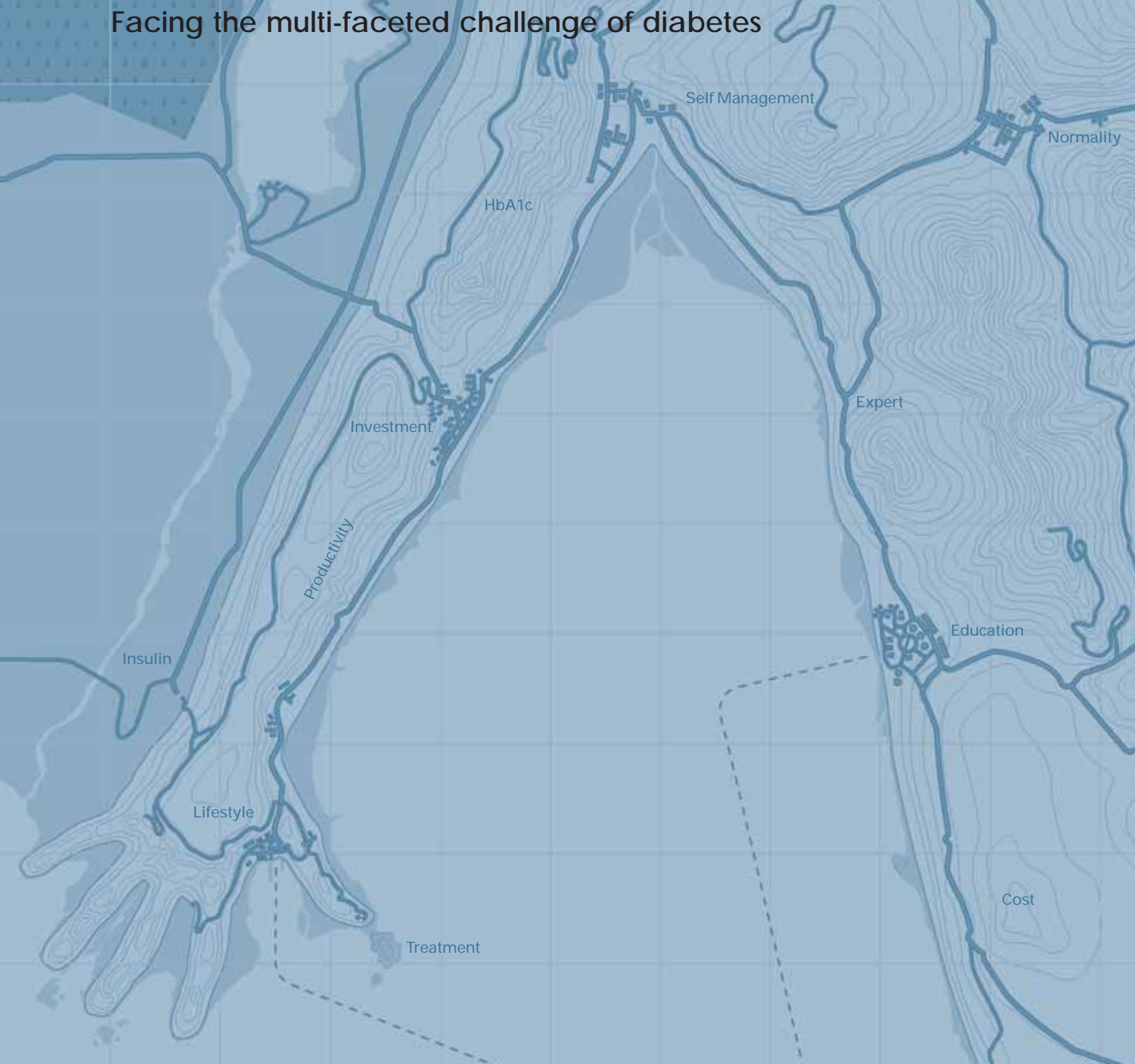


Diabetes: finding excellence?

Facing the multi-faceted challenge of diabetes



Foreword

The MODEL group (Management Of Diabetes for Excellence) is a new initiative bringing together a range of healthcare experts who advocate excellence as the only effective response to the diabetes epidemic.

In forming the MODEL group we are also answering the call issued by our colleague Dr. Sue Roberts when she wrote in her introduction to the third progress report on the National Service Framework (NSF) for Diabetes that " ... the recent White Paper acknowledges that there is more thinking to be done on how long-term conditions are properly catered for within system reform" .

It is our belief, as leaders in the care for people with diabetes and as members of the NHS family, that current reforms of the NHS do not address adequately the multi-faceted challenges of diabetes as we know them today, and as we know they will expand in the future. Some of the steps taken, including the NSF, are to be welcomed but fall short of providing an excellent, uniform level of care for all people with diabetes. Neither do they address the very significant rise in the numbers of people with diabetes. We see some developments in the NHS acting as barriers standing in the way of excellent care.

Instead, we need a shift in thinking and higher aims when dealing with a disease that already costs £1 in every £10 spent in the NHS, and is predicted to increase costs massively over the coming years.

Our primary role is to enable patients to manage their condition effectively, fitting the disease to their lives rather than their lives to the disease. This has to be achieved for all current and future patients throughout all stages of this life-long challenge. To do this we must commit to a long term view of diabetes, including appropriate investments commensurate with its epidemic nature and impact. We must also change the way we organise care delivery and, while recognising the need for an affordable, cost-effective service, address any culture of destructive competitiveness.

Those with diabetes need different experts throughout their life: primary care clinicians, physicians, dieticians, nurses, educationalists, consultants in secondary care, podiatrists, psychologists, pharmacists, opticians... the list is long. The patients themselves will also be making an important contribution to their own care. We advocate a holistic, integrated and collaborative approach that draws strengths from all parts of the diabetes team and builds goodwill among its members. The balance is achievable but it requires effective communication and dissemination of information, along with development of knowledge and skills for both professionals and patients. We welcome the development of diabetes networks and emphasise that their early successes can be built on to improve the effectiveness and efficiency of services.

An integrated response is also essential to meet the epidemic growth of the incidence of type 2 diabetes, including prevention of diabetes among those at risk, early identification of patients and rapid treatment. This requires new collaborations between different sectors of society that go well beyond the healthcare arena.

Excellence should be an inherent component of a modern diabetes service rather than being dependent on local commitment and historical funding allocations, and vulnerable to shifts in healthcare policy such as the adoption of geographical proximity to the patient as the central principle of healthcare delivery.

We believe that excellence is what a person should expect, a societal obligation, a realistic medical option and a cost-effective long-term investment.

Are we advocating on the part of patients or the professionals? We say both. Only by taking the robust view that we need to invest in the entire range of diabetes care can patients be guaranteed to receive what they need and deserve – from primary care to the specialist services that tackle complications; from prevention in the population to provision of the medical treatment, psychological support and education to enable people to manage their diabetes effectively themselves.

This is model care. We invite you to join us in its pursuit.

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Executive summary

DIABETES – THE SCALE OF THE PROBLEM

The number of people affected by diabetes is growing at such an alarming rate that it threatens to overwhelm the health service. Today, one in 25 people in England and Wales has diabetes, costing 10% of NHS spending, and the costs of caring for the growing number of people with diabetes will increase by up to 25% by 2040. Diabetes is more likely to affect poorer or overweight people, those from the black and minority ethnic communities, and the elderly. Diabetes represents a very significant risk to the increasingly overweight, ageing and urban population of England and Wales.

Much of this epidemic is avoidable. Type 1 diabetes patients cannot produce their own insulin, so need urgent diagnosis and insulin treatment. These are the minority, though: about 85% of people with diabetes have type 2 diabetes with impaired insulin production or function. While initially less urgent than type 1, type 2 diabetes makes people up to 11 times more susceptible to serious complications like heart attacks and stroke, blindness, renal failure, loss of limbs and reduced life expectancy - expensive to treat and needing specialised care. Type 2 diabetes is largely preventable through a healthy lifestyle, and its complications avoidable with appropriate treatment.

This report identifies the gaps in current diabetes care and calls for a focused, seamless diabetes service to ensure that excellence in management and care is available to all people with diabetes, whatever their location or circumstances.

WHAT SHOULD SOCIETY DO?

Investing in keeping people healthy (primary prevention); and preventing them from developing complications (secondary prevention), would reduce the high costs of diabetes. The savings would not only be in direct costs of drugs, procedures and hospital care, but also in the costs to the person with diabetes, their families and carers and to social services. Such investment would also contribute significantly to reducing lost productivity through absence from work and early retirement.

Major studies have shown that primary prevention can reduce the rates of people developing diabetes by up to 58%. But as a public health strategy it is difficult to implement unless focused on high-risk groups and individuals. Secondary prevention requires involvement of the entire multidisciplinary healthcare team and especially full commitment of the patient, so structured information and education are essential.

The National Service Framework (NSF) is a good base line for diabetes care in England and Wales. But while there are many examples of excellent initiatives at local level, there is no coordinated approach or commitment to investment which could ensure that the people of England and Wales receive the same care across the country. Today quality-assured patient education focusing on diet and exercise is rare, psychological support is rarer, and initiatives in schools and workplaces to encourage personal responsibility for health are patchy and under-developed.

Society has a responsibility to address the burgeoning epidemic of diabetes, and to break the vicious circle of poverty, ignorance and chronic disease. Equal access to optimal treatment should be guaranteed.

WHAT IS DIABETES LIKE FOR THE PATIENT?

Because diabetes has no cure, people with diabetes have to accept it as part of life; and they are the ultimate managers of the treatment; not the doctor. Access to the knowledge and confidence to minimise the impact of diabetes on daily life, and emotional support when needed, is essential to good self-management. This is the key for successful treatment outcomes. Properly structured education should be central; not an optional extra; not only for the wellbeing of the patient, but also as a highly cost-effective measure to minimise the costs of medical treatment of complications.

The MODEL Group welcomes the excellent progress made so far in developing the DAFNE, INSIGHT, DESMOND and X-PERT education programmes for people with diabetes, but is concerned at the substantial areas of England and Wales where access to them is not possible for geographical or financial reasons. It calls urgently for a realistic, coordinated approach to providing structured education to all diabetes patients throughout England and Wales.

People with diabetes also need long-term support from their healthcare team. Depression affects one third, and is a particular problem among children and young people, who receive far less than ideal care at present. Information and support are needed by patients and their families, especially where cultural or religious attitudes may conflict with medical advice. One in five diabetes patients fail to follow their treatment plan for these reasons – leading to poor diabetes control.

The ideal is to find the balance in patients' minds between the risk of complications, the effort needed from them, and the direct benefit of choices and actions.

WHAT MEDICAL TREATMENTS ARE POSSIBLE?

Treatment of type 1 diabetes centres on the balance between insulin and blood glucose. Use of modern insulins reduces debilitating and costly hypoglycaemic episodes and offers much greater flexibility, for timing of injections in relation to meals and exercise, to suit the individual's lifestyle.

Type 2 diabetes can initially be controlled by healthy diet and exercise, plus oral drugs to control blood glucose, blood lipids and blood pressure. Treatment will change over time as the disease progresses, and ultimately, people with type 2 diabetes will need insulin. Evidence over 20 years of study is compelling that early conversion to insulin, coupled with control of blood pressure, prevents or reduces complications and so gives a better quality of life.

Children and young people with diabetes need extra care, separate specialist medical treatment and support to help them cope with the long-term disease. In both type 1 and type 2 diabetes, young people have particular problems in coming to terms with and managing their condition.

Much more clinical research is needed on treatment options; not only for new procedures like islet cell transplantation, but also to develop evidence on the long-term implications of different treatment combinations.

The goal of medical treatment for both type 1 and type 2 diabetes is the same: to enable the patient to lead as normal a life as possible, free from adverse effects and complications for as long as possible.

IS THE HEALTHCARE SYSTEM COPING?

In many parts of England and Wales and in many aspects, diabetes care is good; but this is far from true everywhere. The early NSF targets have not been met, especially for care of children and young adults. The new GPs' contract has introduced direct financial rewards for delivering care, which has undoubtedly contributed to increased and regular monitoring of a broad range of factors affecting diabetes patients. Care in poorer areas, however, is still less effective than in more affluent areas, and a significant proportion of those predicted to have diabetes are not recorded on GPs' registers. Of the other main NHS reforms, payment by results and patient choice are geared more to treatment of acute conditions and have limited benefit for people with diabetes, while practice-based commissioning, which could favour multidisciplinary networks to plan and monitor local care, is not yet proven.

Most diabetes care has moved from specialist to primary care providers; in tandem with an erosion of the specialist and multi-disciplinary support available to the GP from hospital departments. GPs experience an ever-increasing workload, with reduced budgets for access to specialist expertise, and specialists report cuts in their resources. The information and education needed to enable patients to take an empowered part in managing their own diabetes is not being provided widely.

Instead of this rivalry and frustration, the MODEL Group calls for a seamless and flexible system of long-term patient care, provided by any and all partners in a collaborative, multidisciplinary team in their own area of expertise, when and as needed by the patient.

WHAT DOES IT ALL COST?

A great deal is known about how to prevent the onset of diabetes. However, more evidence, and a robust, evidence using model based on healthcare and social indicators is needed to assess the financial impact of primary prevention. Evaluating the balance between primary prevention measures targeted at the people most at risk of diabetes, and potential long-term savings through reduced treatment costs, is far from straightforward.

It is clear, though, that the cost of intensive management of blood glucose in type 2 patients is largely offset by savings on the costs of treating complications; and that the cost savings derived from intensive treatment of blood glucose, blood lipids and blood pressure are additive. Mathematical models such as the UKPDS Health Outcomes model now enable the health service regulator NICE to decide on a quantitative basis the cost-effectiveness of proposed treatments. But these assessments focus on medical treatments alone; lacking the overall impact of diabetes. That requires a complex approach, appropriate to epidemic chronic diseases rather than to acute medicine.

Because of the long duration of diabetes, its impact on individuals' income and curtailed economic productivity, the scale must be tipped in favour of investing in targeted prevention and intensive treatment.

WHAT LESSONS CAN BE LEARNT FROM DIABETES?

Dealing with chronic diseases, which are largely caused by unhealthy diet, lack of exercise and smoking, is a major priority of the 21st century. It can only succeed if it is undertaken on many fronts: information (on food, diet, exercise, medicines, tobacco) prevention (monitoring, risk assessment, targeted screening), environment (advertising, architecture), treatment (medications, procedures, healthcare systems), and support (psychological, social, public). Developing this approach would require a change away from a system treating illness to a system promoting wellbeing. However many other partners could help, including employers, schools, local authorities, architects and planners, the food and drink and fitness industries, as well as the media.

Research must continue to uncover new and more effective medications and procedures; not only to resolve conditions but to improve quality of life. Good, collaborative clinical research involving patients is essential to improve the evidence base for future care improvements.

The healthcare system must adopt a different budgeting paradigm based on the long-term realities of chronic diseases, including:

- availability of differentiated levels and types of care to suit the changing course of the disease, and flexibility in procedural guidelines, structures and teams to accommodate change
- special attention, especially in terms of psychological support, to the transition periods throughout life, where crises are more likely
- a systemic overview of the entire care pathway, ensuring that change in one area is not allowed to generate chaos in other parts of the system
- an individualised care plan for each patient, promoting and supporting self-management, and a lifestyle / wellbeing prescription for those able to avoid chronic disease.

Finally, everyone has to acknowledge responsibility to the next generation, and not choose to do nothing.

Diabetes: the challenge of an epidemic

Simon: age 37, type 1 diabetes patient

When I was first diagnosed, part of me definitely thought that I should change my lifestyle. But part of me also thought, well, you've got diabetes, that's enough to put up with, why should you be forced to stop doing what you want as well? There are two approaches I suppose - either you fit your life around your diabetes, or you fit your diabetes around your life. I've definitely tried to do the latter. That's why I hate being called a diabetic. It sounds like I'm a part of the condition rather than that the condition is part of my life. I'm a person who happens to have diabetes - but the person comes first.

