the RCP census, and the RCP–Diabetes UK Manpower survey of 2006.[2,7] Of the respondents, 80% were male, 55% were aged over 46 years, 32% had been in posts for six years or less, and 25% had previously occupied a consultant post in a different trust. The number of single-handed consultants had fallen from 36% of respondents in 2000 to 10%.[4] There were two consultant diabetologists in each acute NHS trust (median (range)) (0–10). Of respondents, 92% were employed on the new NHS contract, carrying out a median (range) of 11.5 (1–15) programmed activities per week; 2.9 (0–10.5) were devoted to acute-GIM, 1 (0–7) to endocrinology and 3 (0–8) to diabetes outpatient activity. Services with two or more consultants took part in more diabetes outpatient activities. Two or more programmed activities were carried out by 92%, compared to 80% of single-handed consultants (p=0.05). Of respondents, 78% provided endocrine services.

Responsibility for acute-GIM

Of consultants, 94% provided a service to acute-GIM, mainly operating through medical assessment units (95%). Only 38% remained on call for unselected emergencies alongside their junior diabetes team. The remainder undertook on-call duties with other junior members of staff. Specialist diabetes sessions were cancelled to cover on-call commitments for 66% of consultants and 88% of specialist registrars. The median frequency of consultant on-call commitment was 1 in 10, compared with 1 in 7 in the 2000 ABCD specialist service survey.[4] The median daily admission rate was 30 (range 7–100) patients. When on call, 24% of respondents participated in a physician of the week system, with weekdays and weekends separated as duty periods in 54% of cases. Medical specialties were fully integrated with care of the elderly for unselected emergency admissions in 52% of responses. A team ward-based system for general on-going care was operated in 81%, but only 67% had access to a designated ward for all diabetes inpatients. Contribution to acute-GIM was proportionately similar among part-time and full-time consultants, and equivalent among younger (aged less then 46 years) and older consultants.

Physicians opting out of unselected acute GIM

Colleagues working in other specialties had opted out of responsibility for an acute GIM on-call rota in 69% of responses. The specialties most frequently cited were: cardiology (77%), neurology (56%), rheumatology (56%), renal medicine (42%), gastroenterology (23%), care of the elderly (13%), respiratory medicine (11%), and least frequently diabetes and endocrinology (9%). Of those who had opted out 14% were aged less than 40, 58% were aged 40–49 years, and 28% were aged 50 years or more. Opting out of acute-GIM was more common in designated teaching hospitals (43%) than in district general (34%) and associated teaching hospitals (23%) (p=0.001).

Qualitative perceptions of interface between diabetes and acute-GIM

The broad themes are summarised in Table 1, with direct quotations in Box 1. Consultants were concerned that the increasing acute-GIM workload compromised the provision of specialist diabetes services. Most respondents indicated there was less time available for specialist service development, and a difficulty in balancing both roles. The commitment to acute-GIM required cancellations or reductions in specialist sessions within a fixed envelope of programmed activities in job plans. Reduced avail-

Table 1. Themes emerging from qualitative analyses about acute-general internal medicine (acute-GIM) and interface with diabetes.

General issues	Effects on specialist services
Increased workload	Decreased time available for specialist services
¥ High pressure throughput	¥ Cancelled clinics
¥ Increased demand for consultant delivered service	¥ Increased GIM component of job plan
¥ Less experienced juniors	
¥ Less availability of juniors	Lack of opportunity for training
¥ European working time directive	Lack of exposure to specialty for doctors in training
Inadequate facilities	
¥ Lack of inpatient beds	Inappropriate case mix
¥ Lack of discharge arrangements for frail elderly without active medical issues	
Lack of continuity of care	
Team fragmentation	
Opt-out of other specialties	
Inappropriate case mix	
Government targets	
¥ 4-hour waits in emergency department	

ability of junior doctors was reported, as a result of the European Working Time Directive, shift work, and fragmentation of the specialist team when on-call for acute-GIM. Consequently juniors were less experienced and more dependent on consultants for support and service delivery. This led to fewer opportunities for training and recruitment into diabetes.

Consultants also highlighted the impact of bed shortages and pressure to meet targets such as the four-hour wait in emergency departments without compromising care. The need to secure inpatient beds often meant that patients admitted primarily with diabetes-related morbidity were not admitted to the specialist ward. Many diabetologists were responsible for an increasing case-mix of less acute elderly care patients who required rehabilitation and social care. However, many considered acute-GIM central to the role of consultant diabetologists. Many consultants enjoyed acute-GIM because of the broader case-mix, pace, diagnostic challenges, and opportunity afforded to teach junior members of the team. The contribution to acute-GIM also helped to raise the profile of consultant diabetologists within acute trusts.

Discussion

This survey provides an insight into the working lives of consultants with a special interest in diabetes and endocrinology. Both quantitative and qualitative data show that there is a growing tension between the provision of specialist diabetes, endocrine and acute-GIM services. Working patterns have changed since the 2000 survey and these changes have had positive and negative effects.

This survey has shown that following the publication of the National Service Framework (NSF) for diabetes, whose aim was to ensure a high-quality service, there has been a clear increase in the number of consultant physicians with an interest in diabetes in the UK. In this regard, this survey is in keeping with the RCP Manpower results.[6] Of specialist services 10%, however, are still provided by single-handed consultants, which is inappropriate on grounds of service, training and governance needs. The expansion of consultant numbers needs to continue to meet the rapidly increasing prevalence of diabetes in the UK. Even the most conservative estimates suggest that specialists should be actively involved with the care of 10–15% of people with diabetes, which will affect over 5% of the population by 2010.[8] It is concerning therefore to see that the growth in consultant diabetologist posts has slowed down dramatically in the last two years.[7] Although the number of consultant diabetologists has increased, the time devoted to diabetes services has not increased proportionately. Although the methodology used in the 2000 survey and the change in the consultant contract makes direct comparison difficult, in 2000, consultants reported that they devoted at least 40% of their time to diabetes compared with 3 out of 11.5 programmed activities (26%) in 2007.

With approximately 75% of current consultant diabetologist job plans devoted to non-diabetes-related activities, it is now estimated that at least three whole time equivalent consultant diabetologists will be necessary to serve a 250,000 population in order to meet the standards set out in the NSF for diabetes.[9]

There may be several reasons why diabetologists have less time for their specialty. Although it may be argued that the reduction in time available to specialty activity has resulted from the shift of

Box 1. Quotations from consultant diabetologists regarding acute-GIM and specialist diabetes services.

A steady erosion of specialty time as general medicine has become more demanding.

Expectations of general medicine are rising —whenever anything comes up, it is always a specialty clinic that is cancelled.

General medical on call means that my specialist registrar is absent from clinics 60% of the time. This affects my ability to provide a service and specialty training.

Senior house officers hardly ever attend clinics this will make it harder to attract trainees as specialty is largely out-patient based.

Chaos at times, poor communication with specialties, high bed occupancy means we cannot admit to base ward . Safari ward rounds.

I enjoy working on acute medical unit where I can make a real difference to people early in their hospital admission.

diabetes care to primary care and a fall in the number of diabetes referrals has been reported, consultants stated that the diabetes workload has not decreased with the more complex case-mix of patients attending hospital outpatient clinics. Furthermore, the introduction of increasing numbers of new therapeutic agents and technologies require the skills and expertise of consultant diabetologists.

Consultant physicians with an interest in diabetes continue to make a major contribution to acute-GIM in the UK and indeed they form the largest group of sub-specialties undertaking this role. Despite their support for acute-GIM, the experience of consultant diabetologists is that there has been an increased commitment to this at the expense of specialty activity, predominantly diabetes but also endocrinology. Consultant diabetologists continue to provide endocrine services in district general hospitals as only 10% of consultant physicians in the RCP–Diabetes Manpower survey exclusively provide endocrinology services without diabetes, and most usually in teaching centres.[7]

There is a discrepancy between the quantitative measures of GIM workload and qualitative reports. For example, the frequency of on-call commitment associated with increased consultant numbers and the reduction from five sessions in 2000 to 2.9 programmed activities suggest a reduced GIM workload. These measures are crude and do not reflect the shift from consultant-led to consultant-delivered care since 2000. The 2000 sessional figures fail to take into account the number of cancelled specialty sessions to allow participation in GIM. In 2006, consultants reported greater frequency of ward rounds and intensity of consultant input as less experienced junior doctors were more dependent on senior support. Furthermore the involvement has increased as physicians from other specialties such as cardiology have opted out of acute-GIM, and part-time consultant appointments have increased.

A further challenge to the split role of specialty and GIM is the need for consultant diabetologists to devote more time working in the community, where they will have an increasing role in providing leadership of community diabetes services, commissioning integrated diabetes care, and training primary care and public health colleagues. The current survey recorded that only 12.8% are currently engaged in community diabetes clinics but this is likely to increase.

The changing nature and uncertainty about the role of the hospital diabetologist may explain the increasing reports of vacancies for consultant diabetologists that are being frozen or converted to acute physician posts. While this strategy may address the provision of acute-GIM within a trust, it seems inappropriate because there are insufficient trainees in acute medicine to fill these posts.

Currently there are 105 trainees in acute medicine, with 85 scheduled to complete specialist training within the next five years (22 by the end of 2008). In contrast there are over 420 in diabetes and endocrinology, with 377 due to complete specialist training within the next five years. Certificates of completion of specialist training will be awarded to 144 trainees by the end of 2008 (N Newberry, personal communication, 2007). The mismatch between acute medicine trainees and posts and diabetes and endocrinology trainees and posts has meant that diabetes and endocrinology trainees are being appointed to acute medicine posts. This situation does not appear to be in the best interest of diabetes and endocrinology trainees and ultimately patients, if career aspirations are frustrated and specialist services are compromised. An online survey commissioned by ABCD and Diabetes UK in May 2006 completed by 44% of specialist registrars indicated that 54% stated they would not consider a position in acute medicine while 52% stated a desire to work in diabetes and endocrinology while supporting acute-GIM.[12]

When considering future development in acute-GIM, diabetes and endocrinology workforce planning commissioners should recognise the contribution that consultant diabetologists make to these three areas of medicine.[13] Adequate levels of specialist staff are needed to support the complex health needs of people with diabetes, including the often unmet needs of diabetes inpatients. Flexibility is needed to allow consultants to ensure that a balance is achieved between time dedicated to GIM and the time needed to develop specialist diabetes and endocrine services by providing leadership and working in the community with primary care and public health colleagues and in supporting the care of all diabetes inpatients in acute trusts.

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Short Report

National guidelines for psychological care in diabetes: how mindful have we been?

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Abstract

Aims To assess the availability and types of psychological services for people with diabetes in the UK, compliance with national guidelines and skills of the diabetes team in, and attitudes towards, psychological aspects of diabetes management.

Methods Postal questionnaires to team leads (doctor and nurse) of all UK diabetes centres (*n*
structured telephone interviews of expert providers of psychological services identified by team leads.

Results Two hundred and sixty-seven centres (58%) returned postal questionnaires; 66 (25%) identified a named expert provider of psychological services, of whom 53 (80%) were interviewed by telephone. Less than one-third ($n = 84$) of responding centres had access to specialist psychological services and availability varied across the four UK nations ($P = 0.02$). Over two-thirds (*n* *12) of centres had not implemented the majority of national guidelines and only 2.6 met all guidelines. Psychological input into teams was associated with improved training in psychological issues for team members* ($P < 0.001$), perception of better skills in managing more complex psychological issues ($P \leq 0.01$) and increased likelihood of having psychological care pathways ($P \leq 0.05$). Most (81%) expert providers interviewed by telephone were under-resourced to meet

Conclusions Expert psychological support is not available to the majority of diabetes centres and significant geographical variation indicates inequity of service provision. Only a minority of centres meet national guidelines. Skills and services within diabetes teams vary widely and are positively influenced by the presence of expert providers of psychological care. Lack of resources are a barrier to service provision.

Diabet. Med. 26, 447 450 (2009)

Keywords consultation liaison psychiatry, diabetes, health services, psychology, survey

Abbreviations NICE, National Institute for Health and Clinical Excellence; NSF, National Service Framework

Introduction

Psychiatric disorders and psychological problems are common in diabetes [1]. There is a twofold increase in depression [2 4] and eating problems [5] and these are associated with suboptimal glycaemic control [6,7]and increased mortality [8]. There are cost-effective treatments for depression in diabetes [9] and psychotherapeutic approaches to improve glycaemic control [10 13] but, despite this, the majority of untreated [2,14].

There are no formal clinical pathways for delivering expert psychological care in diabetes. The National Service Framework (NSF) has set standards to provide counselling (standard 3) and management of depression (standard 12) [15] and the National Institute for Health and Clinical Excellence (NICE) has also made explicit recommendations [16] (Table 1).

The aim of this national survey was to describe and quantify the provision of psychological services for adults with diabetes and the extent to which national guidance was being met.