Diabetes now - the scale and urgency of the problem

- One in 25 people in England and Wales has diabetes, the equivalent of, on average, at least one child in every school class developing the disease during their lifetime
- This means 2.35 million people in England (4.7%) have diabetes and 177,000 have diabetes in Wales (5.7%)* *
- Up to a third are as yet undiagnosed
- The number of people with diabetes in England is predicted to reach 2.5 million (5.05%) by 2010 (equivalent to 1.5 children on average, from each school class developing the disease in their lifetime)
- Half of these people will die from a diabetes-related condition
- Average life expectancy is reduced by 15-20 years in type 1 diabetes and by 5 or 7 years (male / female) in type 2
- The risk of major medical complications is up to 11 times that for people without diabetes and people with diabetes are five times as likely to need hospital admission
- If present trends of increasing obesity continue, more people will develop serious diabetes complications, raising costs of healthcare and costs to patients, their families and the whole economy
- Type 2 diabetes is preventable; **this is a preventable epidemic.**

Sources: 1, 2, 3, 4, 8, 10, 11 ** Sources for Wales: Diabetes UK: 127,000 diagnosed cases in Wales (2006); Diabetes NSF for Wales: 50,000 undiagnosed (2003). Total of 177,000 used on assumption that 50,000 has not risen 2003-2006; so 5.7% of population may be an underestimate

Diabetes:

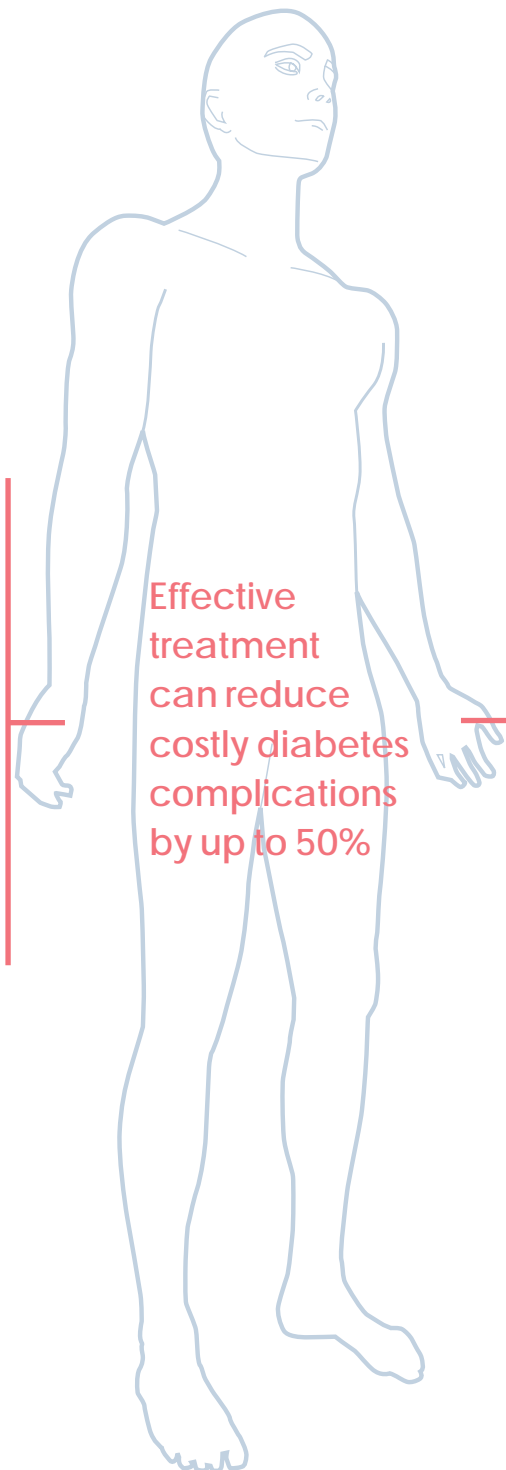
A chronic disease where blood glucose is too high, either because insulin is not produced or is insufficient

Symptoms:

Tiredness, weight loss, increased thirst, passing a lot of urine, blurred vision

Complications:

Serious complications can result from elevated blood glucose, some of which are illustrated here. However these are largely preventable, and can be delayed with early diagnosis and effective treatment



Effective treatment can reduce costly diabetes complications by up to 50%

Heart Attack

Risk:

Increased by 300%, and heart disease is up to 4 times as likely

Effective treatment:

Leads to a reduction in heart failure of over 50%

Stroke

Risk:

Up to 4 times as likely

Effective treatment:

Reduces strokes by more than a third

Amputation

Risk:

15% develop foot ulcers and up to 15% of these need amputations. Most common cause of non-traumatic lower-limb amputations

Effective treatment:

Reduces the number of amputations and effective education reduces the number of foot ulcers

Total Kidney Failure

Risk:

3 times as likely as in the normal population. About 30% of type 2 patients have renal disease

Effective treatment:

Reduces the causes of kidney failure by more than a third

Blindness

Risk:

Single largest cause of new cases of adult blindness in the UK. Nearly all those with type 1 diabetes experience minor retinal damage within 20 years, as do 60% of those with type 2

Effective treatment:

Reduces serious deterioration by more than a third

Figure 1 | Effective treatment can reduce costly diabetes complications by up to 50%

Sources: UKPDS (5, 6) and National Diabetes Audit (7)

DIABETES, A MULTI-FACETED CHALLENGE

Type 1 diabetes occurs when the body is unable to produce any insulin, and can affect people of any age. It is treated by insulin injections (usually two to four daily for the rest of the patient's life - insulin cannot be taken orally because it is destroyed by the digestive system), by careful balance of diet, and exercise. If this balance is not regulated carefully, e.g. a meal is missed and the blood glucose level falls too low, patients can suffer hypoglycaemia, which can lead to unconsciousness if untreated. In the opposite direction, if the blood glucose rises too rapidly the body produces ketones and acids by using fat reserves instead of glucose as an energy source; giving rise to ketoacidosis, which can lead to coma and death.

In type 2 diabetes, the pancreas does not make enough insulin, and what it does produce is not working properly – known as insulin resistance. Type 2 diabetes is more common in those over 40 and those with a family history of diabetes, and is strongly associated with obesity. Type 2 diabetes can be controlled by a healthy diet, weight loss and increased physical activity. But most will need treatment with tablets to stimulate production of more insulin, to improve the use of available insulin, or to slow the rate of glucose absorption from the digestive system. Type 2 patients can also need insulin treatment (the progression is known as insulin conversion) and as in type 1 it is important that glucose levels are managed effectively.

But diabetes is not only about control of blood glucose. Monitoring the levels of blood pressure and cholesterol, and keeping these and blood glucose as near to normal as possible, significantly reduces the risk of the long-term complications of diabetes (2).

OBESITY IS A MAJOR FACTOR

Evidence continues to grow for the adverse effects of being overweight – the risk of type 2 diabetes is almost 13 times as great in obese women as in women of normal weight; or 5 times greater in men. In 2001 about half of type 2 diabetes cases in England were estimated to be related to overweight; this is now likely to be much higher. Childhood obesity is also leading to a new pattern of type 2 diabetes, difficult to control. However the incidence of obesity also mounts. One in four children with two obese parents is obese, compared with one child in 20 with no obese parents. A new generation is entering adulthood already obese, increasing the concern that weight-related chronic disease will be the major health concern of the new century (14) (Figure 2).

Awareness of the risks of being overweight – and the link with type 2 diabetes – is increasing, but management of personal lifestyle involves conscious decision-making which may conflict with personal enjoyment. If the damage done by diabetes to the individual and to society is to be reduced, individuals need to be given the right information, and to use it effectively in their own lives.

POPULATIONS AT INCREASED RISK

Both the symptoms of diabetes and the risk of death are increased in more deprived sections of the population, including the unemployed and those with less education (13). GP registration of diabetes patients suggests that diabetes incidence in the most deprived areas is two-thirds higher than in the most affluent areas. While diabetes is increasing in all areas, the rate of increase is greatest in areas of deprivation.

Ageing is also a significant factor. Diabetes prevalence rises dramatically with age, from 0.33% of the population aged under 30; to 3.3% aged 30-59, to 13.8% of those aged over 60 years. It is now well known that the proportion of older people in the population will increase substantially over the next 30 years, so these two factors will contribute together to fuel the epidemic.

People from the black and minority ethnic (BME) populations are particularly susceptible to type 2 diabetes, especially those with an Asian or Afro-Caribbean background (8a). In these groups, diabetes typically also develops some ten years earlier than in European populations. Diabetes of both types has a strong genetic component, and its effects are additive, so someone with a South Asian background (or from India or North America) and diabetes in the family is at very high risk of developing diabetes (17).

The incidence of type 2 diabetes in children is increasing at an alarming rate. The first cases recorded in the UK were in 2000, in ethnic minority children in Birmingham; a national survey described about 25 children in the UK in 2004, and a further survey in press in 2006 described another 100 children in a 12-month period. The increase has been of the order of six- or seven-fold since 2000 (18).

HOW DOES DIABETES COMPARE WITH OTHER CHRONIC DISEASES?

The death rates from other major causes such as heart disease or cancer are reducing (1), while that for diabetes is not, despite 80 years of treatment and investment. Diagnosed prevalence of diabetes doubled between 1994 and 2003 and is forecast to reach 5.05% of the population of England by 2010 – that is 2.62 million people. The 15% increase between 2001 and 2010 is estimated at 6% due to the ageing population, plus 9% due to increasing obesity (Figure 3).

WHY DON'T WE HEAR MORE ABOUT IT?

Diabetes and obesity have been described as more of a threat than global warming.

The financial costs of treating diabetes and its complications, plus the economic effects of lost working time and effect on families and carers, are very significant. Diabetes is estimated as accounting for 5% of all NHS expenditure - £1.3 billion a year according to the first Wanless report in 2002 (11); more recent estimates (9) suggest that it could now be as high as 10%. This higher spending figure corroborates the observation of patients on coronary care units (16) that about a third of coronary patients have diabetes; a third have impaired glucose tolerance and only a third have normal glucose tolerance. In other words, the prevalence of diabetes or pre-diabetic conditions in hospital populations is much higher than the 4.7% level quoted as the prevalence of diabetes in the overall population. In addition to the costs of treatment, many people with diabetes need social service care; more than 75% of which are in residential and nursing care and the cost of these services increases four times over where medical complications are present.

The first Wanless review of the long-term costs of securing the nation's health also calculated that an extra £600 million per year is needed to implement fully the National Service Framework for Diabetes (NSF) for England by 2010-2011; but that this investment would return an annual saving of £200 million by 2012 as a result. Most of the £600 million would be spent on patients' self-management of their diabetes, which would reduce the risk of diabetic complications.

But despite this, care for and research into diabetes is not a familiar theme for public campaigns – not nearly so high a priority in terms of public or political awareness as HIV/AIDS or cancer. Diabetes UK regularly conducts campaigns to raise awareness of diabetes and how a healthy lifestyle can help prevent its appearance and the development of complications, but still diabetes is not widely understood by the general public.

Diabetes is a chronic disease, in which quality of life deteriorates gradually over a prolonged period. At the time of diagnosis it may not seem very serious; especially for type 2 where all that appears to be needed is a small adjustment of the diet. It is under-diagnosed – many people, especially women over 40, do not report what they see as minor symptoms until they have been established for years. However because it predisposes the patient to a wide range of extremely serious complications, it is responsible for untold human suffering.

Diabetes is also seriously under-reported and frequently is not recorded on death certificates, where the main cause of death may have been one of the typical diabetes complications. Life expectancy is typically reduced by 15-20 years through type 1 diabetes, and by 7 years with type 2.

A CALL TO ACTION

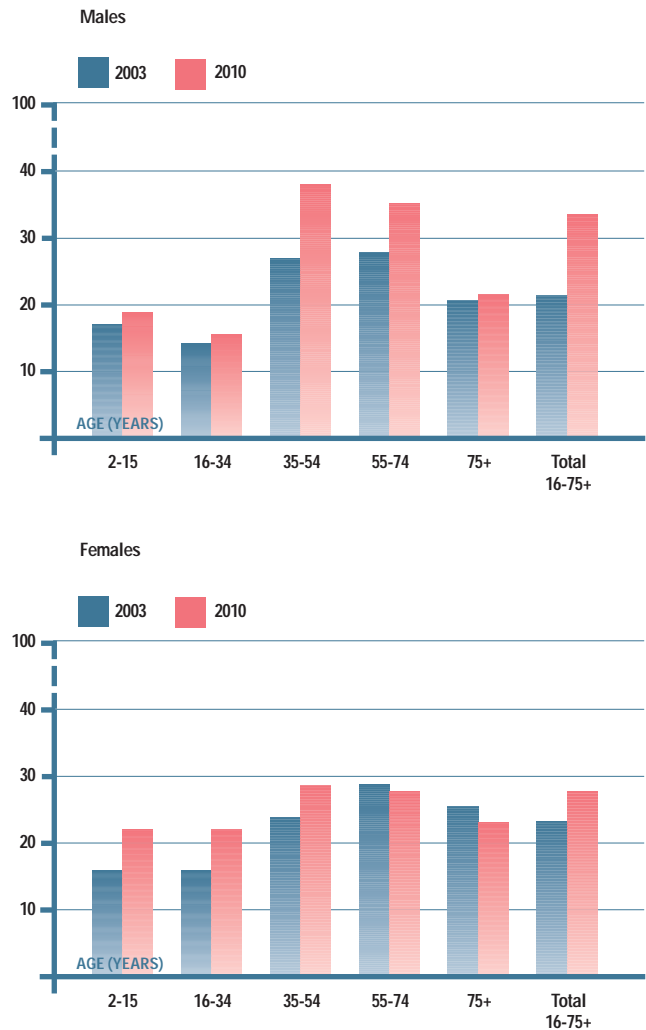
Almost everyone knows someone with diabetes, and it is not considered dramatic, problematic or life-threatening; unlike cancer, or AIDS.

Much type 2 diabetes could be prevented. Attention is urgently needed to preservation of good health, using messages of a healthy balanced diet, not too many calories, regular exercise, together with special education and help for those at high risk. Education, information and health awareness campaigns all play a part because once diagnosed, diabetes can only be tempered; it cannot be cured. And this is all the more vital for children and young people – the adults of the next generation will be even more susceptible to diabetes than their parents unless they take serious care to maintain good health.

People at increased risk of developing diabetes need to be identified and monitored. Early diagnosis and intervention is crucial. Once diagnosed, patients and their supporters and carers should be given full information and advice to enable them to avoid, delay or minimise the chances of developing complications.

The MODEL group believes that we all need to hear more about diabetes. It also believes that more can and needs to be done about it.

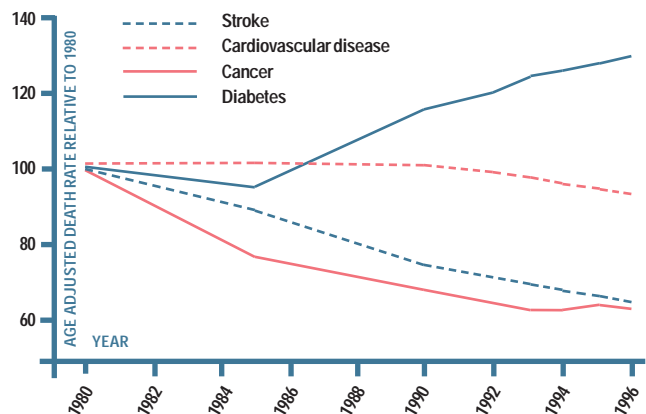
Figure 2 | Increasing obesity in England, 2003 and 2010, Percentage obese children and adults



Source: Zaninotto et al DoH: Forecasting Obesity to 2010 (20)

Note: Obese is defined for adults as body mass index (BMI) > 30 kg/m²; and for children as over the 95th centile of BMI for the child's exact age

Figure 3 | Deaths from diabetes and other chronic diseases, 1980-96



Source: National Centre for Health Statistics 1998

Diabetes: an active role for society

Edward Walsh: age 63, type 2 diabetes patient

I certainly kept it to myself. There weren't many people that knew that I had diabetes - only if I went somewhere and had to have a special diet. I've done that for quite a long time - up until when I went on insulin, really. I then had to tell people at work, just in case there was something, so there were one or two people that I told at work that were what you would call friends, but I didn't let it be widely known. Nobody else knew I took insulin. And it was insulin in the morning, insulin at night, so it didn't affect work too much. Certainly early on, when I was first diagnosed, I didn't know how to cope with it, really. It's the first time in my life that I'd had anything major, certainly, and so there was a bit of apprehension

DOES SOCIETY CARE?

At a time when almost 5% of the population has diabetes, and many hospital patients are there because of diabetes or its complications, does society really care? The current low profile of diabetes, despite its epidemic proportions, might suggest that it does not care enough.

'Society' is taken to include government, healthcare providers, employers, teachers and the general public. Society should care more, because it is ultimately in its own, enlightened, interest to intervene (combined, of course, with a duty of care). Providing the systems and the resources to enable individuals to be healthy and fulfil their own potential, as well as excellent delivery of appropriate care if illness sets in, is not only good for the people themselves, but also for society, national economic performance and for the general good.

Today's healthcare system in the UK is focused on crisis management rather than on illness prevention. It is more a system for illness than a system for health and wellbeing. Most of the budget is spent on treatment of a huge range of medical problems, rather than on the means of preventing their occurrence, because the system waits until patients have developed complications. It's rather like a highway authority refusing to alter an unsafe road junction despite many people having been injured there in collisions, because it is so expensive to maintain the ambulance service and there is no resource left to improve the junction.



Priorities are inverted, spending a great deal on managing complications, when prevention and excellent treatment would produce a better return.

The irony is glaring. When patients do develop kidney failure, stroke, cardiovascular complications or blindness a whole host of services swing into action and they are given expensive treatments. Treating complications accounts for more than 50% of the total costs of diabetes care; the remainder are for the treatment of diabetes itself. The complications can be significantly reduced by control of blood glucose and linked cardiovascular risk factors. Each 10% increase in blood glucose is

accompanied by a 20% increase in microalbuminuria (protein in urine; the first sign of kidney damage), a 56% increase in retinal damage and a 64% increase in the rate of progression of retinal damage (21).