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Table 1 Proportion of diabetes centres complying with each national guideline (n = 267 centres)

Guidance or standard	Agree that guidelines necessary (%)	Currently meet the guidelines (%)	Actively addressing any deficit	Perceived requirements needed to be able to meet guidance/standards
NSF standard 3: counselling/behaviour change support skills	97.0	64.0	39.2%	Not asked
NSF standard 12: depression surveillance and management	89.5	72.0	24.4%	Not asked
NICE 1: alert to depression/anxiety	98.5	24.0	Not asked	68.0% more MDT training 87.0% more psychological staff
NICE 2: detect and manage non-severe psychological problems across cultures	94.0	37.0	Not asked	53.0% more MDT training
NICE 3: familiar with counselling and psychiatric medication	92.0	38.0	Not asked	52.0% more MDT training
NICE 4: alert to eating disorders	99.0	35.0	Not asked	60.0% more MDT training 83.0% more psychological staff

MDT, multidisciplinary team; NICE, National Institute for Clinical Excellence; NSF, National Service Framework.

Methods

Design and setting

A cross-sectional postal survey was sent to all diabetes centres (n = 464) in the UK. Paediatric and retinal screening units were excluded.

The survey was carried out from August 2006 to October 2007 in two stages. Part 1 was a questionnaire sent to both the senior physician and nurse of each centre. Non-responders were sent a second questionnaire 1 month later. Part 2 involved a telephone interview with the relevant provider of psychological care (defined as psychologist, psychiatrist or other mental health professional, such as psychiatric nurse) identified in completed Part 1 questionnaires.

Measures

In Part 1, the questionnaire measured the quantity, as defined by number of sessions per week, and types of psychological services, adherence to national guidelines and intrinsic team skills in and attitudes towards the psychological care of people with diabetes.

We defined psychological services as those provided by mental health professionals (psychiatrists, psychologists, psychotherapists and counsellors). They were labelled ‘expert providers’ if they had sessions specifically for diabetes patients.

Psychological problems were categorized as: mild (such as adjustment problems or difficulties with optimizing diabetes self-care regimen); moderate (such as anxiety or depression, diabetes-specific anxieties including fear of hypoglycaemia and fear of needles); and severe (usually requiring secondary mental health services, e.g. psychosis and high risk of suicide). We derived six standards of psychological care for people with diabetes from the NSF and from NICE (Table 1).

In Part 2, the structured telephone interview with the expert provider covered the nature, type and organization of psychological treatments available, ease of access and setting. Perceived gaps in service provision for psychological problems were explored.

SPSS (v15; SAS Institute, Cary, NC, USA) was used for statistical analyses. Continuous data were non-normally distributed and were analysed using non-parametric tests. Chi-squared tests were used for categorical data.

The full methods and questionnaires used can be viewed on the Diabetes UK website [17].

Results

Expert psychological input into teams

Two hundred and sixty-seven centres (58%) returned Part 1 questionnaires; 85 (32%) reported expert psychological provision and 66 (25%) identified an expert provider of psychological services, 53 (80%) of whom were interviewed for Part 2 (Fig. 1).

There were national differences in the proportion of teams that had expert psychological input (Northern Ireland 44%, Wales 6%, England 33% and Scotland 31%). The differences in provision between Wales and England (P = 0.02, Fisher's exact test) and between Wales and Northern Ireland (P = 0.02, Fisher's exact test) were both statistically significant.

Expert providers were predominantly clinical psychologists (58%), with the remainder comprising liaison psychiatrists (18%), psychotherapists (4%), counsellors (4%) or other therapists (18%). Just over half (59%) of centres provided a defined service for people with diabetes. The median number of sessions (half days) for psychological care was 2.5 (range 0.25–11) per week per team. The most common treatment offered was cognitive behaviour therapy (CBT) and over 90% offered care for psychological problems of moderate severity.

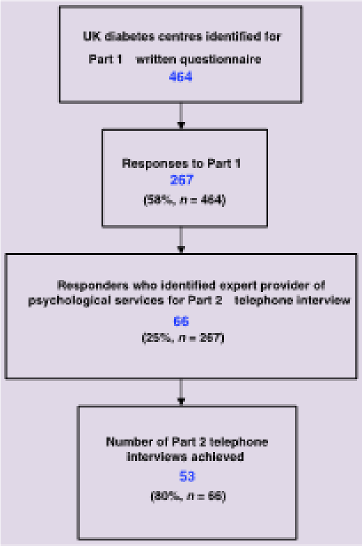

FIGURE 1 Flowchart of responders.

Where it existed, expert psychological provision was associated with a perception by respondents of better skills by the team in managing moderate and severe psychological problems ($P \leq 0.01$), improved training for the team in psychological issues ($P < 0.001$), and increased likelihood of having psychological care pathways ($P \leq 0.001$), but no increase in the availability of screening or assessment tools for psychological well-being ($P = 0.10$).

Psychological components intrinsic to teams

Under half (41%) of questionnaire respondents (Part 1) stated they had one or more non-psychological team member trained in psychological therapies. A minority (12%) of centres had screening and assessment tools for psychological problems and a majority (80%) had no protocols or guidelines for referral of patients with psychological problems of moderate severity. Approximately half (49%) had referral pathways to specialist care for patients with more severe mental illness.

Compliance with national standards and guidelines

With regard to national guidance (Table 1) over two-thirds (69%) of centres did not comply with the majority (≥ 4/6) of guidelines or standards; only 2.6% complied with all six and 26% did not comply with any. This was despite high levels of agreement by respondents with the appropriateness of the guidance.

Discussion

This is the first national study of the state of provision of psychological care for adults with diabetes in the UK. Only one-quarter of diabetes centres had direct access to psychological care for their patients. The majority of diabetes services do not meet national guidance for delivering psychological care in diabetes. Expert psychological care is highly variable in type, quantity and quality when compared among diabetes centres and also among regions of the UK, indicating a clear inequity of service provision. Service availability seems to depend on the presence of an interested psychologist or psychiatrist in the local area rather than a coherent national plan. Lack of resources also appears to be a barrier to service provision.

Our survey relied on subjective reporting of quality and quantity of service provision and our findings may be an overestimate of services because of centres with psychological input possibly being more likely to respond to the postal questionnaires. Similarly, those interviewed by phone may have been biased in terms of optimism about services. Previous surveys estimated availability of psychological care at 50% [18,19]; however, this would be an overestimation when compared with our findings.

The Darzi Report on the future of the National Health Service (NHS) [20] states there is no physical health without mental health and that there has to be equity in the availability of services. One solution to the current inequity suggested by our survey is to encourage commissioners to require services to offer evidence-based identification, assessment and treatment of psychological and psychiatric problems. Another solution would be for the development of local and national guidelines for the resources required to provide expert and intrinsic psychological care within diabetes teams at primary, intermediate and secondary level. It is interesting to note that such guidelines, including recommendations for training of psychological professionals, already exist in Germany [21] and these could serve as models for similar initiatives in the UK.

Future studies should monitor the response to this highlighted shortfall in services to ensure national standards are achieved throughout the UK, with consequent benefits for people with diabetes. Cost-benefit analyses of providing such services are also needed.

Competing interests

Nothing to declare.

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Special Report

A national survey of the current state of screening services for diabetic retinopathy: ABCD Diabetes UK survey of specialist diabetes services 2006

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Abstract

The main aims were to ascertain the progress made in the implementation of retinal screening services and to explore any barriers or difficulties faced by the programmes. The survey focused on all the essential elements for retinal screening, including assessment and treatment of screen-positive cases. Eighty-fiv service and 73% of these felt that they have made significant progress. Eighty-five per cent of screening units use call and recall for appointments and 73.5% of programmes follow the National Screening Committee (NSC) guidance. Although many units worked closely with ophthalmology, further assessment and management of screen-positive patients was a cause for concern. The fast-track referral system, to ensure timely and appropriate care, has been difficult to engineer by several programmes. This is nts identified as needing further assessment and treatment for retinopathy. Ophthalmology service for people with diabetic retinopathy was provided by a dedicated ophthalmologist in 89.4% of the programmes. Sixty-six per cent of the programmes reported inadequate resources to sustain a high-quality service, while 26% highlighted the lack of infrastructure and 49% lacked information technology (IT) support. In conclusion, progress has been made towards establishing a national screening programme for diabetic retinopathy by individual screening units, with resource allocation and compliance with Quality Assurance (QA) standards, especially those which apply to ophthalmology and IT support. Screening programmes need to be resourced adequately to ensure comprehensive coverage and compliance with QA.

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Keywords diabetes, retinopathy, screening

Abbreviations ABCD, Association of British Clinical Diabetologists; EQA, External Quality Assurance; IT, information technology; NHS, National Health Service; NSC, National Screening Committee; NSF, National Service Framework; QA, Quality Assurance

Introduction

Diabetic retinopathy remains the leading cause of visual loss in people of working age in the Western world [1]. Diabetic retinopathy is often asymptomatic until it reaches an advanced stage and therefore regular screening is recommended to allow timely diagnosis and treatment [2]. It is now well established that early detection through screening and effective treatment in the form of photocoagulation prevents visual impairment [3,4]. In addition, strategies including the optimal management of blood pressure and blood glucose slow down the progression of National Screening Committee (NSC) launched a national programme to facilitate the reduction of diabetic retinopathy in 2003 [8] as part of the delivery of the National Service Framework (NSF) for Diabetes [9,10]. The programme set out national targets to offer comprehensive retinal screening to all people with diabetes in England, Scotland, Wales and Northern Ireland. The aspiration was to offer 100% population coverage by December 2007. The national programme is centrally

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co-ordinated and includes a Quality Assurance (QA) scheme with national standards for all aspects of retinal screening [8]. Recent National Health Service (NHS) reforms have led to a shift of routine diabetes care from specialist centres to primary care [11,12]. Also, there has been a drive to make services more patient responsive to improve access to diabetes service, through appropriate and effective commissioning [13,14].

The Association of British Clinical Diabetologists (ABCD) and Diabetes UK have undertaken a series of surveys in the UK and this survey of retinal screening services was part of the larger body of work to determine the provision of diabetes services.

The ABCD has previously conducted a survey of specialist services which was published in 2000. This survey was conducted well before the National Screening Programme was established, but provided useful insights into the state of screening services for diabetic retinopathy at that time. This survey showed that, in 2000, 74% of respondents specialist services were providing a co-ordinated retinal screening but no data on population coverage were available [15].

The aims of this survey were to ascertain the progress made in the implementation of retinal screening services and to explore any barriers or difficulties faced by the programmes during the implementation of this particular service.

Methods

An online survey was undertaken between May 2006 and February 2007 using the Opinion taker website. The survey was designed by the authors and included 73 closed and open questions about the provision of retinal screening. The survey covered demography, infrastructure for retinal screening service, resource allocation, leadership and adherence to NSC guidance, process of retinal photography and population coverage, and explored if mechanisms were in place to deal with screen-positive patients. The survey can be accessed on the Diabetes UK website (http://www.diabetes.org.uk).

The questionnaire was piloted by the professional committees of ABCD and Diabetes UK and modified following comments. All 105 screening units in England were contacted. When duplicate responses were identified, the respondents were contacted by phone. Based on the guidance from the responders, only one response per screening unit was included. Responses were automatically loaded on to a data file.

Statistical analysis

The results were analysed using Excel and the Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA) using parametric and non-parametric tests according to the distribution of the data. Data are presented as frequencies, medians and ranges. Open-ended questions were systematically coded by one of us (CG), using an approach based on the framework method. Each response was read and assigned a code and grouped into themes that emerged from the data. To validate the interpretation, two consultant physicians (DN and CW) checked the interpretation of responses into codes and themes and adjustments were made as required. Codes and themes were counted and ranked in order of frequency to represent the strength of respondent views.

Results

Responses were received from 68 of the 105 retinal screening units (64.8%) in England. Mapping of the responses showed a reasonable geographical distribution of the programmes, with no clustering of responses and no particular area of England being under-represented.

Infrastructure for retinal screening

Eighty-five per cent of screening programmes have a coordinated screening service and 73% of these felt that they have made progress since the introduction of retinal screening in their locality. Fifty-two per cent of programmes provided retinal screening from a fixed location, while 15% had mobile screening services and 34% had a mixed approach. Of the programmes which responded, only 28% had involvement of optometry as part of a centrally coordinated system.

Process of retinal screening

The majority of screening units (85%) operate an appointment system through call and recall , of which 76% used a centrally located register. The NSC guidance is followed by 73.5% of programmes.

Results of retinal screening

Screening rates

Sixty-five per cent of responders were able to provide data on the number of people who were offered screening and 61% on the number who had actually attended for screening. Some programmes were unable to provide this information while others did not know if this information was available within their programme. Of those programmes which were able to provide data, population coverage of those being offered screening ranged from 30 to 100% The accompanying table shows the spread of coverage to the population being offered screening. However, only 60% of programmes were able to provide accurate data about the number of people actually attending screening, which exceeded 80% in 13 programmes, while in the remainder this ranged between 20 and 79%. There were no programmes where there was 100% compliance with population attending screening.

Screening interval

In 55 programmes, screening intervals were approximately 12 months, while in eight programmes screening intervals ranged between 12 and 24 months. Two programmes had a screening interval of 2 years and two programmes reported variable intervals. Thirty-three of the 64 programmes had mechanisms to recall patients for 6-monthly screening if clinically indicated.

Grading of retinal photographs

The grading of retinal photographs were mostly performed by trained retinal screener- graders (84%). However, ophthalmologists (60%), diabetologists (24%), optometrists (32%) and others were also involved and provided secondary grading.