If a smaller amount of money than that spent on treating the multiple complications associated with diabetes were invested earlier, in preventing people from developing diabetes; and preventing them from developing these complications, the spending on acute treatment would be much less.

The focus needs to change.

HOW BIG IS THE PROBLEM?

Diabetes affects 2.35 million people in England, with an estimated 550,000 undiagnosed, and an estimated 10% of NHS resources used in treating this disease. By 2010, 2.5 million people will have diabetes, costing 20% of NHS resources (22). The burden of diabetes falls disproportionately on minority ethnic groups, older people and the poor (23) (Figures 4 and 5).

Most type 2 diabetes patients are treated in primary care surgeries by their GPs, or in hospital clinics as out-patients. Type 1 patients are generally treated by specialist diabetes doctors and nurses in hospitals and outpatient clinics. As a group, however, people with diabetes are very high users of the healthcare services. They will make more GP visits than those without diabetes. Diabetes also figures in the histories of many more hospital in-patients suffering from other, related conditions.

Two studies provide key data on the cost of the illness. CODE-2 (Cost of diabetes in Europe – type 2) examined direct healthcare costs in eight European countries, and TARDIS (Type 2 diabetes accounting for major resources demand in society) calculated the direct and also indirect costs of type 2 diabetes in the UK (24).

CODE-2 determined the healthcare costs for one year of over 700 people with type 2 diabetes, from Belgium, France, Germany, Italy, the Netherlands, Spain, Sweden and the UK – a total of \pounds 29 billion. Hospital costs were the main component, and they were affected principally by the presence or absence of complications.

The T²ARDIS study confirmed these effects for a group of UK patients but added more information. It also found that medical complications increased the personal costs by over three times for both patients and their carers. This included lost working time, time taken off work for out-patient or in-patient treatment, and travel costs. These direct personal costs to patients have been estimated in other studies as £800 per year, not including lost earnings. (27).

“ The relative cost burden of diabetes will increase by up to 50% in the next 30 years as more people develop diabetes and the related complications. A massive increase in healthcare costs is predicted.

Additionally, it has been observed that in coronary care units typically a third of patients have diabetes and a third have impaired glucose tolerance and only a third have no diabetic tendency. Half the patients in intensive care units have been observed to have impaired blood glucose regulation. While on the surface the numbers invested in diabetes seem very large – in England and Wales, total NHS expenditure is £83.8 billion in 2006-7; £92 billion in 2007-08 (28) – expenditure on diabetes is estimated at just 10% (9).

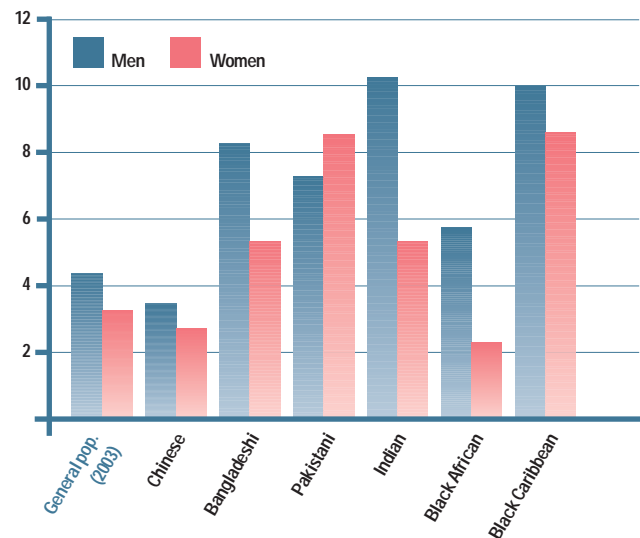
The National Institute of Health and Clinical Excellence (NICE) works by the principle that a cost of £20-30,000 per quality-adjusted life year gained from treatment represents good value (29, 30). The UKPDS showed that

- intensive blood glucose control costs £6,000 per year;
- blood pressure control costs £400 per year
- and metformin treatment (oral medication for type 2 diabetes) is actually cost saving.

These represent a good investment in prevention of diabetes developing into its complications. It is equally important to invest in preventing diabetes occurring in the first place.

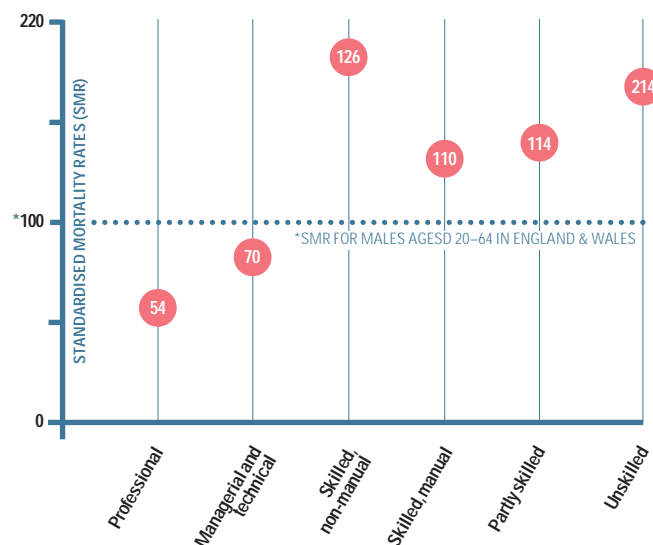
If the costs are high already, they are projected to grow significantly over the coming decade. For example, the county of Leicestershire, which has a high black and minority ethnic population, had 29,000 identified cases of diabetes in 2002 and is predicting a rise to 43,000 by the year 2010. The reasons for the increase are ageing, increasing obesity and improved methods of detection. This drastic increase in numbers has serious implications for the provision of care services; particularly in the hospital environment. A solution that has been identified is the move of the care of type 2 patients without complications to the community. But even this change creates costs elsewhere as it would require a major expansion of GPs' resources (see page 39). Leicestershire predictions are for a very significant increase in workload for GPs, in order to carry out the annual checks on patients – the present level of 25 checks per average GP list of 2,200 patients would rise to 60 per year; not counting the extra interventions found to be needed from those checks.

Figure 4 | Doctor-diagnosed diabetes by ethnic groups, aged 16 and over, 2004, percentage



Source: Health Survey for England 2004: The Health of Minority Ethnic Groups (25)

Figure 5 | Standardised mortality ratios from diabetes by social class, men, England and Wales, 1991-93



Standardised mortality ratios (SMRs) are used to compare death rates in different segments of the population, taking into account differences in their composition. SMRs below 100 indicate lower mortality than expected. SMRs greater than 100 indicate higher than average mortality.

Source: National Statistics: Health Inequalities decennial supplement 1997 (26)

In some areas effective planning and management has absorbed the extra demands for healthcare. In Newham, London, for example, the diabetes population has risen from 8,000 to 15,000 over five years, while the number of cases under hospital care has remained static. An apparent 87% rise (partly an increase; partly better detection) has been absorbed by the GPs, but this was only possible through forward planning, structured care and GP training.

There is no choice for society but to take action; as things stand now the trend is inevitable. Taking into account the reduction in numbers of economically active people over this period, the relative economic burden of the disease has been estimated to increase by 40-50% in the next 30 years (31), due to both the ageing of the population and the increase in overweight and sedentary lifestyle. It follows that the number of diabetes-related complications will also increase and is estimated to peak at up to 30% of present levels between 2035 and 2045. The cost of caring for these patients will rise by about 25% during this period, but its effective increase will be significantly greater, due to the reduction in the numbers of people who are economically active.

WHAT CAN SOCIETY DO?

Society needs to know more and to care more. Instead of disinterest and ignorance, a culture of awareness of the real, lasting benefits of a healthy diet and adequate exercise can go a long way to prevent people from contracting diabetes, and if they do, to prevent complications from developing.

Type 2 diabetes is preventable: 50 - 60% of diabetes could be prevented over four years by healthy eating and 20 minutes spent walking each day. The UK has the highest prevalence of obesity – one of the principal precursors of diabetes – in Europe – at 23% of adults, rising to more than 12 million by 2010 (32).

The study illustrated in Figure 6 followed 84,941 female nurses for 16 years and related their body mass index to their risk of type 2 diabetes. Overweight or obesity was the single most important predictor of diabetes, although lack of exercise, poor diet and smoking were all associated with increased risk of diabetes.



Type 2 diabetes is linked with many factors – overweight and obesity, reduced circumstances, age, and it also has a strong genetic component. However, most cases are preventable.

People do not deserve to contract diabetes due to their behaviour. There is a genetic component, resulting in a higher proportion from the BME groups. Diabetes is also a disease of the elderly and of those with a lower standard of living. Because of the many factors involved, avoiding type 2 diabetes is not a simple choice but an area where positive actions to prevent disease are possible and necessary.

Prevention works – although it involves some costs in the short term (e.g. for patient education, see Figure 16) it generates significant savings in the longer term. Investing in prevention has two levels. Primary prevention involves raising awareness of a healthy lifestyle, with a good, balanced diet, moderate exercise, no smoking and moderate alcohol, such that any predisposition to developing diabetes is not encouraged and that diagnosis is not reached. It should be embraced not only by the individual, but at the highest and all other levels – by government, and in workplaces and schools.

Prevention is very difficult in anything other than general terms, since the environment does not encourage active pursuit of health unless people feel ill, and at the early stage of most chronic diseases they are not symptomatic. However, it has been shown that prevention, or promotion of positive health in defined settings such as the work place or schools, does have major impact on results. Meredith Bullamore of the Geneva Social Observatory pointed to productivity losses directly correlated with the presence of diabetes in the workforce and evidence that costs of lost production were five times as high as those of direct healthcare costs. Companies that have started to adopt practical approaches to addressing chronic conditions have had profits increase (33). Primary prevention is also a difficult political exercise, as seeking investment in preventing a condition which is not yet present, and adopting a long-term view on social investments in a political cycle that promotes short-termism, calls for rare political courage and insight.

However there is evidence that if those with impaired glucose tolerance (pre-diabetes) can be identified at this stage, lifestyle modification can prevent or at least delay the onset of diabetes.

A multi-centre study from the Diabetes Prevention Program (DPP) Group involved a randomised trial on over 3,000 overweight or heavier patients at 27 sites throughout the US. Participants were given the diabetes drug metformin, a prescribed lifestyle and exercise programme, or a placebo. After 2-5 years, those with the lifestyle programme had reduced incidence of diabetes by 58% and those on metformin by 31%, compared to those given the placebo (34). Studies in Finland have shown that people at risk of developing diabetes were 43% less likely to do so if they achieved targets for weight loss, eating less total and saturated fat and more dietary fibre, and increasing their physical activity – and these benefits lasted for years after the study was over (35).

Secondary prevention is easier to understand, if equally difficult to achieve. It involves provision of intensive education on healthy lifestyle, and intensive treatment support to diabetes patients who have been diagnosed, in order to prevent the development of complications. It also involves monitoring the progress of the disease, and particularly of key indicators of the onset of complications, like retinopathy screening. Investing in secondary prevention is vital. Furthermore, investment in primary prevention should not mean depriving secondary prevention of resources and focus (Figure 7).

IS IT REALLY POSSIBLE TO AVOID DIABETES?

Several major studies in other countries have shown that it is possible for a concerted approach to help, and the rates of progression to diabetes diagnosis have been reduced by 58% in the US Diabetes Prevention Program and in the Finnish Diabetes Prevention Study, and by 40% in the Da Qing study in China (9). These studies show that primary prevention is possible, effective and affordable.

The Finnish programme for the prevention of type 2 diabetes – a great example of addressing its multiple complications – is the first national-level programme of its kind in the world. At least a third of Finns have a genetic predisposition to developing type 2 diabetes, and 10–20% have impaired glucose tolerance. The programme is based on the experience gained in the Finnish Diabetes Prevention Study, which involved over 500 overweight, middle-aged men at high risk of diabetes. After four years, those given a better diet and increased physical activity showed more than 50% reduction in diabetes incidence. The whole concept of health promotion was pioneered in Finland in the 1970s and is well established at the municipal level.

“ The Finnish Diabetes Prevention Programme provides evidence and a framework for national primary and secondary prevention strategies. What’s stopping us?

The prevention programme, which builds on this initial experience, has three concurrent strands. The Population Strategy aims to promote the health of the whole population, by means of nutritional guidance and increased physical activity so that the risk factors for type 2 diabetes, such as obesity and the metabolic syndrome, are reduced in all age groups. This is coupled with the High-Risk Strategy which uses individually-designed measures to target people with a particularly high risk of developing type 2 diabetes, including screening, education and monitoring. The third strand is the Strategy of Early Diagnosis and Management - directed towards newly-diagnosed type 2 patients and designed to bring them into systematic treatment to prevent the development of expensive diabetic complications. It includes practical instructions for intensive lifestyle management.

Importantly, putting this multi-pronged programme into action involves improvement of the Finnish healthcare system and restructuring of health-promotion activities, plus the services of non-governmental organisations involved in public health, nutrition and physical education. Cooperation under the Population Strategy encompasses the entire range of Finnish non-governmental organisations as well as participants from the business community and the education sectors. The feasibility and cost-effectiveness of the prevention programme is being assessed in four hospital districts between 2003-7. Training and materials related to the prevention programme have been made available throughout the country. The results available so far show an impressive confirmation of the feasibility of such a multi-stakeholder approach.

WHAT SHOULD SOCIETY EXPECT?

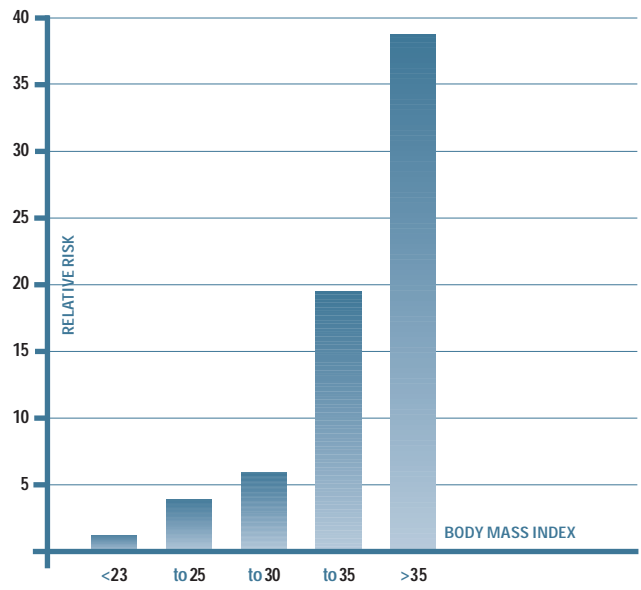
Put simply, it should expect a concerted strategy to prevent the epidemic of diabetes in the long term, and to contain its growth and impact in the medium to short term. Society should also expect to be able to deliver excellent treatment and management of diabetes for the people who already have it.

“ The National Service Framework is a good base but responding to an epidemic needs more. We need a strategy to share local examples of excellence, and real commitment to excellence at all levels of policy and delivery of care.

While England and Wales do not boast a comprehensive prevention strategy at the national level like Finland, the National Service Framework takes major steps toward delivery of secondary prevention and good care. However, given the complexity of diabetes and its complications and the urgency of their increase, what is required goes beyond the NSF. Excellence is needed at all levels of policy and clinical delivery of care.

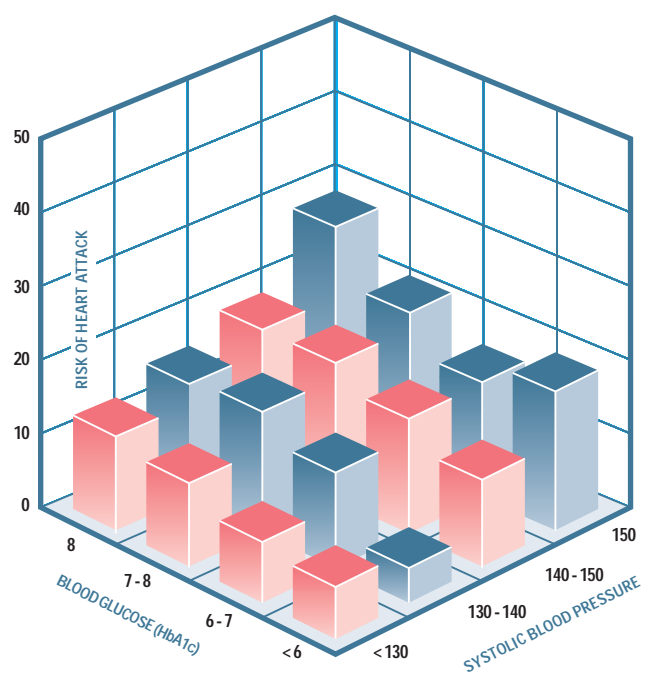
Excellence is definitely possible. The examples that follow are beacons for excellent vision, tremendous personal leadership and the courage to do things differently within the context of the health system. It is critical for the future that they lead the way toward national excellence for everyone; ensuring that diabetes policy and care do not remain a piecemeal collection of great but individual initiatives.

Figure 6 | Body mass index and risk of type 2 diabetes



Source: Hu et al. (9)

Figure 7 | Risk of heart attack is related both separately and additively with blood glucose and blood pressure



Source: Stratton et al. (2006) (10)

One example demonstrates how targeted health promotion, based on readily available marketing tools to pinpoint specific groups and provide insights on their motivations, can achieve tremendous results within a short time and modest budget. Diabetes specialist nurse Grace Vanterpool used Dr Foster software to gather information about the location of Asian businesses and homes in Slough. This enabled her Health Activist team to pinpoint the best locations to offer health information. They took a highly visible double-decker bus to key places frequented by the Pakistani people in Slough, including supermarkets, community centres, leisure centres, and mosques – and enlisted the support of lay community leaders.

Key points about risk factors for diabetes could then be passed on to a large number of people through these well-known and trusted people. Visitors to the bus were given information, the chance to ask questions, and offered pinprick testing for blood glucose. As a result of the initiative the level of diagnosed diabetes in the Slough population doubled (36).

An initiative in Norwich shows how preventive steps toward obese children and young people can become the focus of a multiple stakeholder initiative reaching beyond the healthcare system to enlist the support of other elements in the community. The Nutrifit Kidz Club in Norwich is a charitable programme run by North Earham, Larkman and Marlpit Development Trust, the Norfolk Sports Alliance and the Football in the Community team at Carrow Park. Free of charge, it offers up to 80 young people the chance to exercise, and also build self esteem and a greater knowledge and appreciation of food and health. Young people with weight problems are referred to the club by dietitians, GPs and consultants at the Norfolk and Norwich Hospitals. One in four of Norfolk's population under 15 years (15,700) is overweight, and a third of these (5,700) are obese; giving rise to medical costs of up to £40m a year (37).

The MEND (Mind, Exercise, Nutrition – Do it!) programme is a countrywide initiative with local activities for families with overweight or obese children. Its mission is to educate, motivate and transform children and families to change their unhealthy habits to ones that support a healthier lifestyle, and to ensure sustained health for the whole family (38).

Leicester, with its high South Asian population, is a particular centre for diabetes research and related healthcare initiatives. Project Dil, for example, is a coordinated primary care and health promotion programme aimed at reducing the risk factors for coronary heart disease in the South Asian community. It has used a training and awareness programme for healthcare professionals, organisational changes to develop an effective secondary prevention programme in general practice, and a public awareness programme. Leicester University Hospitals NHS Trust is also one of the 21 universities, hospitals and medical centres participating in the Europe-wide project called Diabetes in Europe – Prevention using lifestyle, physical activity and nutritional intervention (DE-PLAN), which is funded by the EU under its public health programme. This initiative aims to build on the results of the Finnish diabetes prevention study by assessing the risk of type 2 diabetes in European populations and to develop and evaluate a lifestyle intervention programme to prevent its incidence in high-risk individuals (39).

Newham in London has about 14,000 diagnosed diabetes patients but a suspected further 5,000 who are not even registered with GPs. A new public health initiative aims to identify as many people as possible who may be at risk of diabetes in the community, and encourage them to register, when they can begin proper assessment and treatment. Newham's Communities of Health initiative is building on the many natural social groups in Newham, e.g. Somali women's cultural groups or South Asian men's groups. The health messages can 'piggyback' on the activities of these groups; and special events, on hypertension or diabetes for example, can be held to deliver specific information. Those identified

as being at high risk can be given letters to GPs and follow-up can often be shared with the community group leaders. Newham is also encouraging the involvement of pharmacists, who are well placed to identify people at high risk of diabetes and are able to offer advice or even tests for blood glucose. Again, those identified can be referred to a GP. The two approaches also have a secondary impact in the awareness they create in the community (40).

Hull has a population of predominantly white people with a high level of unemployment and at 6-7%, a relatively high prevalence of diabetes. Its programme to improve the situation is well under way and includes both primary and secondary prevention measures. Raising awareness in the general public about diet, exercise and diabetes is being addressed by a variety of means including talks in schools, health promotion DVDs shown in pharmacies and public advertising screens, podcasts prepared by a dietician and open days and other awareness events. For those who have had diabetes diagnosed, care is much more focused in GPs' surgeries than formerly and the improvement programme provides extra training for GPs and practice nurses, to expand their detailed knowledge of diabetes so they can encourage better self-management. Diabetes consultants are now regularly working alongside GPs in their clinics and also conducting case reviews to advise on patient care and develop the skills of the primary sector (41).

In Wales the Inequalities in Health Fund was set up in 2001 to support local action to address differences in access to health services. It supports over 60 projects in disadvantaged communities through joint action by the NHS, local authorities and the voluntary sector. Some examples of projects relating to diabetes prevention are in Pembrokeshire, where screening, nutrition and lifestyle change advice had helped well over 6,000 people by the end of 2005, with clinics held in evenings and at weekends to be more accessible to working people. In Merthyr Tydfil are the Diabetes Peer Support Programme and one on promoting health in small workplaces (42).

WHAT IS PREVENTING MORE PREVENTION?

If it is possible to make such a difference in a few places, what is preventing society from adopting this stance for excellence across the board? What are the barriers that need to be overcome collectively? (Figure 8).

Fundamentally, the answer lies in facing the double challenge of lack of personal and societal or political will.

Individuals have the right to make their own choices about diet, exercise and other health issues. But at the same time they have a responsibility not only to themselves but to their families, communities and society in general to keep themselves and those in their care in health, as far as they are able. This is, of course, subject to the results of people's genetic inheritance, their ethnic origin, their environmental conditions, regional differences and socioeconomic factors.

This is where society comes into play. Society in this sense definitely should not mean government alone, although of course that is a vital part, together with its ministries and the rest of national and local infrastructure, and national healthcare services. As well as that, 'society' means business, industry, food producers and retailers, employers, advertisers, schools, universities, social services, architects and town planners – in fact everyone. Until now there has been a lack of this communal will to change things. Given the personal challenges involved in embarking on a better health regimen, an unprecedented level of multidisciplinary cooperation is needed to make things change.

WHAT NEEDS TO BE DONE?

The MODEL Group's aspiration is an enabling society, creating the right conditions for an individual to be able to make the right choices to preserve health or face up to illness.

Choosing to pursue good health and healthy choices can be a great challenge, especially when it is so easy to buy convenience food and not to bother to take exercise.

In the UK, even if preventive measures against obesity were successful immediately so that not one more person became obese and those already obese gained no more weight, diabetes and its complications would still reach epidemic proportions within 10-20 years (43). Diet and exercise are the key components of not developing diabetes, and of reducing the chance of it leading to complications.

“ The first step is to make healthy choices possible, turning commitments into actions. At present, expert advice for the individual on diet and exercise is not readily available.

Advice on diet is also vital to those diagnosed with diabetes. Type 1 patients need urgent, practical information on how to balance their glucose and other intakes with their insulin medication, and detailed guidance over how to manage their diabetes in the short and long term. Type 2 patients need guidance on the constituents and amounts in a healthy diet, and many will need help with actually reducing their weight (Figures 9 & 10).

Access to a dietician varies considerably across the country – all diabetes patients should ideally have advice from a specialist dietician within four weeks of diagnosis but perhaps 70% do not, and less than half of the dieticians offer an annual review. The UK has about 3,000 qualified dieticians, mostly hospital-based. Waiting times for direct access referrals range from 5 weeks to 27 weeks across different PCTs for all people with diabetes. Also the quality of dietetic advice appears to vary significantly in different regions (44, 45). As well as the regional variation, concern has been expressed about the training of other health care professionals and peer educators to a level of competence to deliver consistently high quality dietary advice (27).

The greatest difficulty associated with improving the quality of dietary education appears to be the shortage of solid evidence linking dietary improvement with prevention or delay of diabetes symptoms or complications. Current studies are attempting to fill this gap.

While access to specialist dietetic advice is in short supply, access to personalised advice on exercise is even rarer. Many people who are overweight or obese have a deep wish to lose weight, but also a barrier in their minds suggesting that the amount of exercise needed to make a difference is so great, so daunting, that they cannot even make a start. But if a plan for exercise can be developed to make a small demand on their resolve; keeping as close as possible to their current lifestyle, the chance of success is much greater. It is not necessary to take up athletics or swimming – even getting off the bus three stops earlier than normal or walking to the shops instead of taking the car can make a real difference (46)

Figure 8 | Barriers to a healthy lifestyle

Commodities:

- Society is avoiding exercise; by heavy use of cars, e.g. to drive to work, to take children to school, for short shopping trips
- Television – the nation's favourite leisure activity; even the TV is operated by remote control without leaving the sofa
- Playing fields are far fewer than they were 30 years ago, and time devoted to physical education in school far less
- Lifts in public buildings are prevalent; no need to walk up the stairs
- Universal availability of fast food; fresh food is far harder to find
- Advertising is everywhere, particularly aimed at children and young people who are setting up their eating habits for the future
- Food labelling gives so much information in tiny print that it is very hard to find a simple indication of what it contains
- Supermarkets give ready access to high-sugar and high-fat, processed foods

Attitudes:

- **Fat is good:** it indicates affluence in many parts of society especially ethnic groups; also it is seen as politically incorrect to criticise overweight or obesity
- **Choice is our right:** the individual's right to choose (even an unhealthy course of action) is held dear; as it was when use of seat-belts was made compulsory
- **Food police:** resentment against being told what is good, or not good, to eat and in what amounts
- **Change is difficult:** inertia, lack of determination or effort; also that it is much harder to lose weight than gain weight
- **Structure of many ethnic societies:** the role of women is that of a provider of food and home, with success shown by a well-fed family
- **Race:** in some groups it is harder to lose weight.

Figure 9 | What do we mean by overweight or obese?

Being overweight or obese is measured using Body Mass Index (BMI), which is defined as a person's body weight (in kilograms) divided by the square of the height (in metres).

BMI ranges are used to indicate:

< 15.0	eating disorder suspected
15.0 - 18.5	underweight
18.5 - 25.0	optimal weight
25.0 - 30.0	overweight
30.0 - 40.0	obese
> 40.0	morbidly obese

Source: WHO

Figure 10 | Benefits of 10% weight loss

- **incidence of diabetes** falls 40-60%
- **deaths related to diabetes** fall by more than 30%
- **insulin sensitivity** falls by more than 30%
- **total cholesterol** falls 10%
- **blood pressure** falls about 10mm of mercury
- **deaths from all causes** fall by more than 20%

Source: Haslam et al, (43)

There is already much evidence to show that increasing exercise for people who are overweight and on the borderline of developing diabetes has a high level of success in preventing or delaying its onset (34). Research now underway in the Oxford Centre for Diabetes, Endocrinology and Metabolism (OCDEM) will measure the blood glucose control in overweight type 2 patients, investigating the effect of exercise on the next stage of the illness. Another – the PREPARE study - involving researchers in Leicester, is looking at the effects of exercise on the body changes that precede diabetes.

One of the greatest difficulties in obtaining evidence on the effectiveness of both diet and exercise is that of human nature. While patients may say they want to lose weight, and that they intend to monitor their diet carefully and adopt more exercise, there are real problems in keeping to the plan. The OCDEM study (46) will emphasise patient involvement by giving full and frequent information about changes in weight, blood pressure, blood sugar and relate that to how much exercise was done and how the patient felt about it. The point, which relates closely with the course taken in developing structured education (see pages 23-24), is that the patients are given the information about how to lose weight or increase exercise, plus agreed targets and support; and then the decision about whether or not to do it is up to them.

It has also been shown in a follow-up to the Finnish Diabetes Prevention Study (47) that the benefits of an intensive diet and exercise are still evident years after it has finished. Three years from the end of the regimen participants were still 36% less at risk from type 2 diabetes than those who had not undergone the study.



The second step is to build public awareness of the risk of diabetes and the fact that it can be prevented. Public knowledge of diabetes, and how a healthy lifestyle can help to prevent it, is poor.

Personal dedication to diet and exercise is less successful if the environment in which this takes place – the general cultural and food habits as well as specific traditions in key vulnerable groups – is counterproductive.

PREVENTING ILLNESS – PROMOTING HEALTH

Increasing public awareness is essential

It is clear that in England and Wales there is a high level of public ignorance of diabetes as a disease, of the difference between the two types, and of the extent to which a healthy diet and moderate exercise can both prevent the onset of type 2 diabetes and prevent or delay medical complications.

In addition, diabetes is under-diagnosed – patients with impaired glucose tolerance and early-stage type 2 diabetes are often symptom-free. It is under-reported, because of the links with other medical conditions which can eventually become more urgent and almost supersede the original diabetes; leading to the under-reporting of diabetes-related deaths.

These factors contribute to the lack of urgency in the public mind about diabetes – and the lack of public calls for attention and investment, such as have been seen for HIV-AIDS and cancer.

Raising public awareness of the risk factors of diabetes would go a long way toward reducing the incidence of the costly and unwanted complications (48). The more risk factors a person has, the greater the

likelihood of diabetes. It is now clear that during the long period without symptoms, diabetes can be detected (49). And early management of impaired glucose tolerance reduces progression to diabetes.

Encouraging people to make healthy choices requires continuing effort

Sustained effort at the local level is needed to help people to make healthy lifestyle choices. Changing habits is more successful if one manageable target is addressed at a time, rather than setting unattainable aims. Although it is well recognised that changing several lifestyle factors will enhance improvement in relation to diabetes incidence or management, they are better taken one by one, together with counselling and support rather than instructions. Changing a lifestyle habit has several stages; which need to be taken in order with time and care; none can be skipped (Figure 11).

Removing barriers to living healthily

In our society it can be hard to make conscious decisions with health advantages. It is much easier to find a white-bread sandwich or a hamburger than fresh fruit. It is much easier not to bother to walk.

Clearer food labelling would make it a lot easier for the consumer to choose food for a healthier diet. The 'traffic light' system being developed by the UK Food Standards Agency has been welcomed by consumers; either as a single red, amber or green light or using separate traffic lights for the total fat, saturated fat, sugar and salt content. Such a system would in some ways parallel the health warnings on tobacco products imposed under EU legislation. Another rival food labelling system was launched in January 2007 by some of the UK's largest food and drink manufacturers, showing percentages of guideline daily amounts of sugar, salt, fat and calories. Both systems clearly have merits – but the consumer would surely benefit from the two labelling camps putting their ideas together and agreeing a single approach.

Another way to encourage a healthier diet is with school meals. During 2006 much publicity was given to the Jamie Oliver initiative to improve the standard of school meals and increase the money spent on them. Christine Hancock of the Oxford Health Alliance now suggests that school meals could play a much larger part in these initiatives. School meals, she argues, should be made of good quality ingredients and should be free – paid for out of the government's health budget rather than from education. Only in this way can parents be dissuaded from sending (often unhealthy) packed lunches. Improved school meals give many benefits in view of documented links between better diet, mental health and behaviour; quite apart from avoidance of overweight and obesity. Similar improvements in the public diet could be made in workplaces, as has been done effectively by Tate and Lyle in Newham. Perhaps the NHS could start with its one million employees – the largest workforce in England (50). Public sector employees account for an even larger number – in poorer areas (the areas of greatest need) representing as many as 60% of employed people (50). The scope for improvement is enormous.

Adopting a long term view – in the UK and beyond

Starting from the very obvious objective of society to enhance the health of its members, healthier people need less medical care and so it follows that health and economic solutions must reduce the need for care, rather than rationing it. To do this effectively and in a sustainable way over a long period of time, programmes are needed which do all of the following:

- improve health
- reduce costs
- ...and can prove it (51).

How do our political leaders approach this? Not very decisively. All parties stress the importance of individual responsibility for health and the need to address the likelihood of high future costs.

“ The third step is to identify high risk individuals and to encourage schools and employers to promote healthy approaches. We need to make prevention attractive to politicians and electors alike.

Speaking on the government's approach to public health in July 2006 (53), the Prime Minister explained its concept of the 'enabling' state, aiming to empower individuals to make their own health decisions, rather than telling them what to do or not to do. While in some areas this enabling state's role is to devolve power and responsibility, in others – of which public health is one – people expect a more active government. In the future, he said, healthcare cannot be just about treating the sick but must be about helping people to live healthily, which requires more from individuals, companies and government. And the government has to encourage, inform and if necessary, in a tougher way than ever before, has to be prepared to act. The alternative, said the Prime Minister, is a future in which the capacity of the NHS to treat people simply will not keep pace with the state of the country's health.