Dealing with screen-positive images

Although many units worked closely with ophthalmology units, the processing of positive patients was a cause for concern for many screening units. The details on the number of programmes providing data on dealing with screen positives are shown in Table 1. These data show the percentages of programmes seeing patients within the specified national standard, by levels of retinopathy. Sixty-nine per cent of the programmes reported that patients diagnosed with proliferative retinopathy (neovascularization) were being seen within the specified 2-week national target. Eighty-per cent of the programmes reported patients with maculopathy being seen within an 8-week period and 94% within a period of 16 weeks. Forty-three per cent of people with unobtainable images were seen within 2 months and 46% were seen according to clinical need in a slit lamp biomicroscopy clinic for further assessment.

In addition, 48% of programmes reported waiting lists for patients who screened positive and needed further assessment and treatment for retinopathy and, of these, 43.3% had to wait 5 weeks or more. For patients who were referred to ophthalmology for diabetic retinopathy, care was provided by a dedicated ophthalmologist in 89.4% of the programmes. Some programmes qualified their responses to illustrate the difficulties they were experiencing with having to wait up to 4 months for review of positive images, and repeated cancellation of ophthalmic clinics, raising concerns about the further assessment of screen-positive patients.

Information technology (IT) and software

The NSC had recommended that programmes should acquire the Purchasing and Supply Agency (PaSA; NHS Procurement Agency) listed retinopathy management software for running of the screening service and for annual reporting of the data. Retinopathy management software was being used by 94% of programmes, with 63% of programmes having acquired one of the two nationally recommended software systems (Digital Healthcare, Cambridge, UK or Orion, Coventry, UK). Other systems were reported as being used and 22 programmes had locally developed systems for the operational side of diabetic retinopathy management. Forty-nine per cent of the respondents identified poor IT support as being a significant problem within retinopathy screening locally.

Quality Assurance

The mechanism of internal quality control as described by programmes (n = 54) was variable. Some programmes reported following the NSC guidance on internal quality control. Based on the qualitative information received from various programmes it appears that programmes had also a very variable understanding of the process of quality assurance and there was confusion between annual reporting and quality assurance. The results of responses to quality assurance can be summarized into the following broad categories. Twenty-one programmes reported following NSC guidance but few of these provided any detail of the process involved. Ten programmes delivered QA through an internal audit and others responded that their system was IT driven. Four programmes used other methods. Eleven responses identified the personnel involved or responsible for QA, six of whom were ophthalmologists.

Resource allocation

Sixty-six per cent of programmes reported that resource allocation is inadequate to sustain a high-quality service. Twenty-six per cent highlighted the lack of infrastructure and 49% insufficient IT support. Thirty-four per cent of programmes felt that the need to establish new programmes had led to the decommissioning of previously well-performing and

Table 1 Data on management of screen-positive patients by retinopathy level according to national standards

National standard	Neovascularization/ proliferative retinopathy, % (count)	Maculopathy, % (count)	Reduced acuity, % (count)
Immediate/within 1 week	43.5 (27)	6.5 (4)	3.3 (2)
Within 2 weeks	25.8 (16)	16.1 (10)	9.8 (6)
Within 1 month	14.5 (9)	25.8 (16)	18.0 (11)
Within 2 months	3.2 (2)	21.0 (13)	26.2 (16)
Within 4 months		12.9 (8)	4.9 (3)
According to clinical needs	12.9 (8)	17.7 (11)	37.7 (23)

good-quality units for screening for diabetic retinopathy. Other programmes commented that funding was withdrawn, they were not able to accelerate to 100% coverage and that there were insufficient funds to achieve the 12-month target.

Discussion

It is estimated that there are currently approximately 2.5 million people with diabetes in the UK and this number is expected to rise to 4 million by 2025 [16]. Up to 20% of individuals with Type 2 diabetes may have retinopathy at diagnosis [17]. Diabetic retinopathy is the commonest cause of blindness in people of working age in the UK and, as it is frequently asymptomatic until advanced, the only means of reducing the burden of visual loss in people with diabetes is through regular screening [2]. This principle was firmly established by the NSF for Diabetes and has been endorsed by the National Institute for Health and Clinical Excellence. Following the publication of the NSF for Diabetes, a national programme for reducing visual loss secondary to diabetic retinopathy was launched in 2003 to facilitate screening for retinopathy. The first survey of specialist services were performed by ABCD in 2000 before the launch of the national programme for eye screening in 2003. Therefore, a direct comparison with retinal screening services at present is inappropriate but does merit discussion. Services in 2000 showed that 74% of respondent's specialist services were providing coordinated retinal screening but no data on population coverage were available. One can therefore conclude that the provision of eye screening to people with diabetes was far from comprehensive at that time [15].

The current survey has shown that there has been significant progress towards establishing a national service, with 105 units providing retinal screening services in England at the outset. Although some are at various stages of development, 96 of these are fully operational and offer systematic screening to people with diabetes. Recent data also confirm that the number of programmes now stands at 93, following the amalgamation of various programmes to attain critical mass and recommended minimum programme size.

The results of the survey, however, highlight a number of important areas of concern. First, many units commented on the inappropriate level of funding, including withdrawal of funding, that has prevented the necessary service expansion to meet the target of offering screening to 100% of the population by December 2007. Data collected by the national screening programme and the Department of Health agree with our findings that much progress has been made, but the last reported Department of Health figures for the first quarter of 2008 show that, while 90.7% of people with diabetes were offered screening, only 66.9% received screening [18]. Recent national data from the Department of Health, presented at the 2nd European Meeting on Retinopathy Screening, showed that, at the end of reporting year 2007, 80.62% of the population had been offered screening. Addressing the issue of inadequate resource allocation to allow programmes to expand and provide population coverage as expected by the NSC remains a big challenge. Secondly, it is apparent from the results of this survey that many retinal screening units are struggling to provide ophthalmic services, in a timely manner, to manage patients who have referable diabetic retinopathy, according to national quality standards. There remain several difficulties in achieving the targets set by the NSC in relation to 'screen-positive' patients. NSC standards stipulate that those patients who are referred for non-proliferative retinopathy or maculopathy should be seen within a period of 13 weeks, with proliferative retinopathy being seen within 2 weeks. Many units were unable to arrange ophthalmology appointments for 'screen-positive' patients within 4 months.

In order to improve the current situation highlighted by this survey, the working relationship between ophthalmology and screening units needs to be strengthened and explicitly supported by appropriate commissioning arrangements. Local commissioners need to commission appropriate services from ophthalmology services that should include responsibility for data feedback to the screening programme [8].

Many retinal screening units are experiencing difficulties in receiving feedback on the outcome of an ophthalmology assessment of a screen-positive patient. There may be several reasons for this, but this is in the main because of the lack of electronic links between the software for retinal screening programmes and ophthalmology. To highlight this issues, feedback from one unit showed that, in order to obtain necessary data for annual reporting as expected by the NSC, a retrospective case note review had to be undertaken of 478 case notes for 1 year [19]. This degree of resource utilization on an annual basis was deemed to be unfeasible, inefficient and unsustainable. This issue of feedback from ophthalmic units to the screening programme needs to be addressed urgently.

Since this survey was undertaken, the authors are aware that the NSC has started the much needed External Quality Assessment (EQA) visits, which are addressing some critical issues, including that of feedback from ophthalmology. In our view, this can only be achieved through close and integrated working between ophthalmology and screening units with robust electronic links to capture data, but also by having clear commissioning arrangements which not only include an appropriate clinical service to deal with screen-positive patients, but also a need for them to provide data on an ongoing basis to the screening services, regarding outcome of these patients. In our view, this is the only way to achieve a fail-safe environment and minimize clinical risk to patients undergoing screening.

Local leadership is identified as a crucial issue in this survey, and would appear to be shared between diabetes, ophthalmology, and public health services. Each of the crucial services have an important role to play and must work together effectively to sustain and run a quality retinal screening service. Recent recommendations from the NSC stipulate that screening services should establish 'Local Programme Boards', which will be responsible for overseeing various important issues, including

Quality Assurance. On a more positive note, since this survey was conducted, the national coordinating team has begun the process of EQA visits to the programmes, starting with those who are having significant difficulties. Initial feedback from programmes who have undergone this EQA process, shows that these visits have helped resolve a number of important issues. Programmes need and would welcome support from the national screening team in resolving local difficulties if progress made to date is to be sustained. Structured feedback to the local commissioners from EQA visits should lead to further improvements in the way programmes are funded and supported. It is only then that the very aim of reducing visual loss as a result of diabetic retinopathy will be realized. We cannot be too overtly critical of the data we received on Quality Assurance, as QA at the time of this survey was in its infancy and there were no well-developed IT systems to support it.

Retinal screening services are provided in the UK, and many other European Community (EC) member states and in North America, but are unique in the UK in terms of the central organization and strict QA standards (D.K. Nagi, pers. comm., Proceedings of the First and Second European Congress on Retinopathy, Liverpool 2006 and Amsterdam 2008). We must acknowledge that this survey has limitations. Firstly, this survey gives a cross-sectional picture during 2006, against a continual improvement of these services nationally and, secondly, the response rate was only 65%. Another limitation is the fact that none of the responses were validated and were taken under the assumption that they represented fairly accurate responses. Many of the general findings of this survey probably still hold true and are generalizable. This survey therefore provides insight into challenges facing this important component of diabetes services. Findings could be further supported with QA data collected by the NSC annually.

In conclusion, progress has been made towards establishing a national screening programme for diabetic retinopathy by individual screening units, with a number of programmes moving on to a level where they are providing a structured retinal screening service. Significant difficulties, however, are being experienced by programmes in resource allocation, and in complying with QA standards, particularly those which apply to ophthalmology and include IT support.

Competing interests

Nothing to declare.

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Special Report

Diabetes specialist nurses and role evolvement: a survey by Diabetes UK and ABCD of specialist diabetes services 2007

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Abstract

Aims To review the working practices of UK diabetes specialist nurses (DSNs), specific clinical roles, and to examine changes since 2000.

Methods Postal questionnaires were sent to lead DSNs from all identifiable UK diabetes centres (*n*

qualitative data were collected on the specific clinical roles, employment, and continual professional development of hospital and community DSNs, Nurse Consultants and Diabetes Healthcare Assistants.

Results 159 centres (44%) returned questionnaires. 78% and 76% of DSNs plan and deliver education sessions compared with 13% in 2000 with a wider range of topics and with less input from medical staff. 22% of DSNs have a formal role in

Consultants are involved in prescribing. 55% of DSNs carry out pump training, 72% participate in ante-natal and 27% renal clinics. 90% of services have independent diabetes nurse-led clinics. 93% of services have a dedicated Paediatric DSN. The mean number of children under the care of each PDSN is 109 (mode 120), which exceeds Royal College of Nursing recommendations. 48% of DSNs have protected time for continuing professional dev

of DSNs are on short-term contracts funded by external sources.

Conclusions The DSN role has evolved since 2000 to include complex service provision and responsibilities including specialist clinics, education of healthcare professionals and patients. The lack of substantive contracts and protected study leave may compromise these roles in the future.

Diabet. Med. 26, 560 565 (2009)

Keywords

Abbreviations ABCD, Association of British Clinical Diabetologists; DSN, Diabetes specialist nurse; PDSN, Paediatric diabetes specialist nurse

Introduction

The diabetes specialist nurse (DSN) role exists to educate and support people living with diabetes and their families at all stages in their lives [1]. The role, first introduced over 60 years ago, became more common in the 1980s with the advent of differing strengths of insulin and the introduction of self-monitoring of

2007 in either the primary or secondary care setting or both [3].

The role of the DSN within the multidisciplinary diabetes team has continued to evolve as diabetes care has changed in response to patient demand as well as the Working Time Directive [4] and Government policies and strategies such as The NHS Plan [5] and the National Framework for Diabetes [6]. The necessity for this

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change was acknowledged in the 2000 Association of British Clinical Diabetologists (ABCD) survey of secondary care services for diabetes in the UK [7]. This survey, which included an investigation of DSN roles and responsibilities, predicted that DSN roles would undergo significant change as a result of changes set out in the NHS Plan, and that these roles would continue to evolve to include more direct responsibility for diabetes clinical management and nurse prescribing.

Given the speed of change within the NHS, Diabetes UK and ABCD considered that it was important that the independent views of specialists involved in diabetes service provision were sought, and commissioned a second series of surveys to review diabetes services throughout the UK in 2007. An integral part of this work was this diabetes specialist nurse survey, the aims and objective of which were to explore the working practices of UK DSNs, specific clinical roles and examine changes since 2000.

Methods

A questionnaire was developed by the Diabetes UK and ABCD Specialist Services Study Group. The survey comprised 80 open and closed questions to examine the organization of provision of diabetes services relating to hospital and community DSNs, Nurse Consultants in Diabetes and Diabetes Healthcare Assistants including Diabetes Care Technicians. The questionnaire included sections on specific clinical roles, prescribing behaviour, paediatric nursing, education and research, employment data, pay banding and continual professional development.

The questionnaire was piloted by a group of in-patient and primary care-based DSNs, and questions that were confusing or poorly answered were amended accordingly. The full survey was carried out between February and December 2007.

Paper questionnaires were mailed to 361 primary and acute diabetes services as listed in internal and external databases including Binley's Directory of NHS Management, 2006, the Diabetes UK internal professional membership list and the Diabetes Inpatient Specialist Nurses membership list.