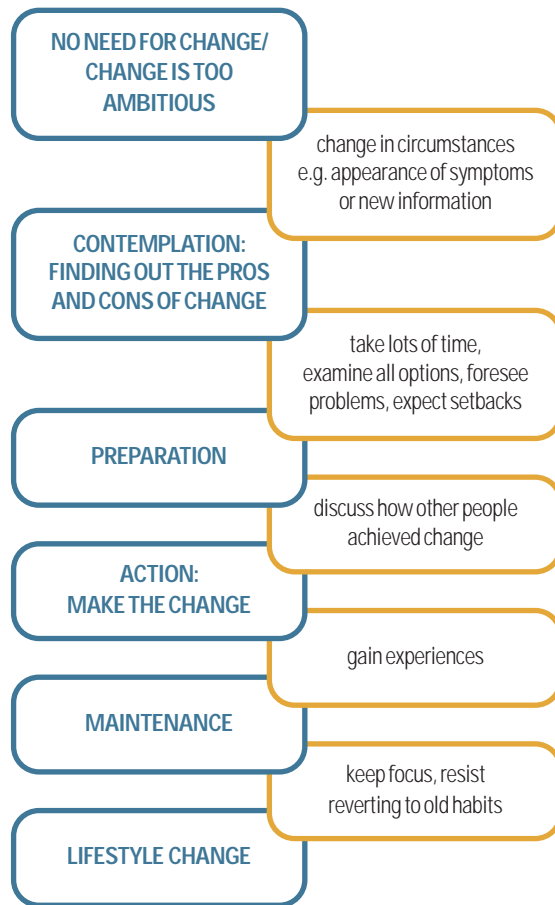
The government has held consultations with the food industry in some areas, like food labelling, and on a code to limit the advertising of junk food to children. Overall, the Government believes that health policy should be about prevention as much as cure; personal responsibility as much as collective responsibility, and about the quality of living as much as life expectancy.

The Conservative party shares the individual responsibility approach, and highlights the benefits both to the health system and to employers which would result from better public health with reduced demand on the NHS and reduced absenteeism from work. Good health is good business. Similar sentiments come from the Liberal Democrats, with more precise objectives including targets for regular health screening, free eye and dental checks and a long-term personal care plan for those with chronic conditions (54).

Perhaps the most provocative ideas come not from the political parties but from policy institutes. The Adam Smith Institute proposes that patients should have control over their own healthcare expenditure, with incentives for people to look after their own health, supported by full internet access to health information, and a viable health insurance system (55). The Picker Institute, Oxford argues for benefits for patients who really care about protecting and improving their health, plus rewards for doctors who are committed to health promotion – this the real meaning of patient-centered healthcare. And going further, individual health risks should be taken into account in health insurance, with premiums calculated according to the risks, and third-party payment abandoned.

There is no shortage of public discussion and discourse on the topic of health policies and the search for the best solutions continues not only in the UK but also throughout the world (Figure 12). In some ways the lack of coherent strategy in the developed world on the chain linking obesity, diabetes and cardiovascular disease can be compared to the lack of AIDS prevention in the developing world (the catch is that the burden of diabetes is already heavier there as well).

Figure 11 | Lifestyle changes



Source: Finnish Programme for the Prevention of Type 2 Diabetes (52)

The MODEL group believes that healthcare professionals, who together with patients are at the heart of the fight for good health, have a major contribution to make in both public discourse and putting policies into practice. The group does not believe that the current state of affairs in terms of prevention and treatment is good enough, given the dimensions and complexity of the problem of diabetes

 **Engaging healthcare professionals in direct action based on five important principles is critical to successful prevention of the diabetes epidemic.**

This report offers a perspective on the role of the healthcare professional and that of the healthcare system in addressing the diabetes epidemic. It takes a view on the central role of the patient in this fight, but also recognises the contribution of medical interventions in helping the millions who need to maintain good quality of life despite their illnesses. The MODEL Group does not feel that economic and public health investment considerations should be avoided in this discussion. Chapter 5 of this report examines the challenge of costs versus benefits, and the Group calls in Chapter 6 for a fundamental change in the approach to chronic diseases.

The following principles, underpinning these beliefs, are shared by the group and many of the expert witnesses involved in the development of this report:

1. Society should be prepared to intervene to improve health where necessary and appropriate, and where the intervention can be effective. Compulsory fluoridation of water, for example, has been shown to reduce significantly the incidence of dental decay, particularly in more deprived areas. But it was controversial when it was introduced in the 1960s in Birmingham and Newcastle, and has continued to prompt objections. The medical authorities took decisive action, but perhaps could have been more effective in their provision of information and support to the population. Effective, convincing and authoritative guidance and support are lacking.

In such circumstances society must be bold; it must hold on to the outcome of scientific evidence and be ready to take a stand. The huge mass of evidence on the steadily rising incidence of diabetes and its complications indicates that this is an epidemic. As in any other epidemic, society has both the permission and the duty to intervene.

2. Society also has to take an active role in breaking the vicious circle of poverty, ignorance and chronic disease. Equality of care and access to best treatments needs to be guaranteed in practice, not only in rhetoric. Because diabetes affects some parts of the population more than others, e.g. type 2 incidence is much higher in less affluent parts of the country and in the BME groups, extreme care should be taken that the inequalities of care now in evidence do not amount to discrimination. For example, type 2 patients living in one borough can be discouraged from attending annual checks in their regional diabetes centre by the high travel cost (51).

More generally, the gap between the health prospects and life expectancy of the richest and poorest communities in England and Wales is wider than it has been since the 1930s. Travelling past the six stops on the Jubilee line between Westminster (one of London's richest boroughs) and Canning Town (one of the poorest areas), each stop represents one year less life expectancy for local people (56, 57). Obesity is also much more prevalent in poorer communities, because of a combination of the availability of convenience food, lack of affordable fresh food, the decline in manual labour, lack of exercise facilities in poorer areas, and poor infrastructure.

3. Society has a responsibility to continue encouraging research and development into tools, approaches and medicines to benefit people with diabetes. Only by continuing to extend knowledge will it be possible to unravel the intricate interrelations of conditions and complications. Research into the development of new medicines such as analogue insulins or improved statins has the potential to complement existing therapies to improve quality of life for the patient; while the development of islet transplantation techniques, which enable patients to produce their own insulin, opens the new and exciting prospect of survival without insulin injections.

4. For society to be able to assess the challenge appropriately there has to be a clear, new understanding of the costs and benefits of broader, more comprehensive diabetes action. Two basic ideas reflect these:

- 'cost' would more accurately be described as 'investment' if it related to all the efforts and inputs needed for preventive action at both the primary and secondary levels
- 'benefit' involves not only the maintenance of individual patients and avoidance of or delay in the progression of their disease. It also means savings in cost to patients and their families, in working time loss, in costs to the social services; and optimal deployment of the critical care resources of the NHS so that a proportion may be freed for other needs.

5. Society needs to be able to offer integrated, comprehensive initiatives involving the whole range of medical and social support. That means:

- Information and education about healthy living and disease prevention for the general public (all sectors, and especially high-risk groups and young people)
- Early screening of high-risk groups
- Early diagnosis and intensive treatment as standard
- Information and education of patients as part of the care pathway; education about disease management and prevention or delay of complications
- Free movement of patients and information between sectors of care
- Assembly and analysis of evidence on chronic diseases, their progress, contributory factors and implications.

While medical research progresses, control of many conditions improves. In the UK the balance of what causes illness in our society has changed, particularly in the last century, away from infectious diseases. In the 21st century the majority of people will die from a wide range of chronic diseases – particularly cardiovascular diseases and cancer. Future generations could look back at the start of this century and see that society did not meet its responsibility to address the growing burden of chronic disease.

Society's aim, therefore, should be a health system able to address the epidemic of chronic disease.

Figure 12| International diabetes and obesity concerns

The concerns and initiatives in the UK are only part of world-scale efforts, with different emphasis for developed and developing countries. Key initiatives are:

WHO / International Diabetes Federation (IDF): The St Vincent Declaration of 1989(58) called on national governments to recognise the size of the diabetes problem and allocate resources to solve it. As a result about 40 national diabetes plans were formulated, but by 1999 the impetus had been lost. However WHO Europe, IDF and the European Association for the Study of Diabetes (EASD) continue to work together.

WHO / EU European conference on counteracting obesity, November 2006, includes adoption of European charter on counteracting obesity

UN Declarations: Unite for Diabetes – IDF campaign to call for a resolution on diabetes at UN General Assembly in October 2007; urging member countries to raise awareness of diabetes and its complications, improve diabetes care and prevent development of diabetes in those at risk. Also a second resolution has designated 14 November each year from 2007 as World Diabetes Day, to improve health and provide access to treatment and education.

European Union: The European Parliament declaration (April 2006) (59) calls on the EU Council of Ministers and the European Commission to prioritise diabetes in the EU health strategy as a major disease creating a significant burden, to develop an EU diabetes strategy and draft a Council recommendation for diabetes prevention, diagnosis and control, to encourage EU member states to establish national diabetes plans and to develop a strategy to encourage consumption and production of healthy food.

The Council of Ministers' conclusions (July 2006) on prevention of type 2 diabetes call on the member states to collect, monitor and report epidemiological and economic data, to develop plans on evidence-based disease prevention, screening and management, to measure health outcomes and cost-effectiveness, to develop sustainable public awareness and primary and secondary prevention measures, to adopt a holistic, multidisciplinary management approach and to ensure further diabetes training for healthcare professionals. The European Commission is asked to facilitate European diabetes research and undertake a range of other measures.

The EU already sponsors diabetes research through the Sixth Framework Programme for R&D (2002-6): e.g. the \approx 14 million, 24-centre, 5-year Diabesity project to develop new drug targets for obesity and type 2 diabetes. The EU has also set up an expert forum on diet, physical activity and health, to develop initiatives and reverse current trends. In August 2006 the forum released its first set of 96 pledges, including campaigns to promote healthy lifestyle, reduce sugar in food, improve nutritional labelling on food packages and encouraging manufacturers not to market directly to children.

Diabetes: the person behind the patient

George Saunders: age 43, type 2 diabetes patient

I chose what I wanted to eat myself rather than to stick to the rations that the hospital set out for me really, and I found that it worked better, to be honest. I never mentioned anything about my diet at all to the hospital. I just go in and see them and take my samples in as usual, and they would say "everything is all right", and "come back in another six months". Being a diabetic for such a long time, I know exactly how my body reacts, and I adjust my insulin intake according to the way my body reacts, in order to keep healthy. If I do exercise I would use up a lot of energy, and for that reason sometimes I lower my insulin just that little bit, and if I am not really doing anything physically I just stick to my normal insulin intake.

Diabetes is a disease for life. A diagnosis of diabetes of either type causes fundamental changes in the way the person lives: daily routines, relationships with others in the family or at work, and even in personal perception. Research conducted globally under the label of DAWN: Diabetes Aspirations, Wishes and Needs indicates that these changes, and the often neglected psychological burden of the disease, are directly related to the person's ability to cope with the disease and to the healthcare team's ability to help the patient achieve positive outcomes (60).

People with diabetes are the ultimate managers of the disease – how well it is managed depends on their decisions and actions. Providing the knowledge and confidence to minimise its impact on their daily lives, and providing emotional support, when needed, are the two factors that contribute most to excellent self-management and positive outcomes.

In the case of type 1 diabetes, referral to specialist care is usually rapid and newly-diagnosed patients will quickly learn the new practical survival skills needed to manage their diabetes on a day-to-day basis. As well as gaining the immediate practical techniques, people with type 1 diabetes also need advice and support on healthy diet and exercise, to give a foundation for successful self-management. A partnership with healthcare professionals is forged from the beginning and the 'contract' between patient and a dedicated healthcare team is generally clear.



Excellent self-management is the key to a positive outcome.

That, in turn, depends on having the right knowledge and the emotional confidence to deal with the disease, daily and in the long term.

For both type 1 and type 2 diabetes, it is the patient who will manage the disease. Apart from the increase in routine monitoring that has recently resulted from the QOF requirements under the NSF, the patients' decisions and actions will be crucial to how well they can remain. And many more adjustments are needed than the addition of medicines. People need

emotional support from those around them; they need a trusting relationship with a healthcare team and they need good quality information and guidance to manage their illness.

WHAT IS LIFE LIKE FOR SOMEONE WITH DIABETES?

In many ways type 1 diabetes is more urgent, because patients need to learn very quickly how to balance their glucose intake with their insulin treatment, if they are to avoid the risk of serious hypoglycaemia (blood glucose too low) or hyperglycaemia (blood glucose too high) as discussed in Chapter 3. Insulin injections are usually self-administered, and managing the balance between food and insulin involves active commitment and constant monitoring.

In type 2 diabetes, as the first treatment option is adaptation of diet and exercise, which appears on the surface to be much less imperative than medication, it can be difficult to find enough motivation to make changes, especially if the person does not feel ill. It has been said that 'the doctor gave me diabetes; I didn't have a problem before that.' It also does not seem to be very urgent if there are no immediate repercussions of not making those changes. But people with type 2 diabetes are more likely to suffer adverse complications and reduction in life expectancy than well-managed type 1 patients (16). Those with type 2 diabetes, being treated with insulin or sulphonylurea drugs may also suffer hypoglycaemic attacks if their blood sugar falls too low (see Chapter 3 for more details).

It's not worth cheating

"But what I remember most of all, in them early days, was 'this is something I've got, but oh, there's no problem to it - you can cheat', because I was told 'you mustn't have this, that and the other'. And going from normal life into a completely different way of life, it took a bit of accepting, in as much as I found myself having the odd choc-ice or a piece of cake. And I didn't feel any worse afterwards - no, I felt good psychologically. I thought 'well, there's nothing wrong'. And, of course, in them days, I just used to have to go every so often to a doctor, and they just examined you and asked how you were, and I felt absolutely fine. I thought 'there's nothing to this diabetes at all'. But, of course, as life's

gone on, I'm the first one to put my hand up now and strongly try to advise anybody who's been told they're diabetic is please take notice right from the word go, because it's one of these illnesses that catches up with you afterwards. You feel great at the time, but when you start having various complications with different parts of your body, you wish to goodness you never had that cream cake. Although it's only one, I know, but that's how it starts."

Colin Gates: age 69, type 2 diabetes patient

It is vitally important for people with diabetes to manage their disease. To do that they need medical treatment, and also information, advice, respect, psychological support and understanding from their families, friends and work colleagues. According to the NSF for Diabetes, self-management is the cornerstone of effective diabetes care (61). People who take on this responsibility have been shown to have reduced blood glucose levels with no increase in hypoglycemic events, and general satisfaction with their improved quality of life.

It is important for people with diabetes to feel that their health professionals care what happens to them, but in a way that works alongside the person (e.g. we can work out a way to reduce your blood sugar) rather than in opposition (e.g. if you don't lose weight, you will get worse). Constancy, consistent messages and a positive approach are very much more important in treatment of chronic diseases like diabetes than in acute conditions (62).

 **How much the health care team is perceived to care is a critical component of patients' confidence and sense of coping well with their diabetes.**

A diabetes diagnosis is often followed (and sometimes preceded) by depression. This can lead to poor adjustment, including self-blame and denial, which can make it harder for the patient to understand and implement the changes needed for effective care of their diabetes (63). So, effective communication is essential for people with diabetes, to help maintain their self-esteem and the confidence to make informed choices about their own care.

Empathy and personalised treatment are vital in diabetes care, especially at times of life changes, like the transition from childhood to adolescence, as well as the point of diagnosis which changes a relatively well person into a person with diabetes. These transitions are important not only in the patient-doctor relationship but also for the family as a whole. A diabetes diagnosis is traumatic for the family and the person's extended circles of friends and work colleagues.

Fear and concerns about changed relationships are fed by a low level of knowledge of diabetes in the general public, and some of the many myths which compound the general ignorance and lack of understanding about it.

Many people with diabetes find that social stigma is attached to the condition and they fear the reaction from family, employers or others. One example tells of a father with diabetes who did not tell his son, who lived in

the same house, for many years. Some people are afraid to tell work colleagues because they want to avoid being seen as different, or unreliable, or even do not want to be fussed over. Also of great concern is the tendency in some cultural groups, especially in Asian families, to prevent marriage to someone with diabetes or to someone with a high incidence of diabetes in their family (36, 39).

Fear of being found out

"Some of the people at the [DESMOND] seminar were very worried about the effect of being diagnosed on their daily lives. One man even said: 'If my employers get to know that I have it I'll be given the sack.' Others pointed out that would be discrimination but he was certain his bosses would find a way of getting rid of him if they discovered his secret."

Clive Gresswell: type 2 diabetes patient

It gets you down

"It has affected me over the years. There were times when I wanted to go off and do things, and it has annoyed me that I've had to think everything through and everyone else hasn't. If I go out for the evening and take insulin or blood testing things, people ask why I've got so much stuff with me, and that hurts; it invites ridicule. You have general problems in life like everyone does, and when you've got the extra problem of diabetes, it can push you further down than other people."

Martin Harris: type 1 diabetes patient

Related to the issue of social stigma is the question of simply different social attitudes. Many communities, for example, view overweight or obesity as a sign of affluence and of success in the world. This view is very widespread in Asian communities; also in Afro-Caribbean families, especially in older first-generation immigrants.

The price of rich food

"My family was quite a happy family. We were five brothers and three sisters,....and we had a huge house. I think it was the biggest house in Gujrat - we had about twenty-two rooms in it.... My father had diabetes, my elder brother had diabetes, and the third brother - you know, he's two years older than me - he had diabetes, and funnily enough, all three died with a heart attack, just due to diabetes. So, I'm very careful, watching their example. Whatever they did, I'm not doing! They didn't care about, you know, the food and diet. They ate whatever they liked. They used to eat sweet things - I don't touch sweet things, they never did any exercise - I do quite a lot of exercise. The main diet is, you know, the curry with rice and bread. And when my mother and the cook used to cook, you know, the curry, he made sure that he put a lot of fat in it. Over there, till you had quite a big layer of fat, you would think the food is not nice."

Tas Bokhari: age 69, type 2 diabetes patient

“ The NHS provides no psychological support to families, or information to employers and friends, so ignorance, mistrust and cultural prejudices continue to surround diabetes.

Families, friends and carers need information about diabetes too; as do employers, because if they understand better the difficulties and needs of the person with diabetes, then even small adjustments to what they might ask of that person can make a huge difference to helping maintain confidence and self-esteem. They can prevent embarrassing moments and make diabetes just another part of life.

Families and friends may need support as well, so as not to feel overwhelmed by diabetes. They may want to know how best to manage on a practical level - how to adapt the cooking, for example - or want a better understanding of how to avoid medical complications developing in the future. While the diabetes patient is getting the medical and lifestyle advice, many patients' families say they have had no help at all from the health service.

Hypoglycaemia (a low blood glucose level caused by relative excess of insulin) can be a cause for particular stress to families and carers. While mild hypos can be dealt with by the person with diabetes taking a sugary drink or snack, another person will be needed to help them if the hypo is moderate or severe, and if confusion or loss of consciousness has occurred. But if the person with diabetes is normally well and independent, carers can frequently feel shut out of day-to-day management of the diabetes, and even from early-stage hypos because it is common for the patient to deny that they are happening (64).

Families need help, too

“My precious eleven-year-old son, Joshua, became type 1. His life has not been easy: he has dyspraxia, asthma, hay fever and now diabetes. How could this happen to him? To us? I was devastated - lost and alone. Nine months later I am still grieving for what could have been, what should have been. However, my drive and my push are now replenished, I cannot change direction, I have to stay and fight. This is personal, it is for my son. (He tells me he is lucky to have a diabetes nurse as a mum). I am determined to make a noise and be heard. I would like to continue counselling and to set up a service that is side by side with the regular diabetes service and with special emphasis on the transition from paediatric service to adult care. I do not believe that there is enough emphasis placed on psychological care, as I know from my work as Diabetes Specialist Nurse and from my personal experience of diabetes.”

Norma Grundy: mother of type 1 diabetes patient

The family has diabetes

“It's not just my husband who has diabetes; the family has diabetes, because it is part of everything. The family has had no support since he was diagnosed a year ago. I feel guilty if he gets a high blood glucose level because I feel I have failed with his diet. I also feel guilty if I enjoy food myself. I can never relax because I'm always concentrating and planning - so much so, I must be boring other people about it.”

Janice Turner: wife of type 1 diabetes patient

Children and young people with diabetes have special problems which can often lead to depression and a variety of social anxieties. About 96% of young people with diabetes have type 1 (65), although a growing number of type 2 diagnoses have appeared in children in the last five years. Children and young people with type 1 diabetes have to contend with the prospect of perhaps losing years from their adult life. Those who have diabetes from childhood are a forgotten population, at high risk of complications. Eating disorders are also prevalent in girls and young women with type 1 diabetes. The greatest problems face young people diagnosed just as they go into puberty, because they are suddenly removed from normality just as they are on the threshold of adulthood (4-27).

Young type 1 patients need to learn the practical skills of glucose monitoring with blood tests and insulin treatments several times daily from a very early age. Even three-year-olds can be taught with pictures (for example sites for injection) and learn about healthy diets with fruit and vegetables (37). Here, as for children and young people of all ages, it is important to use the right language and to use the most acceptable means of communication, for example text messages and email for teenagers.

As children enter their teens, dealing with diabetes often becomes an unbearable problem. At a time when their life is becoming full of all sorts of other responsibilities and worries like exams, dealing with parents and becoming sexually aware, they have the burden of an insistent medical condition requiring attention every single day.

Schools can be less than helpful; not providing enough support for young people to test blood and inject themselves during the school day. Children with diabetes may still be stigmatised as presenting a risk during school trips. So it is not surprising that 60% of young people with diabetes have depressive symptoms (37), and in today's healthcare system their access to psychological or psychiatric support is almost zero. Many become overwhelmed with the difficulties and drop out of diabetes clinics at this time, so extra effort is needed to keep in touch with them, and to provide a sympathetic environment that is neither a children's nor an adults' clinic.

Adequate provision of school nurses would be helpful, not only in supporting the practical issues of the relatively few type 1 children and young people, but also in providing support and guidance on healthy living for those with either type 1 or type 2. The potential contribution of school nurses has been recognised as valuable to deliver the government's Every Child Matters programme, and the government is reported to be encouraging primary care trusts, schools and children's trusts to increase the number of school nurses. But the 2006 annual conference of the Royal College of Nursing was told by delegates that the government's target of one school nurse for every secondary school and cluster of primaries by 2010 was simply not achievable; no extra posts can be funded and morale has never been so low. A 2005 survey carried out for the Royal College on school nurse provision found that the current staffing level for school nurses is about half that needed to meet the government's target (67).

Society as a whole could be more understanding and accommodating. One area where this can be particularly important is with the police - if someone with type 1 or insulin- or sulphonylurea-treated type 2 diabetes becomes hypoglycaemic they can appear drunk, confused and aggressive, so the police are often called. Some people do not experience the milder symptoms and this can lead to a sudden loss of consciousness, particularly if they have had diabetes for a long time. The balance can usually be restored easily by taking glucose in an easily-absorbed form, like glucose tablets or a sweet drink. In a more serious hypo, ambulance attendance is needed and an injection of glucagon may be given, which stimulates

release of glucose from the liver. So it is important that this sort of incident is dealt with in the knowledge that diabetes may be involved. Patients can help themselves by carrying diabetes identification cards to show that they have diabetes (36).

WHAT DO PATIENTS WANT AND NEED FROM THEIR HEALTHCARE PROFESSIONALS?

Diabetes care should be a partnership between healthcare professionals and patients, enabling management of the condition in a way that fits into their normal lifestyle as far as possible. Ideally it should be a plan of care developed with patients, rather than 'given' to them. Successful self-management depends on the patient being able to draw on long term relationships, on the right skills from each member of the team and on trust among all care team members. This long-term relationship is the main feature of caring for a chronic disease. Healthcare providers must also recognise that patients are first of all people, influenced by their own background, culture, beliefs and current circumstances. To reach a stable and satisfactory management plan, patients must be treated with respect as partners and allowed enough flexibility to make their own decisions.

“ Sixty per cent of children and young adults with diabetes have depressive symptoms, but psychological or psychiatric support is hardly available.

People with diabetes want accessible support and medical care from their GP and other health professionals, including

- enough time to discuss their concerns
- enough information and access to education courses to help them understand how to manage their condition
- an approach that is likely to build trust, confidence and allow a long-term partnership
- provision of supporting services in primary or intermediate care referral to appropriate specialist care as needed (62, 39).

Providing information and education is as necessary a part of the healthcare process as measuring blood glucose. If self-management is to succeed, patients urgently need honest and practical information, especially about checking their blood glucose and taking their medications through the day. Alarming details on the need for information right from diagnosis come from the 2006 Diabetes Medicines Information Survey (68). This showed:

- Almost 60% of people with diabetes do not fully understand their diagnosis or as much as they would like about the available medicines
- 65% do not take their medicines as prescribed
- 33% do not understand what insulin or oral medicines are for or how to take them, because they feel stupid asking questions
- 36% do not know what questions to ask to find out about treatment options
- More than 60% of pregnant women with diabetes do not know that stillbirth and congenital malformations can result from not managing their condition
- More than 33% do not know that they will have the condition for life
- 40% and 30% respectively do not know that stroke and kidney failure can result from not managing their condition
- 50% do not know that diabetes can reduce life expectancy
- 32% do not know that heart disease is a common complication of diabetes
- 18% do not know that diabetes can result in amputations.

Clearly there is a great deal to be done, both in terms of providing accurate and understandable information, and giving patients the opportunity to come to terms with it all without losing dignity and hope.

Figure 13 | Diabetes myths

- Diabetes is caused by eating too much sugar
- Type 2 diabetes is mild diabetes
- People with diabetes can't drive
take part in sport
eat sweets or chocolate
do certain jobs
- People with diabetes will eventually go blind
- People with diabetes should eat diabetic foods

All of these statements are at least partly false.

- Diabetes can lead to blindness but there are many ways in which the risk of blindness (like other diabetes complications) can be reduced.

- While there used to be blanket bans preventing people with diabetes from working in a range of jobs, since October 2004 the only occupation specifically excluded from the Disability Discrimination Act (which aims to protect people with disabilities, including diabetes, from being treated differently from other employees) is being a member of the armed forces. While the police force and firefighting were also formerly excluded, people with diabetes in these occupations now have to be individually assessed for their medical fitness to work.

- People with diabetes are able to drive, with the exception of those treated with insulin who are not entitled to hold driving licences for large goods vehicles and passenger carrying vehicles. A Group II licence is needed for vehicles in the C1 and D1 categories (like minibuses) and these cannot normally be issued to someone on insulin; although it is now possible for someone on insulin to obtain a concession for C1 vehicles following a medical assessment.

Source: Diabetes UK

Several specific areas have been identified where information provision to people with diabetes is less than adequate (69), and it is important that their beliefs are taken into account.

Figure 14 | Gaps in diabetes information


More clear information is needed, particularly in the following areas:

- Type 1 / type 2 diabetes: still much confusion remains about the differences between them and much less information is available for type 1 than type 2
- Black and minority ethnic groups: many factors affect the availability and uptake of information – higher incidence in these groups (up to six times as higher as white Europeans), language problems, cultural differences in diet and view of exercise, close observance of family traditions. Less than 60% of PCTs in England and Wales have an education strategy for BME groups
- Pregnancy: little advice is available for those who develop diabetes during pregnancy or those with a pre-existing condition; even though pre-conception and early pregnancy care can reduce both maternal and foetal deaths, and malformations
- Information and guidance for children and young people with diabetes is important, especially in taking on responsibility for self-management, dealing with school life, diet and exercise plans etc. There is currently no appropriate information programme in the UK
- People with problems of physical access (elderly people, visually disabled, poor households) or learning difficulties, who have special problems in coming to terms with their complex disease

Source: *The Diabetes Information Jigsaw* (69)

REAL UNDERSTANDING AS THE BASIS OF EFFECTIVE SELF-MANAGEMENT

Patients need to be encouraged and motivated to take responsibility for their own lifestyle. One aspect of this is taking medication – many people with diabetes have multiple medications, especially if they develop complications. Taking different drugs to control blood glucose, blood pressure and lipids is common. Diabetes UK believes that advice on medicines can be poor, and the message that medicines need to be taken consistently and regularly is not clearly made (75, 76). People need guidance to deal with the progressive changes in treatment for type 2 from lifestyle management, through oral medication to insulin.

 **The patient needs to reach a balance between the risk of complications, the effort needed to avoid them and the direct benefit of the choices and actions taken.**

Because of this lack of understanding, it is easy to see why many people lapse, not only with their medications but also in their diet and exercise plans. The DAWN programme has shown that less than one in five of people with diabetes feel that they comply with their management plan in all respects; their healthcare providers reported even fewer (70). Many patients said their treatment was too complicated. Young people in particular are not good at following their medication plan, partly because

they do not want to be different from their friends, partly to express independence and partly because of the other social, emotional and physical pressures they are experiencing (71).

Conversely information and guidance is more likely to help patients to follow their management plan, including medication, if this enables patients to understand the relationships between the various factors. Understanding how monitoring blood glucose can be used to assess the effects of food can be helpful (72).

Non-observance of prescribed medication is more than just a problem for the individual: it is a major health economics problem since it contributes very significantly to the fact that less than half of those diagnosed with diabetes achieve satisfactory blood sugar control, despite the availability of effective treatments. As a result, many will suffer serious complications which could have been avoided (70).

The most effective self-management programmes are likely to be those which address many different aspects of coping with everyday life. According to Naquib (73), these

- include strategies for changing behaviour
- recognise the importance of the patient's personal and unique experience of living with diabetes
- are patient-centred
- take social, emotional, cultural and psychological aspects into account
- include setting of personal goals led by the patient's own priorities
- include social learning e.g. problem-solving and self-efficacy
- involve a partnership between health professional and patient.

In motivating patients with both type 1 and type 2 diabetes to become effective self-managers a balance must be reached between the perceived threat (chance of a heart attack, or severity of other complications), the barriers to be overcome (effort, cost) and the benefits of action (less risk to health, feeling fitter). In relation to diet, exercise and medication, the greatest success is achieved if patients are able to exert choice and influence – if they like their diet or their choice of exercise and feel empowered in the partnership (74).

However provision of quality information and advice on diet is sparse. For example, people with newly-diagnosed diabetes are ideally seen by a specialist diabetes dietician within four weeks of diagnosis and at their annual review. This level of input is rare – many patients have never seen a dietician, even though a medical student might fail an exam on diabetes for failing to mention diet as a cornerstone of treatment. In most cases dietary advice for type 2 is given by a GP or practice nurse, but still many do not receive any written information or indication of what to expect or the targets for treatment. Type 1 patients would be advised in specialist facilities (45).


Although the NSF and NICE will require specialised dietetic support for an expansion of intensive control with continuous subcutaneous insulin infusion pump and carbohydrate counting schemes, primary care commissioning groups have paid little attention to the deficient levels of dietetic services. While expansion of primary care diabetes services may use multidisciplinary teams to deliver dietetic input, this will not address the issue of specialised support (76).

Similarly it is rare for patients to be given any more than general encouragement to take exercise. Very few have a specific diabetes exercise coach who guides them through what sort and amount of exercise they should be doing. Diabetes patients are often surprised to learn that even walking for 30 minutes, three times a week would be of great benefit to them (46).

DIABETES AND DEPRESSION

People with diabetes are about twice as likely as the rest of the population to suffer from depression, and just under a third of people with diabetes have significant symptoms of depression. For them it also lasts longer and recurs more often (63). It occurs in both type 1 and type 2 diabetes, especially where complications are present, and it is more prevalent in women; possibly because of a link with overweight. There is also a strong indication that depression may be a risk factor for type 2 diabetes and precede it; a major review of previous studies has indicated recently that depressed adults have a 37% higher risk of developing type 2 diabetes (66). There is a need for a study to test whether effective treatment or prevention of depression can reduce the incidence of type 2 diabetes.

Apart from the mental distress it causes, depression is critical because it is linked with poor self-care, and so the medical control of diabetes is compromised. The risk of complications is increased up to three times by even a low level of depression. It is hard to say whether the diabetes or the depression comes first – there is some evidence that depression often precedes a diagnosis of type 2 diabetes and follows a type 1 diagnosis – but the effect on self-confidence and ability to self-manage is the greatest danger (63). It is also known that the risk of developing type 2 diabetes is much greater in people who have depression or severe mental illness – some 20% have diabetes compared to about 4% in the general population (16).

 Depression is twice as likely to affect people with diabetes as those without it. Self-management is impossible until depression is treated.

Checking for signs of depression is now among the QOF requirements and some are arguing that it should be used at diagnosis as well as at the annual review, which is welcomed by the MODEL Group. These patients need treatment for their depression before they can begin to cope with their diabetes (39). The MODEL Group believes that there is a need for systematic review of diabetes patients to address this issue, and notes that patients who benefit from the DESMOND education programme are already routinely screened for depression and referred for treatment if necessary.

Determining whether a patient has depression is an easy task using standard triage tests like WHO-5 (78), and then a range of others can be used to assess the severity of depression. NICE guidance suggests that screening for depression should be undertaken in high-risk groups, and should include the use of at least the following two questions:

- During the last month, have you been bothered by feeling down, depressed or hopeless?
- During the last month, have you often been bothered by having little interest or pleasure in doing things?

By tackling first the symptoms and treatment of depression, the patient stands a greatly increased chance of success in managing his diabetes. However, little professional psychiatric or psychological support is available in primary care. The Diabetes UK / All Party Parliamentary Group for Diabetes State of the Nations report in 2005 (79) noted a significant gap between the need for emotional support and services provided. None of the local health boards in Wales reported access to a specialist psychologist, and in England a total of 58 whole-time equivalents were reported from all the participating PCTs (64% response rate). About half of the PCTs indicated that they had access to a psychologist, but few people with diabetes reported that they had seen one.

Children and young people with diabetes are in particular need of emotional support. Most of these have type 1 diabetes, where regular and careful attention to self-management skills is essential, so control over depression is as well. The NSF standard 5 indicates that children and young people, with their families and other carers, must be offered support; and the NICE Guidelines extend this to advise access to mental health professionals. This is important because they may experience psychological disturbances – such as anxiety, depression, behavioural and conduct disorders and family conflict – that can impact on the management of their diabetes and wellbeing. There is a growing body of evidence that psychological support can improve self-management and therefore offer a cost-effective option. But this is far from reality in many regions.