The lead DSN from each locality was invited to complete the survey. The first question was designed to examine whether the local service was operated across primary and specialist services. Where services were not integrated, the recipient was asked to copy the questionnaire to obtain responses from both primary and specialist services.

The questionnaire was posted in February 2007 and replies collected until December 2007. A second questionnaire and reminder was sent to all non-responders after 1 month, followed by telephone calls to the centre concerned in order to maximize the final response rate.

Data process

The completed questionnaires were collated and data entered onto a database designed to assist with data entry (SNAP; SNAP Solutions LLC, Evanston, IL, USA) and later exported into the Statistical Package for Social Sciences (SPSS; SPSS Inc., Chicago, IL, USA).

Localities providing responses to both 2000 and 2007 surveys were identified to compare trends in service provision between this sub-sample and the complete sample of respondents in both surveys.

Statistical analysis

The results were analysed using Excel and SPSS using parametric and non-parametric tests according to the distribution of the data. Association and correlation between variables were measured by Pearson's r or Spearman's ρ and chi-square tests. One-way ANOVA was used to assess variance between means. A P-value of < 0.05 was considered statistically significant. Data are presented as frequencies, medians and ranges. Open-ended questions were systematically coded by one of the research team (C.G.), using an approach based on the framework method. Each response was read and assigned a code and grouped into themes that emerged from the data.

Data are presented as percentages, with the actual number of responders in parentheses.

Results

One hundred and fifty-nine responses were received, representing a 44% response rate. Of responders, 18% (28) were from primary care organizations, 81% (129) from acute trusts and 1% (two) from nurses working in specific general practice surgeries.

Seventy-five percent (119) of responses were from England, 9% (15) from Northern Ireland, 8% (12) from Scotland and 6% (10) from Wales. In addition, there were three responses from the Channel Islands and the Isle of Man. Sixty-five percent (100) reported they operated within a service that spanned primary and secondary care service.

Trusts in the South of England were more likely to report an integrated service than the rest of England ($P = 0.019$) and there was a trend towards national differences between the four nations (Scotland 91%, Northern Ireland 79%, England 62% and Wales 40%, $P = 0.059$).

Where services were not integrated, 76% (41) of respondents were based in specialist services and 24% (13) in primary care. Five did not respond to this question.

Clinical roles

Virtually all DSNs (315, 95%) were involved in some aspect of patient management, although this varied according to the role. Overall, two-thirds of services offered patients a named nurse contact with no difference between hospital (63%) and community DSNs (69%).

Hospital DSNs were more likely than community DSNs to undertake specialist clinics such as pre-assessment clinics prior to surgery ($P < 0.000$), ante-natal ($P < 0.000$), renal

Table 1 Specific roles undertaken by diabetes specialist nurses (DSN)

	Hospital DSN [(*N* = 132), %]	Community DSN [(*N* = 104), %]	Paediatric DSN [(*N* = 67), %]	Nurse Consultant in diabetes [(*N* = 29), %]	*P*
Patient management	99	96	93	76	
Prescribing	49	56	27	66	
Non-medical prescribing	47	46	9	55	
Dose adjustment only	68	62	63	17	
Pump training*	55	36	43	21	0.003
Hypertension clinic*	22	11	5	21	0.019
CVD	30	20	3	28	
Foot clinics*	34	14	2	10	0.000
Renal clinics*	27	9	2	14	0.000
In-patient work*	98	36	54	24	0.000
Ante-natal clinics*	72	41	12	35	
Pre-assessment clinics prior to surgery*	23	5	0	7	0.000
Education for nursing staff*	98	89	88	90	0.007
Education for medical staff*	92	81	73	76	0.008
Education for other allied healthcare professionals	91	91	70	79	
Education for patients	93	95	75	76	

*Significant differences between hospital DSN and community DSN.

($P < 0.000$), foot clinics ($P < 0.000$) and pump training ($P = 0.003$).

Eleven percent of DSNs undertook roles other than diabetes such as general medicine and endocrinology compared with 8% of DSNs in 2000.

Ninety percent of services offered separate clinics where the nurses worked without immediate medical supervision, whereas in 2000 this role was not identified. The type of clinical work undertaken in nurse-led clinics was diverse and complex (Table 1). The mean number of weekly independent clinics provided in each centre was 3.3 (median 4, range 0 to > 4).

Of hospital-based services, 71% provided a telephone help-line available to all patients. Thirty-three percent offered a paediatric telephone help-line and 27% had a dedicated pregnancy telephone service, whereas 16% offered telephone access to other specific patient groups. Of those with a telephone service, 91% offered this during weekday office hours, but only 12% offered the service 24 hourly 7 days a week. Five percent operated a weekday evenings service and 2% a weekend office hours service. Most (94%) of the help-lines were operated by hospital DSNs, but the help-line was also manned by secretaries (11%), education centre staff (5%) and other staff including junior doctors. There are no data concerning help-line services operated by primary care staff.

Nurse prescribing

Although 77% of trusts had one or more nurses who had attended a nurse prescribing course, nurse prescribing was undertaken in only 48% of responding trusts (Table 2). The reasons for this difference included delayed implementation and lack of approval for trust protocols and formulary.

Table 2 Comparison data of role components 2000/2007 surveys

	Overall			Comparable hospitals		
	2007	2000		2007	2000	
	Percentage	Percentage	*P* value	Percentage	Percentage	*P* value
Patient management	99.2	97	NS	98.7	100	NS
Prescribing	48.5	31	0.002	53.9	31	0.02
Dose adjustment only	68.2	77	NS	60.7	76	0.03
Education for nursing staff	97.7	98	NS	98.7	98	NS
Education for medical staff	92.4			93.4		
Education for other allied healthcare professionals	90.9			90.8		
Patient education	93.9			93.4		

As the indicators for education are not comparable, we were not able to check for significant differences.

Table 3 Topics covered in education sessions

	Percentage 2007 (N = 151)	Percentage 2000 (N = 183)	P
Nature of diabetes	99	99	
Why metabolic control is important	95	97	
Impact of diet and exercise	95	97	
Coping with diabetes during illness	94	98	
Hypoglycaemia	94		
Driving	93	94	
Home blood monitoring*	90	98	0.002
Travel	89	91	
Insurance	89	92	
Employment	89	86	
Smoking	88		
Footwear*	87	76	0.008
Injection technique*	86	97	0.000
Carbohydrate dose adjustment	83		
Prescription charges	81	83	
Contraception	76	81	
Pre-conception counselling	74		
Erectile dysfunction	71		
Home urine monitoring*	44	73	0.000
Group initiation of insulin	41		
Intensive insulin therapy	22		
Other	15		

*Significant differences. Italics indicate new topics introduced since 2000.

Paediatric nursing

Ninety-three percent (113) of services had a dedicated PDSN, of whom 97% had a paediatric nursing qualification. The mean number of children per PDSN was 109 – 7 (mode 120), which exceeds the Royal College of Nursing (RCN) recommendation of one whole-time equivalent PDSN for 70 children with diabetes [8]. The number of dedicated PDSNs in most services was one (121 respondents), with only 38% of services having two or more. There was a wide variation in the provision of dedicated PDSNs. For example, in one service there was only one 0.4 whole-time equivalent unqualified PDSN for a caseload of 270 children.

Diabetes education provision

Most DSNs and Nurse Consultants were involved in diabetes education provision for both healthcare professionals and patients. Education for healthcare professionals was provided by 94% (132) of hospital DSNs, 87% (104) of community DSNs, 82% (29) of Nurse Consultants and 76% (67) of Paediatric DSNs.

Ninety-seven percent of services provided patient education sessions in both primary care and secondary care locations. The majority (97%) offered sessions on weekdays, but 19% also held sessions in the evenings and 4% at weekends.

Structured education sessions for people with Type 1 and Type 2 diabetes were commonly available with around 85% (115) providing National Institute for Clinical Excellence (NICE)-approved programmes [9]. There were no significant regional differences in the provision of structured education sessions. Patient education sessions covered a broader range of topics than were identified in the 2000 survey. New topics included pre-conceptual counselling (74%), carbohydrate counting and dose adjustment (82%), smoking cessation (88%) and erectile dysfunction (71%) (Table 3).

Research

One in five nurses had a formal role in diabetes research (22%) compared with 48% in 2000 (P < 0.000).

Employment data

Acute trusts employed the majority of hospital DSNs (95%), Health Care Assistants and Diabetes Care Technicians (63%). Primary care organizations employed most of the community DSNs. Nurse Consultants were employed and managed by both types of organization: 48% (14) were employed by primary care, 38% (11) by the acute trust, 3% (1) by both and 10% (3) by another organization. Thirty-three percent [8] were managed by the acute trust, 54% (13) by primary care organizations, 4% (one) by both and 13% (three) by another organization.

Approximately one in five trusts did not have a written job description for the role of the hospital DSN. One-third of responders identified DSNs on short-term contracts funded by external sources.

Locality of employment

The locality of work varied depending on who employed the DSNs. DSNs employed by secondary care worked mainly in hospital wards and out-patient departments, whereas one-third reported DSNs working across hospital and primary care. Hospital and community DSNs employed by Primary Care Organizations worked mainly in primary care, although nearly half of the community DSNs worked in both the hospital and community setting. General practice-employed DSNs tended to work wholly in primary care.

Only 35% of hospital DSNs employed by acute trusts and 44% of community DSNs employed by the primary care provider worked in both hospital and community settings. This is a significant reduction compared with 2000, when 85% of nurses worked across both the hospital and community. These findings are consistent with results obtained from services involved in both the 2000 and 2007 surveys. In this sub-group, 91% of the 2000 comparable services worked in both settings compared with only 30% in 2007 ($P < 0.000$). The nature of service integration was a common theme reported by DSNs and was described in both positive and negative terms. The dimensions of the theme ranged from changes over time, being a costed activity and how collaborative working had developed. Comments received included:

We all used to work together as a team, now very separate and less communication if any

The Acute Trust don't allow community cross over unless paid for

Poor integration with acute trust, inpatients discharged

Twice monthly multi-disciplinary team across primary and secondary care

Specific service level agreements for diabetes services were reported by 56% of responders.

DSN grading

Most nurses had been banded according to the new pay structure set out by Agenda for Change. There were no significant differences between the mean numbers of nurses in each band by region.

Continuing professional development of staff

Forty-eight percent (73) had protected time for the continuing professional development (CPD) of staff, but only 15% (22) had a protected CPD budget. This varied regionally; those in the South of England (27%) were more likely to have protected funding for training than DSNs in the North (9%) or Midlands (5%, $P = 0.013$).

Discussion

This UK survey of diabetes nurses has demonstrated the diverse and expanding role of the DSN over the last 8 years and the integral role that nurses have in the clinical care of people with diabetes and within the multidisciplinary diabetes team. DSNs are now taking on more complex aspects of clinical care and education that would previously have been undertaken by doctors. In addition, there has been the creation of diabetes care technicians, who have adopted some of the roles seen as traditional parts of the DSN role. This diversification of role should be seen as a positive step forward in response to the changing needs of people with diabetes and the changing NHS. Indeed, the development of the DSN roles was predicted by the 2000 ABCD survey.

At the same time, we are witnessing a fragmentation of services, with fewer nurses working in both primary and secondary care settings, which threatens the ability of the health service to provide high-quality integrated services. Furthermore, there are a large number of nurses who are on short-term externally funded contracts, which may hamper the retention of skills in diabetes services when these contracts expire. The lack of time and resources dedicated to CPD and research is worrying at a time when many new and more complex treatments are becoming available.

There have been many changes in the role of DSNs since their inception 60 years ago and it is likely that these changes will continue. There has been a widening of the clinical role, which now includes responsibilities for nurse prescribing, pre-assessment clinics, ante-natal, renal, foot clinics and pump training. More nurses are working independently, as shown by the frequency of nurse-led clinics.

DSNs have also adopted new working practices to meet the changing demands of people with diabetes. Most services offer telephone help-lines that are manned by DSNs.

As the work of DSNs has become more complex to meet the challenge of new therapies and technologies and the move to integrated diabetes care, two new roles have emerged. The role of Nurse Consultants with strong leadership and clinical skills was predicted in the 2000 survey. These posts were expected to evolve from senior hospital DSN roles, but in practice the Nurse Consultant role has been adopted by both primary and acute trusts, with more Nurse Consultants working in primary care.

What was not predicted was the creation of the Diabetes Health Care Assistant or Diabetes Care Technician role. This role has developed in response to the need for a wider skill mix in diabetes care and incorporates competencies aligned to the diabetes annual review. This role would more commonly be expected to be placed in primary care, where many of the annual reviews are now undertaken; however, the majority of these are based in acute care.

These new roles have led to the development of a new career structure for diabetes nursing and have supported the shift by DSNs towards increasing specialization in diabetes management.

The number of paediatric DSNs (PDSN) working entirely with children with diabetes has greatly increased, with only six services (5%) in 2007 reporting no separate PDSN compared with 41% in 2000. Although there has been clear expansion of this role, it still falls short of the levels recommended by the RCN. There is marked variation in provision between hospitals, and some services appear particularly stretched with large case loads per nurse.

In addition to the expanding roles, DSNs play an increasingly crucial role in patient and healthcare professional education. Although there is still a multidisciplinary approach to course planning, it is often the DSN who leads the planning and delivery of education programmes. The programmes have also become more sophisticated following the NICE guidance to introduce approved structured education. Given this additional complexity, it is reassuring that so many services now offer these programmes.

At the same time as these new developments and initiatives, Agenda for Change was being implemented to assess pay and conditions. Following this, a survey of DSNs by Diabetes UK in 2007 revealed considerable variation in grading and responsibilities [10]. Although the Agenda for Change process appears to have reduced geographical differences in pay as highlighted in the 2000 survey, almost one-fifth of nurses banded by 2007 had no job description on which to base pay bands. This suggests that some DSNs may have been banded accorded to generic group job descriptions. It is therefore unlikely that the new expert clinical roles being taken on by DSNs are being recognized in terms of pay progression. This, coupled with a number of barriers to role progression, may lead to frustration with these issues.

The innovation in nurse prescribing has been impeded by trusts failing to provide pathways to facilitate this new skill. Furthermore, specialist knowledge and skills need to be underpinned by continual professional development. It is concerning that 40% and 45%, respectively, of DSNs reported that study leave time had been reduced and funding requests denied. Access to study leave or funding has not improved in recent times, with still only one-half of DSNs having protected time and only 15% having protected CPD budgets. The successful integration of DSNs into advanced clinical care is in danger of being undermined further by lack of commitment to support nurse engagement in research.

One-third of hospital DSNs and community DSNs are employed on short-term contracts, funded by external sources. This lack of long-term job security may further affect recruitment and retention of highly skilled specialist nurses.

Access to high-quality integrated care at the right time by the right person for people with diabetes is a central tenet of both ABCD and Diabetes UK. There is evidence that since 2000 there has been a fragmentation of services. In 2000, diabetes specialist services were characterized by cross-boundary working of diabetes nurses. Since then, there has been significant splitting of services between primary and secondary care settings. This is contrary to the concept of integrated care, and the long-term effect it will have on the diabetes nursing profession and care of people living with diabetes remains to be seen.

There are a number of limitations to the survey. Overall the response rate was only 44% and therefore there is a possibility of responder bias. There are important differences between this survey and the previous ABCD survey in 2000. In 2000, the answers were completed by Consultants answering on the nurses' behalf and therefore may not be directly comparable. Nevertheless, when the results of those trusts that took part in both surveys were analysed separately, there was no change in the findings, suggesting that the results are representative of services at both time points. A further limitation of the survey is that questions were not asked about the competencies and qualifications required to be a DSN.

In summary, the diabetes specialist role has expanded and developed to meet the needs of the ever-growing diabetes population and government directives. There has been considerable progress over the last 8 years since the previous survey. The lack of opportunity for study leave and research opportunities is concerning. This, coupled with lack of long-term job security, may affect the retention and recruitment of DSNs in future years. It may also be that DSN training and education needs to be underpinned by a formal training curriculum, as suggested in the 2000 survey. Fundamental changes that have led to services developing separately in primary and secondary settings may affect the continuity of patient care.

A number of recommendations follow the findings of the survey. In order to facilitate best practice in the care of people with diabetes, it is essential that DSNs have protected access and funding to continual professional development in the form of study leave and through participation in research activities. The case-load of existing PDSNs should be reduced to the levels recommended by the RCN to improve care of children and young people with diabetes.

Having developed a career structure for DSNs, it is vital this is enabled through accurate job descriptions on which to base pay and that job security is supported through permanent contracts.

In order to promote and facilitate the ethos of integrated diabetes care, DSNs should have the opportunity to meet regularly with their peers, whether working in primary or secondary care.

Competing interests

J.J. and C.G. have none to declare; R.I.G.H. is an Honorary Consultant Diabetologist working in the NHS.

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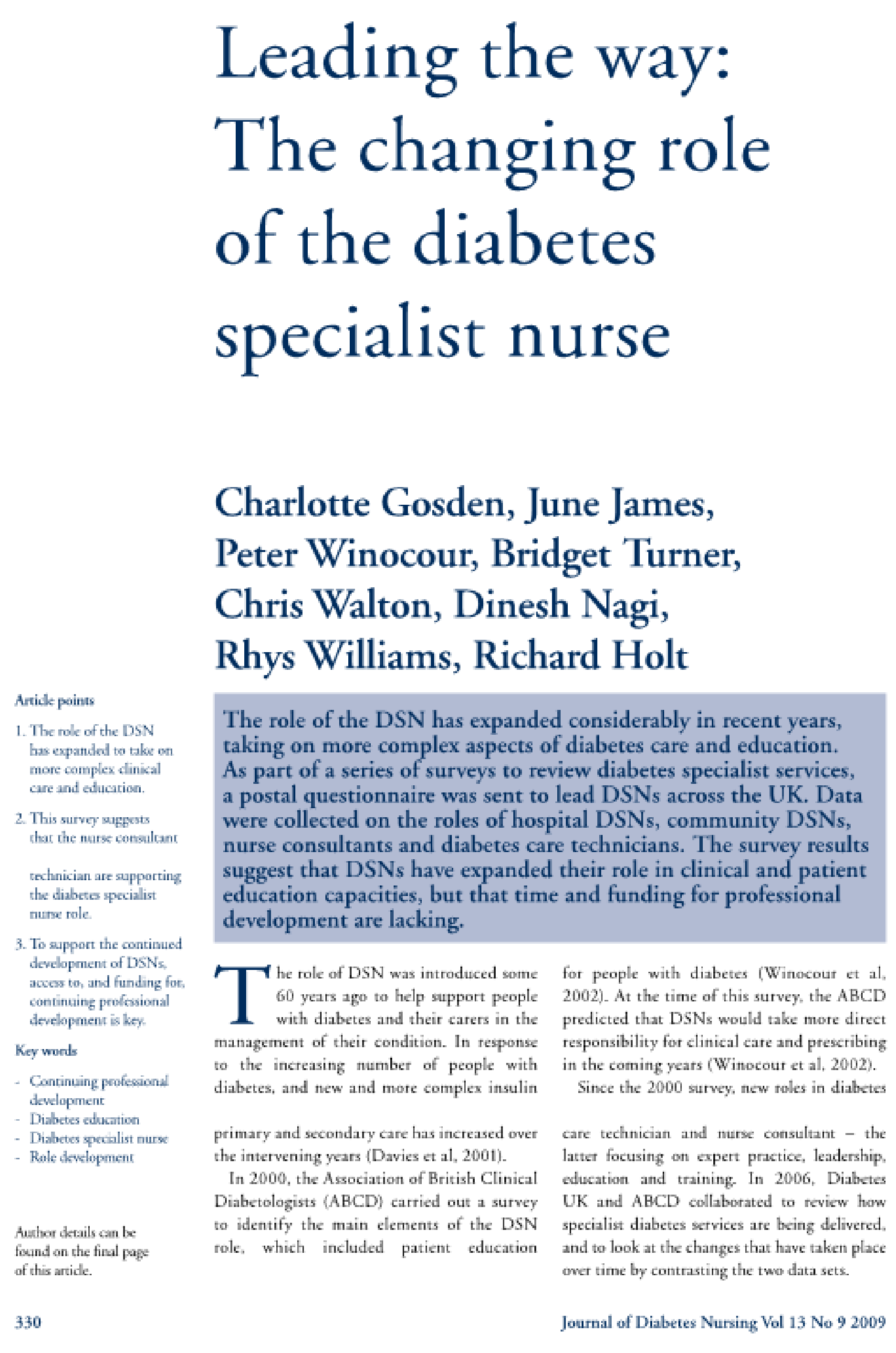


Leading the way: The changing role of the diabetes specialist nurse

Charlotte Gosden, June James,
Peter Winocour, Bridget Turner,
Chris Walton, Dinesh Nagi,
Rhys Williams, Richard Holt

Article points

1. The role of the DSN has expanded to take on more complex clinical care and education.
2. This survey suggests that the nurse consultant

   technician are supporting the diabetes specialist nurse role.
3. To support the continued development of DSNs, access to, and funding for, continuing professional development is key.

Key words

- Continuing professional development
- Diabetes education
- Diabetes specialist nurse
- Role development

The role of the DSN has expanded considerably in recent years, taking on more complex aspects of diabetes care and education. As part of a series of surveys to review diabetes specialist services, a postal questionnaire was sent to lead DSNs across the UK. Data were collected on the roles of hospital DSNs, community DSNs, nurse consultants and diabetes care technicians. The survey results suggest that DSNs have expanded their role in clinical and patient education capacities, but that time and funding for professional development are lacking.

The role of DSN was introduced some 60 years ago to help support people with diabetes and their carers in the management of their condition. In response to the increasing number of people with diabetes, and new and more complex insulin

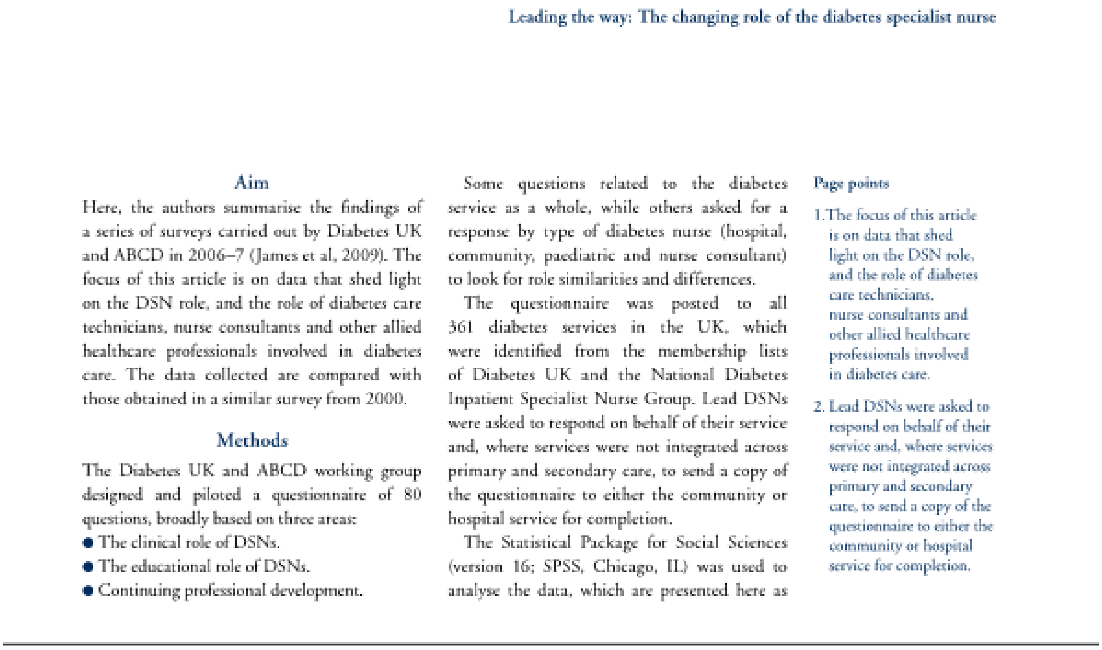
primary and secondary care has increased over the intervening years (Davies et al, 2001).

In 2000, the Association of British Clinical Diabetologists (ABCD) carried out a survey to identify the main elements of the DSN role, which included patient education for people with diabetes (Winocour et al, 2002). At the time of this survey, the ABCD predicted that DSNs would take more direct responsibility for clinical care and prescribing in the coming years (Winocour et al, 2002).

Since the 2000 survey, new roles in diabetes

care technician and nurse consultant – the latter focusing on expert practice, leadership, education and training. In 2006, Diabetes UK and ABCD collaborated to review how specialist diabetes services are being delivered, and to look at the changes that have taken place over time by contrasting the two data sets.

Author details can be found on the final page of this article.



Aim

Here, the authors summarise the findings of a series of surveys carried out by Diabetes UK and ABCD in 2006–7 (James et al, 2009). The focus of this article is on data that shed light on the DSN role, and the role of diabetes care technicians, nurse consultants and other allied healthcare professionals involved in diabetes care. The data collected are compared with those obtained in a similar survey from 2000.

Methods

The Diabetes UK and ABCD working group designed and piloted a questionnaire of 80 questions, broadly based on three areas:

- The clinical role of DSNs.
- The educational role of DSNs.
- Continuing professional development.

Some questions related to the diabetes service as a whole, while others asked for a response by type of diabetes nurse (hospital, community, paediatric and nurse consultant) to look for role similarities and differences.

The questionnaire was posted to all 361 diabetes services in the UK, which were identified from the membership lists of Diabetes UK and the National Diabetes Inpatient Specialist Nurse Group. Lead DSNs were asked to respond on behalf of their service and, where services were not integrated across primary and secondary care, to send a copy of the questionnaire to either the community or hospital service for completion.

The Statistical Package for Social Sciences (version 16; SPSS, Chicago, IL) was used to analyse the data, which are presented here as

Page points

1. The focus of this article is on data that shed light on the DSN role, and the role of diabetes care technicians, nurse consultants and other allied healthcare professionals involved in diabetes care.
2. Lead DSNs were asked to respond on behalf of their service and, where services were not integrated across primary and secondary care, to send a copy of the questionnaire to either the community or hospital service for completion.

Page points

1. Of the services surveyed, 90% held independent DSN-led clinics.
2. In 97% of services, DSNs provided education to people with diabetes and healthcare professionals in both primary and secondary care settings.
3. The current survey revealed that 93% of services had one or more paediatric DSNs on staff.

percentages. Associations between variables were calculated using the Chi-squared test. $P<0.05$ was considered statistically significant.