Unravelling depression from diabetes

“I think it’s under-appreciated how teenagers really feel. There’s quite a significant incidence of depression in teenagers who are well, and that incidence rises dramatically in those with chronic illness, and diabetes is no exception. It seems to be a fairly consistent figure that 60% of adolescents experience depressive symptoms, if they have diabetes, and it seems to be similar for other illnesses. Our ability to access psychological or psychiatric support is practically zero. It really is wretched. We’re probably worse off than most; most places can at least get some support. I’ve only made three referrals to child psychiatry locally in four years from a case load of 360, and they’ve refused two of them, because they have diabetes. They see the diabetes as the issue and not the psychological ramifications.”


Paediatric diabetes consultant, England

The conclusions from the State of the Nations report (79), which are supported by the MODEL Group, are that:

- Doctors and nurses need to pay greater attention to listening to and supporting the emotional and psychological needs of individuals
- Greater resources need to be invested to increase access to specialist psychological and emotional support for people with diabetes
- Further research is needed to investigate the types of emotional support which would be of benefit.

LEARNING TO LIVE WITH DIABETES

If people with diabetes are to be able to manage their condition on a day-to-day basis, as well as information, they need structured education, which is at the heart of self-management and is recommended by the NSF. Its aim is to improve the knowledge, skills and confidence of people with diabetes, enabling them to take increasing control of their own condition and to integrate diabetes-management into their daily lives. If they are able to do that, not only will they gain self-esteem, independence and improvement in quality of life, but they are less likely to need early, costly medical intervention and the investment in education will be justified.

 Structured education to improve knowledge, skills and confidence is the principal tool for effective self management. Like medicines, it requires validation and expert delivery by accredited professionals.

NICE guidance recommends that structured education is undertaken at the time of diagnosis and then as required, based on formal assessment of need. Education should be in the hands of an appropriately trained multidisciplinary team. NICE guidance also recommends that children and young people with type 1 diabetes and their families should be offered opportunities to access information about the development, management and effects of type 1 diabetes; and adds that the method of delivering education and its content will depend on the individual and should be appropriate for the child's or young person's age, maturity, culture, wishes and the existing knowledge within the family.

The framework for standards-based planning and assessment of health and social care for 2005-2008, to be used in planning, commissioning and delivering NHS services was set out in the Department of Health paper: National Standards, Local Action (80). It is clear from this that NSFs and NICE guidance have a key role in supporting local improvements in service quality. The performance of healthcare providers will be assessed increasingly on whether they are delivering high quality standards across a range of areas, including NSFs and NICE guidance.

NICE had noted (81) that while most newly diagnosed patients were given some information about diabetes, the length, content and style of education varied considerably: some programmes were unstructured, very few were formally evaluated and few of the providers had been trained for the purpose. The features of a high-quality education programme that would meet the NICE requirements were then developed by a Department of Health / Diabetes UK working party (82), which decided that they should have a structured, written curriculum, trained educators, and that they should be quality assured, and audited.

Two national programmes that meet the NICE requirements are Dose Adjustment for Normal Eating (DAFNE) (83) for type 1, and Diabetes Education and Self-Management for Ongoing and Newly-Diagnosed (DESMOND) (84) for type 2. DAFNE offers 35 hours of structured group education given by diabetes specialist nurses and dietitians over a five-day period. It has been developed over 20 years including a randomised controlled trial, feasibility trial and economic analysis. DAFNE has been shown to cover its own costs in about four years. People with diabetes who took part in DAFNE achieved improved blood glucose control and a better quality of life. Up to the end of March 2007, 748 DAFNE courses will have trained 5611 people with type 1 diabetes. The cost to train two DAFNE educators and one doctor (the minimum required to run a DAFNE course) is £2615; the cost per patient participating is £545 and the overall cost saving is £668 per patient trained (85). A number of other training programmes for people with type 1 diabetes have been developed in different regions, brought together by the Type 1 Education Network (86). Among these are Insight (Oxford), BITES (York), Pastie (Plymouth) and Dafydd (Gwent).

DESMOND offers 6 hours of structured group education for people with newly-diagnosed type 2 diabetes. It was developed by a group of diabetes specialists in response to the NICE comments on the lack of structured education for type 2 diabetes. A randomised control trial is due to report in 2007, but DESMOND is already used by about 100 PCTs as it is the first quality evidence-based programme recognised by the Department of Health which meets the standards laid down in the Diabetes NSF. DESMOND is also developing further education programmes designed to meet cultural as well as linguistic differences appropriate to various ethnic minority communities.

In addition to DAFNE and DESMOND, there are a number of other local programmes developed by dedicated individuals or groups, including INSIGHT for type 1 diabetes (ref), and the Diabetes X-PERT programme for type 2 diabetes (87) which has also been validated by randomised control

trial and has training and quality assurance modules. The Type 1 Education Network coordinates local programmes for the needs of those with type 1 diabetes. Finally, the Expert Patients programme is available through PCTs and offers general, non-disease-specific guidance on living with a chronic disease.

Patient comments on DAFNE and DESMOND

"I've taken control of a condition that had previously controlled me. The health carers I have spoken to are convinced of DAFNE's benefit, those that completed the course with me feel the same. It seems bizarre then that the waiting list, which I heard is now more than two years, is talked about in frustrated terms and seems to be merely a subject of ongoing discussion rather than concrete action. It would be a real shame that whether because of funding or operational constraint DAFNE's progressive approach could not soon become available to the majority."

M. Smith: DAFNE course participant 2003

"On the course we learned which foods are good for us and what choices we could make. And those of us who smoke - like me - were encouraged to quit. Suggestions included being more active... building up to at least 30 minutes of activity five days a week. I've started slowly by taking up dancing around the house to my record collection. Well, it's a start and the experts say any extra exercise will be of benefit. We were asked to look in our booklet to a page called 'What Am I Going to Do Now' which gave a list of risk factors for us to circle individually which ones we were going to focus on. After the session I was certainly determined to work on some of those areas and to that degree I think these sessions are a great idea. The idea of making people responsible for their own battle with diabetes is, I think, a good one. And I certainly haven't given up."

Clive Gresswell: DESMOND course participant 2006

The DoH / Diabetes UK report on structured education (82) also noted that there were considerable gaps in the education programmes available. One of the main deficiencies was that the type 2 education available is for newly-diagnosed people – while the approximately 1.8 million people already diagnosed manage on what information they have been able to gather. Several other important gaps were identified, which are shortcomings compared to the NSF and NICE objectives (Figure 15).

I can manage

"I was involved in managing my diabetes from the word go. From the beginning it was about knowing what to eat and what not to eat. I was at school during the day and couldn't get hold of my parents to ask; I just had to sort it out for myself."

Martin Harris: type 1 diabetes patient

In November 2006 more guidance for local care commissioners came in the form of a toolkit on how to assess patient education on diabetes (88). As it is quite specific in its reference to the NICE criteria, it should stimulate a marked improvement in what is offered at a local level; subject of course to funding. It aims to help service commissioners to examine their current arrangements for providing information and to identify the shortfalls. The facilities they offer should:

- Provide knowledge and skills
- Be tailored to the needs of the individual
- Include skills-based approaches to education
- Help people to adopt and maintain a healthy lifestyle

- Improve vascular risk factors including blood glucose, lipids and blood pressure
- Prevent and manage complications
- Improve quality of life
- Enable people to have control of their own lives
- Integrate self management
- Encourage health care professionals to be involved in partnership and decision-making
- Encourage health care professionals to facilitate and support self management.

These objectives match very well with the outcomes of a comprehensive literature study with interviews of health professionals across Australia (89). This concluded that the absolute aims of diabetes patient education are optimal adjustment to living with diabetes, optimal health outcomes and optimal public and personal cost effectiveness. In order to achieve these results, patient education must be recognised as an integral component of good diabetes care, and selected diabetes education indicators should be adopted into national and local monitoring of diabetes outcomes. In other words, patient education needs to be of a measurable high quality, presented by trained educators according to an optimum model appropriate for the type of patients, and be subject to regular quality assurance.

Getting rusty

"I know education and discussion groups do take place but I haven't been involved. That's something that does concern me, because you do tend to get a bit rusty and need the rejuvenation of a group session. I think it would be good to hear about the latest findings and thrash out how you are coping. I think you can gradually slide into bad habits over the years; I don't think I'm as careful as I used to be."

Martin Harris: type 1 diabetes patient


 NICE guidelines set quality standards for structured education programmes, and so far two national programmes meet them. But these programmes are not widely available, despite their proven cost-effectiveness; while other programmes are not quality-assured

Figure 15 | Gaps in diabetes education

The DoH / Diabetes UK Patient Education Working Group identified a lack of adequate provision for structured education in the areas of:

- One-to-one training – still a major component but one where full use of effective educational techniques like goal-setting, problem-solving, of practical aids and involvement of family need to be employed
- Ongoing support – refinement of consultation skills in the healthcare professional is needed in the context of the patient managing the disease. Both DAFNE and DESMOND are examining how best to support patients throughout the progress of care
- Children and adolescents – their needs change with time and are also affected by ethnic background, sex, level of psychosocial support available and educational achievement. There is currently no evaluated paediatric or adolescent education programme in the UK although two are in preparation; what is available is unstructured and many trainers have no training in education. Two of the better courses are the Birmingham Children's Hospital at Home course for paediatric diabetes nurses and dieticians, and the Warwick Diabetes Care course.
- Insulin pump therapy – according to NICE this should be initiated by a specialist trained team including a physician, diabetes specialist nurse and dietician. The UK has no standardised training in insulin pump therapy for healthcare professionals, although training is available through local diabetes services, PUMP (Pump Management for Professionals) and from some drug companies. The MODEL Group believes that DAFNE provides a good grounding for patients.
- Black and minority ethnic groups – cultural differences mean that conventional teaching methods may be less appropriate than novel approaches like 'sharing stories' – where positive changes in health behaviour follows stories told by another member of the community rather than information given by a health professional. The approach is being tested in a randomised controlled trial (90) and in groups of Bangladeshi women with gestational diabetes, older Somali women, Gujarati and Urdu-speakers and an Afro-Caribbean group
- Impaired glucose tolerance – there is no UK programme to identify and treat impaired glucose tolerance or impaired fasting glucose; i.e. those at risk of type 2 diabetes. Education is needed for the public, for primary care and hospital staff. The MODEL Group notes the work being undertaken through the DE-PLAN project, mentioned in Chapter 1.
- Carers – no definitive education is available for carers of people with diabetes. Carers of children and young people need also to be able to transfer care responsibility progressively to the young person.
- Pregnancy - pre-conception counselling and care can reduce maternal morbidity and avoidable foetal morbidity and mortality, including congenital malformations, often to levels observed in the general population. All women with type 1 or 2 diabetes who are of childbearing age should as a minimum be offered, at least annually, information about the risks associated with pregnancy and the benefits and risks of tight blood glucose control before and during pregnancy. There are no structured education courses specifically for pregnant women, although they do sometimes have access to DAFNE courses or one-to-one training.

Other groups which would need special provision are people with poor language and literacy skills or learning difficulties, and hard-to-reach groups like travellers, refugees and asylum seekers.

Source: Department of Health / Diabetes UK (82)

“ Who trains the trainers?
Who monitors what happens?
Who decides how much education to
deliver? Who says which patient should
attend? Who determines what the
impact should be?

The cost-effectiveness of giving information and guidance to people with diabetes is clear. Helping people to preserve their health and to avoid or delay onset of the complications of diabetes must delay or minimise costs of later medical interventions. This is hard to prove in monetary terms because of the many factors involved in the period between providing the education and measuring the outcome.

But there are some very strong indicators. Comparing the costs of an education course with the costs of treating some of the major complications reveals major long-term savings to be made by investing in education.

Figure 16 | Costs of diabetes education compared to costs of complications

For type 1 patients:	
Cost of DAFNE education programme per patient participating:	£545
Cost to train two DAFNE educators and one doctor (the minimum required to run a DAFNE course):	£2615
Overall cost saving per DAFNE-trained patient:	£668
For type 2 patients:	
Cost of DESMOND education programme per patient:	£60
Cost to train DESMOND educator for first year:	£800
plus per year thereafter:	£440
By comparison, the cost (2002 prices) of treating:	
heart attack:	£4,070
stroke	£2,367
retinopathy	£872
amputation	£8,459

Sources: Carey (91), Clarke et al. (92, 93), Loveman et al (85)

Investing in patient education does not necessarily mean an additional expense for the healthcare commissioning bodies. Instead, early investment that involves the patient in preventing deterioration should actually reduce treatment costs at a later stage. For example, it has been estimated that the cost of six hours' patient education is roughly the same as two weeks' treatment with glitazone. So if glitazone treatment was delayed for a month, the whole education programme could be funded through this change alone (39). In this light, investment in education becomes not only affordable, but essential. The relative cost-effectiveness of providing patient education compared to medical services needs to be questioned carefully by service commissioners (16).

One of the main problems in making the provision of patient education across England and Wales is that there is no clear delineation of who in the healthcare system is responsible for education.

At present, apart from the limited-availability structured education courses with trained educators, like DAFNE, DESMOND, INSIGHT and XPERT, training and education can be given one-to-one in primary care by GPs, practice nurses; or in intermediate and secondary care by community consultants, diabetes consultant nurses and diabetes specialist nurses. But this is an ancillary function for these healthcare professionals, and not a role for which they are trained specifically. It is also an expensive use of the time of health professionals whose expertise lies in other areas. NICE recommends that structured education is best offered to groups of patients, which is both cost-effective and has other benefits as people share the learning experience and feel less isolated (39, 81).

In practice much good work is done by the specialist nurses, but it can be seen that the depth of all these inputs, the amount of time available and coverage of the information will vary and have no quality assurance. Many are still giving outdated, traditional advice about diabetes with mixed messages (91). This situation contrasts strongly with the position in Germany where GPs and practice nurses have a structured training programme with quality assurance and audits.

Some patients become very involved in learning about their diabetes, to the extent of becoming 'expert patients' who can take a much more active role through various routes. Diabetes networks (chapter 4) include patient representatives (known as care user representatives) who can contribute the patients' point of view in discussions of healthcare provision at the local level. The Diabetes Research Network, set up to facilitate the coordination of diabetes research studies and diabetes patients, includes patient advocates on its clinical studies advisory group, and is closely linked to INVOLVE – the government's patient public involvement group. These are people with diabetes or relatives or carers, who have an insight into what research outcomes would be of real benefit to them. Diabetes UK also has voluntary groups all over the country, and finally the NHS expert patient programme, which is not disease-specific, covers various general aspects of chronic diseases.

Expert patients can undoubtedly play an invaluable part in how the future develops for people with diabetes. They are encountering a little resistance, however, for example in diabetes networks where some user representatives can find their views are listened to but not acted upon. It can be a difficult path to find between complaining about inadequacies of health service provision and presenting positive suggestions (94). Expert patients in other groups can supplement the expertise of the healthcare professional, and help support other people with diabetes with friendship and shared experiences, but they cannot replace the professionals in providing the education, because of the quality controls required.

“ Patient education will become part of QOF and with it will be needed a concerted, professional and integrated approach to providing the resources, people and materials for this critical component of care

GPs will soon see patient education added to the QOF requirements, so the provision of structured education programmes will have to be expanded. Added attention will need to be focused on the information and education needs of the 1.8 million people who have already been coping with diabetes for some time.

It is also important that providing information to patients does not widen inequalities – often the people who attend education courses are those least in need of them, while the minority ethnic communities (with cultural barriers) and the poor (often with an unhealthy choice of diet) are less likely

to have access to information. It should not be assumed that they are less interested in learning and taking a role in the management of their condition, but at present they are certainly less likely to be offered the chance (17, 39).

Special problems are linked to the cultures of some ethnic groups; particularly the South Asian, Afro-Caribbean, and Chinese. Often extra imagination and sensitivity is needed in the provision of advice; for example dietary practices may be very different and if the advice is to stand any chance of success, it must be presented in a way that has meaning and fits with the normal foods eaten. Religious and cultural practices may also present practical difficulties - inability to travel alone, or to attend mixed-sex education groups. Medical advice may well be more acceptable from a (familiar) GP or pharmacist than from a more anonymous clinic; hence the importance of choice of the best channel for conveying information. There have also been examples of simple refusal to accept medical advice on the grounds that having diabetes is inevitable and a result of fate or that prayer is the best medicine.

Delivery of structured education needs to be rigorously controlled in a manner almost comparable to the controls over medicines. The UK has improved its record greatly but much more remains to be done to reach a common minimum standard in terms of quality assurance, and training and accrediting the trainers.

The MODEL Group believes most strongly that structured education is vital; not only for the benefit and wellbeing of the patient, but also as a highly cost-effective measure to improve patient outcomes and minimise the costs of medical treatment of complications.

The Group welcomes the excellent progress made so far in developing the DAFNE, DESMOND, INSIGHT and X-PERT Programmes, but is concerned at the substantial areas of England and Wales where access to them is not possible for geographical or financial reasons.