Results

Responses were collected between February and December 2007, following both postal and telephone reminders. One hundred and fifty-nine completed questionnaires were returned, giving a response rate of 44%. Of those that returned the questionnaire, 65% represented services that were integrated across primary and secondary care settings.

DSN role in clinical care

Clinical care tasks, and the percentage of diabetes nurses from any setting (hospital, community, paediatric and nurse consultants) who carried them out, are shown in *Table 1*. Of the services surveyed, 90% held independent DSN-led clinics, on average three times per week.

Table 1. Specific (a) clinical, and (b) educational tasks undertaken by DSNs in a variety of settings. Adapted with permission from James et al (2009).

	Services (%)			
	Hospital DSN (n=132)	Community DSN (n=104)	Paediatric DSN (n=67)	Nurse consultant (n=29)
(a) Clinical tasks undertaken by DSNs				
Patient management	99	96	93	76
Prescribing	49	56	27	66
Non-medical prescribing	47	46	9	55
Dose adjustment only	68	62	63	17
Pump training*	55	36	43	21
Hypertension clinics*	22	11	5	21
Cardiovascular disease	30	20	3	28
Foot clinics*	34	14	2	10
Renal clinics*	27	9	2	14
Inpatient care*	98	36	54	24
Antenatal*	72	40	12	35
Pre-assessment clinics prior to surgery*	23	5	0	7
(b) Education undertaken for various groups by DSNs				
Education for nursing staff*	98	89	88	90
Education for medical staff*	92	81	73	76
Education for other AHPs	91	91	70	79
Education for patients	94	95	75	76

*Statistically significant difference between hospital and community DSNs ($P<0.05$).
AHP = Allied healthcare practitioner.

DSN role in prescribing

In 77% of services, one or more of the nurses had attended a course in nurse prescribing. However, only 48% of these were putting the prescribing skills learned into practice. In some cases, this failure to use the nurses' training resulted from either Trust policy preventing or delaying the implementation of nurse prescribing. Delays in the development of protocols or agreement in the formulary were also reported.

DSN role in education

In 97% of services, DSNs provided education to people with diabetes and healthcare professionals in both primary and secondary care settings. DSNs and nurse consultants working in all settings were involved in education provision (*Table 1*). Sessions were usually held during working hours (97%), but some took place in the evening (19%) or on weekends (4%).

The range of topics covered in these educational sessions had increased since the 2000 survey. Pre-conception counselling, carbohydrate counting and smoking cessation were new additions to the curricula (*Table 2*). Compared with 2000 data, the current survey revealed that hospital DSNs in 2007 had taken on more of the planning and delivery of educational sessions than other members of the multidisciplinary team (*Table 3*).

DSN role in paediatric diabetes care

The current survey revealed that 93% of services had one or more paediatric DSNs on staff. Nearly all of these nurses had a qualification in paediatric nursing (97%). Clinically, paediatric DSNs are primarily involved in patient management, dose adjustment, inpatient care and providing insulin pump training (*Table 1*).

The high percentage of services with at least one paediatric DSN is in contrast to the data from 2000, in which only 59% of services reported the same. Despite this improvement, the current survey reveals that the average case load of children per paediatric DSN remains unacceptably high (109; range 15–300).

Table 2. Educational topics covered by DSNs in (a) both the 2000 and 2007 surveys, and (b) new topics for 2007. Adapted with permission from James et al (2009).

	Services 2007 (%) (*n*=151)	Services 2000 (%) (*n*=183)
(a) Topics covered (2000, 2007)		
Nature of diabetes	99	99
Importance of metabolic control	96	97
Impact of diet and exercise	95	97
Managing diabetes during illness	94	98
Driving	93	94
Home blood monitoring*	90	98
Travel	89	91
Insurance	89	92
Employment	89	86
Footwear*	87	76
Injection technique*	86	97
Prescription charges	81	83
Contraception	76	81
Home urine monitoring*	44	73
(b) New topics covered (2007)		
Hypoglycaemia	94	
Smoking cessation	88	
Carbohydrate dose adjustment	83	
Pre-conception counselling	74	
Erectile dysfunction	71	
Group initiation of insulin	41	
Alternative intensive management scheme	22	

*Statistically significant difference between hospital and community DSNs ($P<0.05$).

Table 3. Education planning and delivery undertaken by DSNs and other healthcare professionals (HCPs).

	Services (%)		
	2007		2000
	Education planning	Education delivery	Education input from other HCPs
Hospital DSN	78	76	
Dietitians	64	72	88
Podiatrists	32	44	84
Medical staff	14	23	66
Pharmacists	5	6	8

Diabetes care technician role

The majority of services (66%) reported having one or more diabetes care technicians. Diabetes care technicians were reported to carry out a range of activities, the majority relating to the annual reviews of people with diabetes (*Table 4*).

Continuing professional development

Less than half (48%) of the services reported offering guarantee time for continuing professional development for DSNs. In only 15% of services was there a protected budget for professional development. Comparing present data with the results from 2000, significantly fewer nurses has a formal role in diabetes research (22% vs. 48%; $P<0.001$). Specific, personalised job descriptions for DSNs were reported by 78% of services, compared with 86% in 2000.

Telephone helplines

Telephone helpline support was offered to people with diabetes by 71% of hospital-based services. These helplines were available during weekday office hours (91%) and were operated by hospital DSNs (94%) with support provided by secretaries (11%) and education centre staff (5%). Few services operated helplines outside of normal office hours, with 12% providing a 24-hour service, 5% available on weekday evenings and 2% on weekend office hours.

Discussion

The results of this survey demonstrate that DSNs play a key role in caring for people with diabetes through patient management, delivering education and giving telephone support. In the 8 years since the first DSN survey (Winocour et al, 2002), the role has continued to evolve and expand as predicted, with DSNs taking on more complex aspects of clinical care, such as pump training, prescribing and foot clinics, as well as working independently in DSN-led clinics.

Furthermore, the current survey found that DSNs have more responsibility for planning and delivering education on an increasingly broad range of topics. This is with less input from the multidisciplinary team than was seen

Page points

1. The expansion of the DSN role has been supported by the introduction of two new roles in diabetes care services: the nurse consultant and the diabetes care technician.
2. There is still a shortfall in the number of paediatric diabetes specialist nurses, with many services failing to meet the Royal College of Nursing recommendation of one paediatric diabetes specialist nurse to every 70 children and young people with diabetes.
3. To provide high quality care, it is key that DSNs are able to access continuing professional development through study leave and funding that is protected for this purpose.

in 2000 (although, it is important to ensure that all diabetes education is undertaken with the support of the full multidisciplinary team).

Significantly fewer hospital DSNs reported having a liaison role with primary care practice nurses than in 2000 ($P<0.001$). This means that there is less opportunity to provide support and education to develop practice nurse competencies, which is a core part of providing a diabetes service. However, it may be the result of the increased number of community DSNs during the intervening time.

The expansion of the DSN role has been supported by the introduction of two new roles in diabetes care services: the nurse consultant and the diabetes care technician. This survey reveals that diabetes care technicians have taken on responsibilities for core elements of the annual diabetes review. These tasks traditionally fell to the DSN or practice nurse, and this sharing of care increases the time available to DSNs to carry out prescribing, teaching and running clinics. The introduction of the nurse consultant role has created a career structure for DSNs that promotes and recognises their increasing leadership and clinical expertise, and opens up avenues for research (Pennington, 2000).

There is still a shortfall in the number of paediatric DSNs, with many services failing to meet the Royal College of Nursing (2006) recommendation of one paediatric DSN to every 70 children and young people with diabetes. While the number of paediatric DSNs has improved since the 2000 survey, the improvement has been patchy and suggests geographical inequalities in service provision for children and young people with diabetes.

Table 4. Activities carried out by diabetes care technicians.

Activity	Services (%)
Weight/height/BMI	95
Urine testing	91
Blood pressure	83
Visual acuity	56
Waist circumference	47
Exercise advice	31
Injection site check	28
Foot screening	27
Smoking cessation advice	27
Pre-conception advice	18
Medication review	16
Other	10

In the Department of Health (2008) publication, *A High Quality Workforce: NHS Next Stage Review*, the role of nurses was recognised as being at the heart of shaping patient experience and care delivery. The document states that achieving high-quality care without high-quality nursing is impossible. To provide high-quality care, it is key that DSNs are able to access continuing professional development through study leave and funding that is protected for this purpose.

It is disappointing that this survey demonstrates that support for DSNs to access continuing professional development has not improved since a Diabetes UK survey on specialist staffing cuts in 2006, at which time is was found that 40% of nurses had their time for study leave reduced, 45% had their funding for professional development had been reduced and 40% said that requests for study leave had been denied (James et al, 2007). This increasingly limited access to professional development, together with the finding that significantly fewer nurses are engaged in research, suggests that the skill and knowledge development of DSNs is being undermined.

Conclusion

The quality of care for people with diabetes, and the support of services developments, can only be achieved through consistent and regular access for nurses to professional development opportunities. Such allowances are key in maintaining the leadership role of DSNs, and to the status and function of specialist nurses in general.

The DSN, especially in the community, is an expert resource who is accessed by a variety of other clinicians for advice, support and guidance in diabetes care. Such a position can only be fulfilled and sustained if the DSN's knowledge is up-to-date and specialist.

Having developed a career structure for DSNs, it is key that their progression is supported. This extends not only to adequate time and funding for professional development, but also to opportunities to take part in research, and to the provision of accurate job descriptions on which to assess pay. The latter would be supported by a database of DSNs that contains accurate information on job titles and qualifications to support both nurse career progression, and would indicate whether a service's workforce included staff with the necessary skill sets to meet the needs of people with diabetes.

Across the UK, the number of paediatric DSNs needs to be increase to reduce inequalities in the support and care of children and young people with diabetes. Furthermore, seamless and integrated service delivery would be facilitated through greater opportunities for DSNs working in both primary and acute care to meet regularly for collaboration and support, thereby ensuring continuity of care for people with diabetes. ■

The DSN, especially in the community, is an expert resource who is accessed by a variety of other clinicians for advice, support and guidance in diabetes care.

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The fifth UK paediatric diabetes services survey: meeting guidelines and recommendations?

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The fifth UK paediatric diabetes services survey: meeting guidelines and recommendations?

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ABSTRACT

Aim To assess the provision of UK paediatric and adolescent diabetes services and examine changes in service delivery since 2002.

Method Questionnaires were sent to the lead paediatric consultant from all paediatric and adolescent diabetes services (n=205). Questions were based on National Institute for Health and Clinical Excellence and Scottish Intercollegiate Guidelines recommendations for diabetes care in childhood. Results were analysed using parametric and non-parametric tests.

Results 129 Services (63%) returned questionnaires involving 220 clinics. Staffing has improved and 98% of consultants have a special interest in diabetes (89%, 2002). In 88% of services, the diabetes specialist nurse worked solely in paediatric diabetes (53%, 2002). Only 21% of clinics have a psychological professional integrated within the diabetes team (20%, 2002). Over 94% of services offered support with intensive insulin regimens causing problems at school for 36% of services. Almost all services offer annual microvascular screening (98–100%) but transitional care was variable; only 76% of services have specific local protocols for transition and 21% organise transfer by letter only.

Conclusion Paediatric and adolescent diabetes services are rising to the challenge of providing high-quality care despite rising prevalence and increasingly complex insulin regimes. Services have improved in a number of key areas but serious deficiencies remain.

What is already known on this topic

- In 2002 services for children had improved; children were seen in larger, more specialised clinics by consultants with an interest in diabetes.
- There was poor access to specialised psychological and psychiatric services.

What this study adds

- Transitional care is still variable, only 76% of services have specific local protocols for transition and 21% of services still organise transfer by letter only.
- There is a need to improve support services such as 24-h telephone contact with professional advisors and access to psychological support.

INTRODUCTION

The incidence of type 1 diabetes has doubled in the last decade especially in younger children.[1] The management of these individuals has become more complex to avoid long-term complications of diabetes yet maintain good quality of life. Recent national audit data suggest that diabetes control is consistently poor throughout the UK.[2] It is possible that deficiencies in clinical service provision may have an adverse impact.

Since 1988, there have been four surveys of UK childhood diabetes services which have shown an improvement in service provision.[3–6] The last survey in 2002 highlighted serious deficiencies in dedicated paediatric staff numbers, poor access to psychology support and difficulties in transitional care.[6] Since then, the National Institute for Health and Clinical Excellence (NICE)[7] and the Scottish Intercollegiate Guidelines (SIGN) Network[8] published guidelines for standards of diabetes care for children. A fifth national survey has been performed to assess services against these criteria by Diabetes UK, Association of Children's Diabetes Clinicians, British Society of Paediatric Endocrinology and Diabetes (BSPED) and Association of British Clinical Diabetologists (ABCD).

METHODS

A working group developed and piloted a questionnaire comprising 73 open and closed questions examining the provision of paediatric diabetes services in England, Northern Ireland, Scotland and Wales. Topics were based on recommendations from NICE and SIGN. It was recognised that some clinical *services* would operate more than one *clinic* in different geographical locations. Therefore some questions related to the whole *service* and some to individual *clinic* provision. Although the questionnaire was designed so comparisons could be made with previous surveys, some comparisons proved difficult.

Lead consultants from all identifiable services were invited to complete the survey. Services were emailed via 'opinion-taker' website. Where emails were undelivered, postal copies were sent. A reminder questionnaire was emailed or posted after 1 month followed by a telephone reminder. Data were collected between April and December 2008.

Data analysis

Results are presented by service, except where responses by clinic were invited.

Completed online questionnaires were exported into Microsoft Excel and SPSS v16 for analysis. Results were analysed using parametric and non-parametric tests according to the distribution of the data.

RESULTS

A total of 205 questionnaires were posted and responses received from 129 services (63%) involving 220 clinics. Responses were received on behalf of 196 paediatric consultants caring for a total of 17 071 children and young people (CYP) of whom 13 721 were aged 15 and under. Table 1 summarises key survey results and compares to findings from the four previous surveys.

Workforce

Most services were led by consultants with an interest in diabetes: 9% were paediatric diabetologists/endocrinologists, 51% were paediatricians with a special interest in diabetes and 38% were paediatricians with a special interest in diabetes and endocrinology. Only 2% of services were staffed by general paediatricians (11%, 2002, p=0.004). Fifty-eight per cent (73) of services were run by one consultant and 60% of consultants dedicate 1–2 programmed activities (4-h sessions) to diabetes.

Most clinics (94%) were attended by a Paediatric Diabetes Specialist Nurse (PDSN) 88% of whom worked solely in paediatrics (53%, 2002). Twenty-four per cent of services have support from adult-trained DSNs (28%, 2002) and 72% (123) of PDSNs work in both hospital and community settings (91%, 2002, p<0.000). Nursing caseloads have decreased from one nurse to 147 patients in 2002 to 1:92 in 2009.

Ninty-three per cent of clinics offer CYP dietetic support (87% of clinics reported that a dietitian regularly attended clinics, 2002). Only 21% of clinics have a psychological professional working as an integrated member of the diabetes team. The median whole time equivalent available to these clinics is 0.2 (range, 0.02–2). Where there is no dedicated psychological professional, referrals may also be made to the following: 73% to a clinical psychologist (87%, 2002; p=0.005), 40% psychiatrist (90%, 2002), 16% counsellor (27% in 2002), 14% social worker (18%, 2002), 10% nurse therapist (49%, 2002), 10% family therapist, 6% psychotherapist and 1% health psychologist. Appointment waiting times ranged from 0 to 40 weeks, the median being 10 weeks (1–18 months, 2002).

Fifty-five per cent of services provide diabetes training for junior doctors. Four per cent reported that trainees spent no time attending the diabetes service and 60% had trainees who spend 10% or less of their time in outpatients, where the majority of children with diabetes are seen.

Organisation of paediatric diabetes services

Eight per cent of services reported that children are not seen in a designated paediatric diabetes clinic (2%, 2002) and fewer (44%) operate age-banded clinics (71%, 2002 (p<0.000)).

Transition

Seventy-six per cent of clinics have specific local protocols to transfer young people from paediatric to adult services (84%, 2002). A variety of models of transition were reported with services often using more than one model (table 2). Transfer started at 16 years (median; range, 11–18 years) ending at 18 years (range, 14–25 years).

Education

Ninty-five per cent of services report that they offer CYP educational opportunities; 70% offer a structured education programme for those newly diagnosed with type 1 diabetes.

Half of services offer an alcohol education programme to young people, 98% inform CYP about general health problems associated with smoking and 51% offer CYP smoking cessation programmes if appropriate. Eighty-seven per cent of services advise about driving and 78% give contraceptive advice.

Management of diabetes

Although NICE recommend that children with newly diagnosed diabetes are managed at home only 26% of services offer this option and 68% of services manage all children as inpatients. Thirty-one per cent of services report that CYP and their families are involved in making decisions about care

Table 1 Comparison of results to previous surveys

						p Value
	1988	1994	1998	2002	2008	2008 vs 2002
Total number of consultant responses	360	325	244	187	196 Consultants representing 129 clinical services	NA
Response rate	86%	94%	81%	78%	63%	
Consultant with a special interest in diabetes/ endocrinology	32%	48%	78%	89%	98%	0.004
Consultant caring for more than 40 young people per clinic (2002)/service (2008)	23%	45%	74%	94%	99% (by service)	Not comparable
Designated paediatric diabetes clinic (service in 2008)	63%	88%	91%	98%	91%	Not comparable*
Diabetes specialist nurse in clinic	61%	87%	93%	98%	94%	p=0.03**
Paediatric dietitian in clinic	37%	57%	65%	61%	93%	Not comparable
Psychologist/psychiatrist in clinic	9%	22%	22%	22%	22%	Not comparable
Glycated haemoglobin at each visit	91%	90%	88%	86%	Yes always 75%	p=0.02***

*In 2008 this is measured by service rather than by clinic.

**However in 2008 the question asked if PDSNs attended the clinic rather than DSNs. In 2002, 82% of DSNs working with child had been children trained (p<0.000).

***Significant difference between 2002 and 2008.

PDSN, Paediatric Diabetes Specialist Nurses.

Table 2 Models of transition used in clinics

Models of transition used in the clinics	% Of clinics
Repeated joint clinic with adult colleague, then gradual transfer	51%
One-off joint clinic with adult colleague, then transfer	20%
Adult diabetologist in paediatric clinic, then transfer	9%
Paediatrician attends adult clinic with patient for handover	9%
Paediatrician runs separate transition clinic in adult diabetes centre	11%
Transfer only between consultants by letter	21%
Adult nurses meet patient before transfer	27%
Clinic other	1%

provided by the diabetes team through a written care plan, 65% involve patients but not a written plan.

Only 44% of services offer 24-h access to advice from the diabetes team. Most services keep a register of patient data: 66% keep this electronically, 25% on paper, 4% have both and 6% have none.

Insulin regimens

Ninty-four per cent of services offered support with intensive insulin regimens and 78% offer continuous subcutaneous insulin infusion (CSII). Seventy-eight per cent of the services who offer CSII have a trained specialist team available to initiate insulin pump therapy. The median number of CYP using insulin pump therapy per service is 5 (range, 0–69); 5.7% (5) of clinics who have pump facilities had no patients on pumps.

Monitoring glycaemic control

The mean HbA_{1c} reported by services for CYP under 16 years was 8.6% (70 mmol/mol) (range, 7.7–9.7% (61–83 mmol/mol)). Most (97%) services inform CYP that the target for long-term glycaemic control is an HbA_{1c} level of less than 7.5% (58 mmol/mol). Services take a more flexible approach to younger children and reported aiming for a mean of 7.8% (62 mmol/mol; median, 7.5% (58 mmol/mol); range, 6.5–9% (48–75 mmol/mol)) for 0- to 5-year olds, 7.6% (60 mmol/mol) for 6–11-year olds (median, 7.5% (58 mmol/mol), range, 6.5–8.5% (48–69 mmol/mol)) and 7.5% (58 mmol/mol) for CYP 12 years or older (median, 7.5 (58 mmol/mol), range, 6.5–9% (48–75 mmol/mol)). Seventy-five per cent of services ensure that HbA_{1c} measurements are available at every outpatient clinic (86% of clinics, 2002, p=0.02).

Guidelines

Most services have local protocols in place for CYP with diabetes to support diabetic ketoacidosis (99% follow BSPED's protocol), hypoglycaemia (94%), surgery (94%) and sick day rules (92%).

Complications and associated complications

Table 3 presents data on how often screening for diabetes related complications and associated conditions is offered. This survey did not examine uptake of screening within services as this is examined by national audit.[2]

Sixty-six per cent of services offer CYP an annual podiatric examination and injection sites are inspected at each clinic visit in 92% of services. Eighty-five per cent of services have access to the national retinal screening programme for all young people over 12 years old.

Managing diabetes in schools

All services report that the diabetes team liaise regularly with school staff to offer diabetes education and information. However, 36% have found it difficult or very difficult to arrange for someone at primary school to carry out blood glucose monitoring and 66% found it difficult or very difficult to find someone to administer insulin. Eighty-three per cent of services report that where the child is unable to inject insulin themselves, parents provide this support. Other support comes from other school staff (43%), the teacher (33%) and the school nurse (18%).

Table 3 Services offering screening for complications and associated complications

NICE recommended screening	2008 % Of services offering screening (count)
Coeliac disease at diagnosis	94
Coeliac every 3 years until transfer	89
Thyroid disease at diagnosis	97
Thyroid annually after diagnosis	88
Retinopathy annually from 12 years	100 (123)
Microalbuminuria annually from 12 years	99
BP annually from 12 years	98 (122)

BP, blood pressure; NICE, National Institute for Health and Clinical Excellence.

DISCUSSION

As in previous surveys these data suggest that paediatric services in the UK are improving but there is wide variation in how services are provided and significant shortfalls exist in key areas.

The trend towards specialisation of clinicians continues and 98% of services are led by consultants with a special interest in diabetes however this is in jeopardy with the apparent lack of dedicated training of junior doctors. The provision of specialist nursing care has improved with the majority being paediatric nurses. There are still serious deficiencies in psychological support which has remained static for 14 years, despite the emphasis placed on this in national guidance.

Services felt they provided support through education and engagement with CYP through collaborative care planning: 70% offer structured education, most likely a locally developed programme as currently no validated educational programmes for children exist. Most offer a wide choice in insulin regimen, however alarmingly of those providing pump therapy not all are compliant with NICE by ensuring all staff have received the necessary training. Fewer than half of services offer 24-h access to advice from the diabetes care team which is concerning given the increasingly complex nature of diabetes management.

The data suggest almost all services *offer* screening for microvascular complications and associated conditions, yet only 60% of CYP have had blood pressure measured and 26% had retinal screening (National Diabetes Audit (NDA) 2007–2008). It is not possible to link our data with NDA data so the reason for this discrepancy remains unclear. The presence of an electronic register in services which may help with data collection and correlation between surveys has not changed since 2002.

The process of transition remains problematic. Only three quarters have local protocols for transitional care and less than half operate age-banded clinics despite data which suggest CYP prefer being seen in clinic with their peers.[9] A number of different methods of transition are used reflecting the lack of robust data on the optimum method of transfer.[9] Almost a quarter of services arrange transfer by letter only which is unlikely to prepare an adolescent adequately for transition.

The difficult issue of diabetes care in schools has recently been highlighted by a Diabetes UK survey.[10] Two thirds of services reported that it was difficult or very difficult to find school staff to administer insulin and 83% of services reported parents doing injections at school. Children spend up to a third of their waking hours at school during term time and need support to manage their diabetes in this environment if overall control is to be improved.

There are a number of limitations to the survey. The response rate has declined to 63% which may reflect the overwhelming number of surveys emailed to clinicians and a lack of perceived benefit in participation if no improvements arise from surveys. As such results cannot be generalised to all units. Furthermore, as results are based on self-report there is a risk that some units may overestimate their responses. There are also methodological considerations since the introduction of NICE and SIGN standards of care which have made direct comparisons between 2002 and 2008 problematic.

In conclusion, national guidance may have influenced service delivery since 2002, in particular clinician and nurse specialisation and access to complication screening. Improvements are not universal and there are persistent deficiencies in dietetic provision, psychological support and transition process. In the future it will be important to link service delivery with outcomes, as collected by a national audit which should be made mandatory, if we are to deliver high quality diabetes services to increasing numbers of CYP with more complex management regimens.

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UK workforce survey of DSNs and nurse consultants: Update

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Article points

1. The aim of this study was to establish a database of DSNs working in the UK to help predict service needs over time and assist with workforce planning.
2. Most DSNs are qualified to the level required but it is worrying that some services are operating without a clinical lead.
3. Nearly half the DSNs and nurse consultants surveyed are expecting to retire in the next 10 years.
4. It is expected that this study will be repeated in 2010, and in all four UK nations, to build up national and regional pictures of the qualifications, work setting and roles of DSNs and nurse consultants.

Key words

- DSN
- Nurse consultant
- Survey
- Workforce

Author details can be found at the end of this article.

Aims: To establish a database of UK DSNs to help predict manpower needs over time, assist with workforce planning, and to identify roles, qualifications, work settings and banding. *Methods*: A questionnaire was developed and distributed to all identifiable UK DSNs (*n*=1363) in September 2009 and responses (*n*=838) colle[redacted]nuary 2010. Respondents could often give multiple answers, and missing responses have been omitted from the analysis. *Results*: Respondents gave 238 separate job titles representing the role of the DSN; 47% of DSNs work in hospital, 22% in the community and 28% work in both; 76% indicated that their role includes general adults, 41% inpatients, 23% paediatrics, but only 10% in research; 74% have a diabetes diploma/certificate, 14% h[illegible] undertaken diabetes-related degree; 18% have completed ad hoc masters modules and 8% have a diabetes-related masters degree; 44% expect to retire within the next 10 years. *Conclusion*: Fewer DSNs are working across both hospital and community settings, jeopardising opportunities for joint working, sharing knowledge and skills. Most DSNs are qualified to the level required of DSNs, however some services are operating without a clinical lead. By repeating this study annually, it can help to identify trends with which to guide service and manpower planning in the future.

The role of the DSN was first introduced over 60 years ago and became more common in the 1980s with the need to educate people with diabetes in the transfer to 100 strength insulin, and with the introduction of self-monitoring of blood glucose (Davies et al, 2001). Owing to the vast number of people requiring this support and education, more effort was directed towards establishing nursing posts rather than considering their roles, entry criteria or development. This led to a profusion of job titles being used to describe the role of DSN, a variety of pay scales and no clear role definition (Da Costa, 2000).

In response to this lack of career structure and guidance in qualifications, *An Integrated Career and Competency Framework for Diabetes Nursing* was launched in 2005

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1. DSNs should be registered nurses with a minimum 3 years' practice and they should have a proven interest in diabetes management, teaching and counselling.
2. All new-in-post specialist nurses are now required to have, or be working towards, a degree-level qualification to fulfil the national job profile for band 6 specialist nursing, and senior DSNs should be working towards a masters degree-level qualification for the advanced nurse job profile.
3. The aim of this study was to establish a database of DSNs and nurse consultants working in the UK to help predict workforce planning and services needs over time.

to guide strategic workforce planning and career development (Davis et al, 2007). This framework was updated in 2010 by TREND-UK (Training Research and Education for Nurses in Diabetes – UK, 2010).

What is a DSN?

Castledine, working with the Royal College of Nursing (RCN) in 1991, gave minimum recommendations for new DSNs, stating that the role exists to educate and support people living with diabetes and their families at all stages of their lives (Castledine, 1991):

- DSNs should be registered nurses with a minimum 3 years' practice and they should have a proven interest in diabetes management, teaching and counselling.
- DSNs must work entirely in diabetes care, with adults or children with diabetes, or both.
- The role should encompass specific elements, including leadership, innovation, research and education.
- DSNs should work within multidisciplinary teams with a consultant physician or paediatrician as their clinical lead.

This definition was reviewed and then endorsed by Diabetes UK following input from nursing groups, including the Diabetes Nurse Consultant Group, Diabetes UK Nursing Forum, the Diabetes Inpatient Specialist Nurse (DISN) UK Group and TREND-UK (Diabetes UK, 2010).

DSNs are usually part of a multidisciplinary team, however not all work with medical consultant colleagues as recommended by the RCN (Castledine, 1991). In addition, all new-in-post specialist nurses are now required to have, or be working towards, a degree-level qualification to fulfil the national job profile for band 6 specialist nursing, and senior DSNs should be working towards a masters degree-level qualification for the advanced nurse job profile (NHS Employers, 2010). At present, there is no single recognised qualification for the DSN role (TREND-UK, 2010).

The evidence so far

A study by Llahana et al (2001) found that most paediatric DSNs (PDSNs) were based both in hospitals and in community settings (88%), had undergone further training (83%), and a wide range of job titles were identified.

Findings from the Association of British Clinical Diabetologists (ABCD) survey in 2000 also found that the majority of nurses worked in both hospital and community settings (85%) (Winocour et al, 2002). The survey found that there was a wide variation in nurse qualifications required, grading of DSNs, and in day-to-day roles, which suggested a need for a nationally coordinated approach to training (Winocour et al, 2002).

A further survey in 2007 described how the roles and responsibilities of DSNs had expanded considerably with opportunities for career development into nurse consultant roles and prescribing, although few (22%) had a formal role in research (James et al, 2009). The survey also identified that nurses were less likely to work across both primary and specialist settings, and approximately one in five trusts did not have written job descriptions for the role of hospital DSN despite most nurses having been banded according to the new pay structure set out by Agenda for Change (Department of Health, 2004).

These changes in the role and work settings of DSNs have been in response to the increasing prevalence of diabetes and government directives, such as moving the focus of care from specialist into primary care settings.

The *Directory of Diabetes Care* (CMA Medical Data, 2009) identified 1363 DSNs working across the UK in 2009, but more information was needed to track gaps in provision, assist with workforce planning, inform commissioning and provide essential information around the qualifications of NHS-employed DSNs.

Aim

The aim of this study was to establish a database of DSNs and nurse consultants working in the UK to help predict workforce planning and service needs over time by addressing the following questions:

- How many DSNs and nurse consultants are working in the UK?
- What are the job titles of these DSNs?

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1. A Diabetes UK and NHS Diabetes working group designed a questionnaire in 2009 consisting of 12 open and closed questions covering topics, including: job title, post-basic qualifications, length of experience, anticipated retirement date, banding, present employment type, hours worked in diabetes, work setting and role, and presence of a clinical lead.
2. A total of 788 respondents gave 238 separate job titles representing the role of the DSN, which were grouped into the following categories: 76% (600) DSN, 16% (128) paediatric DSNs and 2% (18) nurse consultants. The remaining 5% (42) comprised dual roles, roles in education, facilitators and research nurses.
3. Fifty-seven per cent (478/836) of DSNs work full-time in diabetes (37.5 hours per week), with hours worked ranging from 5.25 to 37.5 hours. Of 810 respondents, 98% (790) are employed by the NHS, 0.7% (6) by universities, 0.7% (6) by pharmaceutical companies and 1% (8) by "other".

- Where do DSNs and nurse consultants work?
- What roles are DSNs and nurse consultants carrying out?
- What qualifications have DSNs and nurse consultants gained?
- What band level have DSNs and nurse consultants been awarded?
- How may think they will retire in the next decade?

Methods

A Diabetes UK and NHS Diabetes working group designed a questionnaire in 2009 consisting of 12 open and closed questions covering topics, including: job title, post-basic qualifications, length of experience, anticipated retirement date, banding, present employment type, hours worked in diabetes, work setting and role, and presence of a clinical lead. The questionnaire was piloted by a group of DSNs and nurse consultants and modified according to the comments made.

Questionnaires were mailed to all DSNs and nurse consultants identified from Diabetes UK, the DISN UK Group and *The Directory of Diabetes Care* (n=1363) (CMA Medical Data, 2009) and followed up with reminders 1 month later. The questionnaire was advertised on the Diabetes UK and NHS Diabetes websites and promoted in the *Journal of Diabetes Nursing*. For the first year of the study it was agreed to limit responses to DSNs and nurse consultants in diabetes only.

Completed questionnaires were collated and the data were analysed using Excel and Statistical Package for Social Sciences (version 17). Both parametric and non-parametric tests were used according to the distribution of the data, which are presented here as percentages with actual numbers in brackets.

Table 1. Work settings of survey respondents (n=830).

Work setting	Percentage (n)
Hospital	47% (388)
Hospital and community	28% (233)
Hospital, community and "other"	1% (8)
Hospital and "other"	0.8% (7)
Community	22% (182)
Community and "other"	0.8% (7)
"Other"	0.6% (5)

Results

Of 1363 questionnaires sent out, 838 were received, giving a response rate of 61% across the UK. Missing responses have been taken out from the analysis and the data reflect those who provided an answer to the questions.

Job titles

A total of 788 respondents gave 238 separate job titles representing the role of the DSN, which were grouped into the following categories: 76% (600) DSN, 16% (128) PDSNs and 2% (18) nurse consultants. The remaining 5% (42) comprised dual roles, roles in education, facilitators and research nurses.

Work settings and role

A total of 830 respondents described a variety of work settings (*Table 1*), and 810 described their role: 76% (612) indicated that their role includes general adults, 41% (332) inpatients, 23% (185) paediatrics, but only 10% (77) included research in their role. Seven per cent (58) included "other" as part of their role, examples of which included specialist midwife, education, management, endocrinology and maturity onset diabetes of the young.

Qualifications

Respondents (n=793) were asked to describe the post-basic qualifications they had gained (*Table 2*). Five per cent (45/838) either did not respond to this question or have no further qualifications.

Diabetes experience

Fifty-seven per cent (478/836) of DSNs work full-time in diabetes (37.5 hours per week), with hours worked ranging from 5.25 to 37.5 hours. Of 810 respondents, 98% (790) are employed by the NHS, 0.7% (6) by universities, 0.7% (6) by pharmaceutical companies and 1% (8) by "other".

On average, DSNs had 9.6 years' experience working as a DSN; of the 813 responses to

Table 2. Post-basic qualifications of DSNs (*n*=793).

Qualification	Percentage (*n*)
Diabetes diploma/certificate	74% (587)
Diabetes-related degree	17% (138)
Diabetes-related masters	8% (65)
Ad hoc modules degree	54% (424)
Ad hoc modules masters	18% (145)
Diabetes counselling course	16% (126)
Non-medical prescribing	40% (320)
PhD, completed or undertaking	1% (11)
General degree	10% (80)
Teaching	4% (34)
Other	6% (51)

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1. Eighty-nine per cent (725/819) of respondents reported having a clinical lead for their service.
2. The findings presented here confirm the results of other studies which show that DSNs are involved in a variety of roles, including general adults or paediatrics, while involvement in research remains disappointingly low.
3. These data show that nearly half of respondents are expecting to retire in the next 10 years. This has important implications for succession planning to ensure there are sufficient numbers of DSNs to meet the needs of an increasing diabetes population and ensure they receive high-quality care.

this question, 3% (26) had less than 1 year of experience, 27% (218) had between 1–5 years' experience, 34% (278) had 6–10 years and 36% (291) had 11 years or more experience.

Regarding band level, 83% (1131) were either band 6 or 7 (median band 7), 0.6% were band 5, 10% were band 8 (including 8a, 8b and 8c) and 0.1% were band 9; 49% (667) were at the top of their band, and 44% (304/693) expect to retire in the next 10 years.

Leadership

Eighty-nine per cent (725/819) of respondents reported having a clinical lead for their service. In 85% (604/715) of services this was the consultant; in 9% (64/715) this was a nurse; in 4% (25/715) this was stated as "other"; in 3% (21/715) this was a GP with a special interest (GPSI) in diabetes; and in 0.1% (1/715) of cases this was jointly held by the consultant and a GPSI. Where "other" was stated, examples included coordinator, dietitian, doctor, education lead or services manager.

Discussion

The proliferation of job titles in diabetes nursing has persisted over the past 10 years, which may reflect a lack of national guidance to support consistent role descriptions to describe the role and functionality of the DSN.

The findings presented here confirm the results of other studies which show that DSNs are involved in a variety of roles, including general adults or paediatrics, while involvement in research remains disappointingly low. It is essential that role diversity is recognised by those who have an influence on service design so that all aspects are taken into account when reviewing services. Standardised job descriptions and job titles could help to resolve this lack of clarity.

The trend towards the fragmentation of work settings, identified by Diabetes UK and ABCD in 2007 (James et al, 2009), appears to have continued over the past 10 years, with fewer nurses working across hospital and community settings. This is concerning as it is unknown what effect this will have on the care for people with diabetes. It also jeopardises opportunities for joint working, sharing of knowledge and skills, such as prescribing for DSNs, which are unique to the UK.

Most DSNs in the survey were qualified to the minimum level required of DSNs, and it was encouraging that only 5% did not have further qualifications, or did not respond to the question – an improvement since 2000 (Winocour et al, 2002) – and most likely in response to new directives which state that DSNs should either have or be working towards a degree or masters degree. Nearly half of the DSNs surveyed also have a qualification in prescribing, while in 2007 it was found that many were not able to implement prescribing (James et al, 2009) – the present survey does not provide enough information to assess whether this has improved.

Alarmingly, these data show that nearly half of respondents are expecting to retire in the next 10 years. This has important implications for succession planning to ensure there are sufficient numbers of DSNs to meet the needs of an increasing diabetes population and ensure they receive high-quality care. In addition, as nearly half of respondents reported that they are at the top of their band there is a need to ensure that a career pathway exists to support progression.

Of concern was that nearly one in ten DSNs did not have the appropriate clinical leadership for their service, which suggests they are working without access to specialist clinical support. This may lead to inconsistencies in knowledge and skills and eventually to unacceptable variation in the competencies of

DSNs, which could impact adversely on the care of people with diabetes.

There were a number of limitations to the study. It was difficult to determine an accurate number of DSNs to send the questionnaire to as there are no readily available lists of DSNs employed by pharmaceutical companies, GPs or primary care commissioning groups. To reach as many DSNs as possible the survey was promoted via the *Journal of Diabetes Nursing*, NHS Diabetes and Diabetes UK websites and other appropriate organisations. However, it cannot be certain that all DSNs in the four UK nations were given the opportunity to take part. Also, given that people change jobs and change names through marriage, some questionnaires may not have reached the intended person.

Conclusion

This study provides information on DSN and nurse consultant roles, qualifications, work settings and banding. The establishment of an accurate database of DSNs will help to ensure that the workforce is appropriate for the needs of people with diabetes and that plans can be made to ensure that it remains or becomes so. It can also be extended in future years to highlight the level of provision of time and funding for study leave and opportunities to take part in research.

The study has provided a starting point for mapping the progression and development of a key part of the workforce available to diabetes services. Additional research is required to gather information to map available competencies to the qualifications and role of DSNs.

Used in conjunction with *An Integrated Career and Competency Framework for Diabetes Nursing* (TREND-UK, 2010), this database has the potential to provide an invaluable resource to commissioners and service managers involved in the design and planning of diabetes services. This is vital to ensure that over time there will be appropriately trained individuals to deliver increasingly complex care to the growing population of people with diabetes in a rapidly changing healthcare environment

It is expected that this study will be repeated in 2010, and in all four UK nations, to build up national and regional pictures of the qualifications, work setting and roles of DSNs and nurse consultants. ■

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