Many other education initiatives have been developed on a local level; particularly those using university-level courses to train

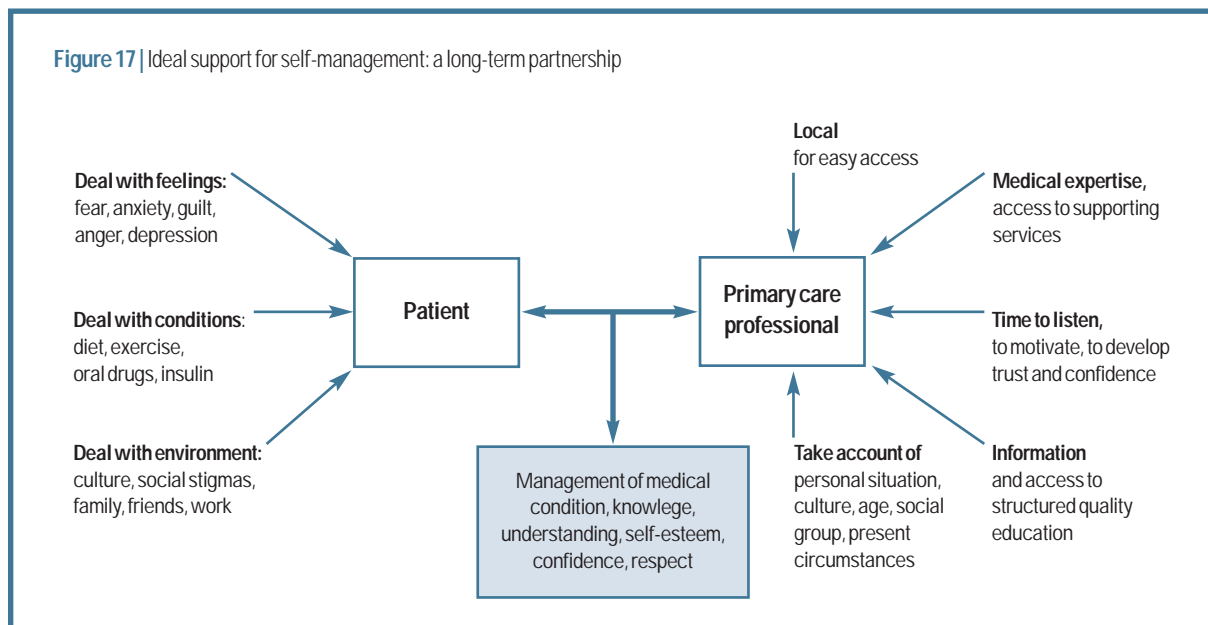
educators who may also be health professionals; and those using existing social groups and community leaders to communicate health advice. The Group applauds these initiatives developed at local levels, but calls for a realistic, coordinated approach to providing structured education to all diabetes patients.

“ Healthcare professionals deliver medical care, but in the changing healthcare system, the pressures on them mean that time and financial resources are not always – not often – able to provide ideal holistic support for people with diabetes.

TOWARDS AN IDEAL PATIENT - PROFESSIONAL RELATIONSHIP

GPs are under pressure to monitor an increasing list of measurables under the QOF requirements. At the same time they are expanding their administrative role as purchasers of secondary care services. They are now being asked to look for incidence of depression, and to treat that first if they hope for progress in compliance with diabetes treatments. The provision of education and information calls for investment of time and human resources, either to train educators or to obtain cover while existing staff use their own (retrained) expertise. In secondary care the picture is no better - erosion of specialist services is viewed from all sides with concern as patients move wholesale into primary care, supported by few, patchy intermediate services.

The ‘softer’ areas, of which encouraging and supporting persons with diabetes to manage their own condition are key, are often woefully neglected. An ideal view of self-management shows the issues to be confronted, the resources which will contribute to addressing those issues, and the indicators of a successful outcome.



Diabetes: multiple medical options

Bena: age 53, type 1 diabetes patient

I was passing out every week; mostly, somebody was with me, but once I was on my own. I'd eaten about twelve o'clock and then I felt a bit odd, so I thought I'd better eat some more. I just collapsed on the floor and shouted 'help, help', because I thought somebody might hear me. I have got a mobile phone, but once the brain stops, you can't do anything; brain's telling you to get the phone, but your body's not functioning at all. I dialled 999, they asked me a few questions, my name. They asked me to repeat my husband's telephone number, but I said half of the number and kept saying 'I don't know'. They asked me if the door was unlocked, if the paramedic would be able to enter the house. I told them 'no, the windows are open, so you'll have to climb in the window'.

THE GOAL OF MEDICAL MANAGEMENT

Typical treatments for type 1 and type 2 diabetes have some essential differences because although they share the name, the diseases are different in their aetiology. As some aspects of type 1 diabetes (dramatic hyper- or hypoglycaemia) can be life-threatening, its treatment at diagnosis is more urgent. People with type 1 diabetes lack the ability to produce insulin. They need insulin injections every day for the rest of their life to keep blood glucose levels normal. They will also be recommended to keep to a healthy diet and to take regular exercise.

People with type 2 diabetes have a relative deficiency of insulin, and what is produced functions less well (insulin resistance). They may be unaware of diabetes in its early stages. It is treated in the first instance with recommended lifestyle changes including weight loss if appropriate, a healthy diet and increased physical activity. It may be necessary to take a range of oral medications to control blood glucose, blood fats and blood pressure. As diabetes is a progressive disease, these medications are likely to be increased over time, and usually insulin will ultimately be needed.



The goal of medical treatment for both types of diabetes is to retain a normal life, free from adverse effects and complications, for as long as possible

The aims of type 1 treatment are firstly to avoid acute adverse events, and to control them if they occur. Longer term, the aim is to avoid or minimise complications, which typically begin to show themselves many years after diagnosis. In addition to the medical interventions needed to do this, and underlying all treatment, is a need to help the patient into a sense of well being and balanced, normal functioning. It is important to ensure that the diabetes management fits into a normal way of life - the patient manages the disease rather than being managed by it. This is one of the most challenging goals for both patient and healthcare professional, especially immediately after diagnosis, or at times of major life changes.

Type 2 diabetes is not 'mild' diabetes, as sometimes thought, but a different, equally dangerous though less acutely dramatic illness. While it does not entail the urgent episodes directly related to blood glucose which are seen in type 1, people with type 2 diabetes are at significantly increased risk of a range of complications including heart attack, stroke, renal failure, blindness and amputation. The main goal of treatment for type 2 diabetes is therefore to avoid, or reduce the extent of these complications, or to delay their onset.

Again, as in type 1 diabetes treatment, underlying all the options is the need to provide enough information, education and skills to enable people with diabetes to be comfortable with managing their condition to fit in with the other parts of their life (36).

HIDDEN FACTORS

The role of the healthcare team for both types of diabetes is to provide appropriate medication, advice, support, knowledge and context for self-management. Additionally, the primary care provider should monitor regularly the patient's blood glucose, blood fats (lipids) and blood pressure. The ideal is to keep all these indicators as near to normal levels as possible, in order to protect against both short-term problems like hypoglycaemia and long-term complications like renal damage (Figure 18).

These three factors are not obvious to the patient, especially if they are not feeling ill, but if they are outside the normal range they all are involved in and indicative of damage. Regular surveillance, as required by the NSF, is vital – these are clues that the body's systems are not working fully and they reveal that some help is needed before that damage leads to a major complication. In a sense, monitoring these factors is like lifting the bonnet and servicing a car before it has suffered a breakdown. What modern medicine does is to look at these secrets instead of waiting for the systems to go wrong (62).


Figure 18 | Ideal ranges for the three key factors

Blood glucose (HbA1c)	normal range: 4 – 5.9%; target: less than 6.5%
Blood fats (lipids)	total cholesterol level: less than 4.0mmol/l LDL (“bad”) cholesterol: less than 2.0mmol/l HDL (“good”) cholesterol: 1.0mmol/l or above in men and 1.2mmol/l or above in women triglycerides: 1.7mmol/l or less
Blood pressure	130/80mmHg or less

Source: Diabetes UK (3)

TREATMENT OPTIONS

In practical terms, the role of the healthcare team is also to determine the optimal treatment pathways. It is the nature of chronic disease to evolve over time in line with changes in the person's age and life circumstances. It is wrong to assume that one treatment pathway will suit everyone. Universal guidelines are useful only as frameworks for individual choices made within the ‘contract’ between the patient and the diabetes care team. At the current stage of knowledge, these care plans are developed through clinical experience and adjusted over time. A much more robust evidence base is needed in long term studies to ensure that the choices made are suitable to the type of individual and type of circumstances at hand. As one senior diabetologist put it: ‘long-term chronic disease studies are essential to develop a truly sensitive model for treating chronic diseases’ (95).

 **Treatment will change over time to reflect medical needs and personal circumstances. More long-term evidence is needed for choice of an optimal long-term pathway**

Diabetes is a complex of different effects on different systems of the body, and its treatment often involves prescribing and taking a combination of different medications. It is perhaps easiest to look first at what is happening in the body in type 1 and type 2 diabetes in relation to blood glucose, and then consider the variety of medications.

In type 1 diabetes, the beta-cells of the pancreas are unable to produce insulin. The glucose concentration in the blood rises because there is no insulin to allow its movement into cells where it is needed as an energy source. This can lead to a hyperglycaemic emergency. Severe hyperglycaemia involves dehydration and drowsiness, and if untreated can lead to diabetic ketoacidosis; a condition which can cause unconsciousness and even death.

Conversely hypoglycaemia occurs if glucose levels become too low – too much insulin is taken or not enough carbohydrate or sugar. ‘Hypos’ can involve feeling shaky, irritable or aggressive, or can lead to frightening and dangerous fits or loss of consciousness. The attack can often be controlled by consuming something containing easily-absorbed sugars, like glucose tablets or a sweet drink, but may need hospital treatment.

Treatment of type 1 diabetes therefore centres on controlling the balance between insulin and blood glucose.

Insulin was first extracted from animal pancreas in 1922 and for many years animal-origin insulins, which are structurally very similar to human insulin, were used to treat diabetes. Insulin cannot be taken orally as it is broken down in the digestive tract and all activity is lost. Instead it is administered by subcutaneous injection, using single-use syringes, an insulin pump with a semi-permanently implanted needle attached to a catheter, repeated-use insulin pens with needles, or an insulin jet which forces insulin through a nozzle placed against the skin. All of these methods are manageable but have limitations and irritations. From the first use of animal insulins, purity improved steadily but they occasionally gave rise to allergic reactions.

Animal insulins have now largely been replaced by human insulin. More recently modern insulin analogues have been developed, in which the structure of human insulin is altered slightly to create new types - one which is faster-acting than original insulin, and can supply the level of activity needed to cope with a meal, and another which is released slowly over 24 hours to supply a basal level of insulin for the whole day. These different types of insulin have great advantages in that they give flexibility and convenience, fitting in much better to the patient's lifestyle. While it is still necessary to monitor blood glucose throughout the day, the quick-acting insulins can be taken just before eating. It is much easier to avoid hypos if a meal is delayed, and to avoid hyperglycaemia if an injection is delayed. Long-acting insulin needs to be taken only once or twice a day, while rapid-acting insulins may be needed to cover mealtimes. The aim is to match blood glucose and insulin levels by adopting one of these insulin regimens or a combination. Modern insulins offer a much more flexible way to balance food intake and medication than ever before.

There are other possibilities for treating type 1 diabetes - islet transplantation and inhaled insulin, which are both already available under limited conditions. Insulin is normally produced in beta-cells in the pancreas, gathered in clusters with some other cells and known as islets. It is now possible to transplant islets from an organ donor into the portal vein of a type 1 patient, from where they travel into the liver and can begin to produce insulin. To date more than 300 patients have received these transplants, and some have gone on to develop insulin independence and a dramatically improved quality of life. This technique avoids the large-scale intrusion and complications of transplanting a whole pancreas. The problem with islet transplantation, as with any transplantation, is that long-term immunosuppression is needed.

Stem cells are individual, undifferentiated embryonic cells which have the potential to develop into any cell of the body. It is hoped that it may be possible in the future to stimulate these cells to become insulin-producing beta-cells – releasing an unlimited supply for transplantation into type 1 patients.

Inhaled insulin is only available in the UK (under the requirements of NICE) in cases where the patient has specific problems with insulin injections. It is not recommended as a routine treatment for people with type 1 or type 2 diabetes, and is only considered for treatment where both the blood sugar is not being controlled by other methods, and where people have needle phobia or severe problems with injection sites. Treatment with inhaled insulin should be started and monitored at a specialist diabetes centre and can only be continued for more than six months if the specialist feels that the lasting improvement in blood sugar will reduce the risks of long-term complications.

In type 2 diabetes, either the body does not make enough insulin, or the insulin produced does not work properly – known as insulin resistance. The insulin fails to ‘unlock’ the receptor sites in the body’s cells to allow glucose to be used to provide energy – the reason why one of the first symptoms of type 2 diabetes is extreme tiredness, linked with excess (unused) glucose in the blood. The aim of treatment is to keep the vascular system healthy for as long as possible through good nutrition, exercise and combination therapies.

Treatment for type 2 diabetes normally changes with the course of the disease. Lifestyle modification is usually the first step, which means advice to the patient on diet and exercise. Smoking is highly inadvisable. Because of the likelihood of other complications, some of which may already be present when the diabetes is diagnosed, type 2 patients will also often need other medications. Diabetes patients commonly need many different types of medications – this is known as polypharmacy. Looking first at the options for blood glucose control, they may be treated with one or more of the oral hypoglycaemics (Figure 19), including:

- metformin (a biguanide) and thiazolidinediones (glitazones) – to stop the liver releasing glucose and to overcome insulin resistance
- sulphonylureas and other insulin secretagogues – to stimulate the beta-cells to produce insulin
- alpha glucosidase inhibitors and metformin – which delay the absorption of glucose from the gut.

“ Insulin will ultimately be needed to replace multiple tablets for most type 2 patients. Early conversion to insulin, and intensive control of blood pressure reduce complications and improve the quality of life.

A number of other new therapies are about to become available for type 2 diabetes. These are GLP-1 agonists which will be available in the UK in May 2007. GLP-1 is a gastrointestinal hormone or incretin, that stimulates insulin secretion, suppresses the release of glucagons by the liver and moderates glucose levels. The natural level of GLP-1 can be reduced in people with type 2 diabetes. Drugs to mimic incretins (mimetics and analogues) are under development and the first of these has been available in the USA since early 2006. In addition to controlling blood sugar levels they also seem to help control weight and may be associated with weight loss.

Figure 19 | Oral treatments for type 2 diabetes

Site of action	Drug type	Mode of action
Pancreas	Sulphonylureas, other insulin secretagogues	Stimulate insulin secretion
Liver	Biguanides (metformin), thiazolidinediones (glitazones)	Decrease glucose production
Gut	Alpha glucosidase inhibitors, biguanides, GLP-agonists	Slow carbohydrate digestion
Muscle and fatty tissue	Thiazolidinediones, biguanides	Decrease insulin resistance

Source: Dudley, after DeFronzo, (96, 97)

In type 2 diabetes patients, the beta-cells decline at about 4% per year from diagnosis (62) and so while one oral agent may be sufficient for a time (most start with metformin), patients will eventually need to take two or three in combination. After about six to eight years from diagnosis, when perhaps 25% of the beta-cells are functioning, most patients will need insulin.

The point at which patients are prescribed insulin (insulin conversion) will be affected by many factors, including

- failure to achieve control of blood glucose within acceptable levels by oral medication
- onset of other illness, diabetic complications or pregnancy
- patients’ preferences
- patients’ memory or understanding
- patients’ vision or manipulation skills

Insulin conversion does not mean that someone who has had type 2 diabetes now has type 1, as is sometimes thought - only that insulin is now needed to keep the blood glucose at a manageable level. There is also a strong argument for giving insulin to people with type 2 diabetes at an earlier stage of their disease. Evidence from the UKPDS has shown that close monitoring and intensive intervention minimises symptoms in type 2 diabetes; with residual benefits for many years.

During the study patients’ blood glucose and blood pressure were measured frequently and if either rose above an agreed target, treatments were increased or other treatments were added. The study showed clearly that the risk of type 2 complications was significantly reduced by tight control of blood glucose (6, 99), with equally good results from insulin and from sulphonylureas, and metformin was also successful in the overweight. Long-term tight control of high blood pressure also showed a significant reduction in diabetes complications including stroke, and in diabetes-related death (5). Equal success in controlling high blood pressure was achieved with angiotensin-converting enzyme inhibitors and with beta-blockers (100), and tight control of blood pressure was seen to be cost-effective (101). Despite the evidence some GPs feel there is a case for trying hard to manage diabetes with weight reduction and exercise rather than hastening insulin conversion (98).

A type 2 patient is typically resistant to insulin, so to get the same level of blood glucose control as in a type 1 patient, the dose of insulin may need to be several times greater (95). In practice this can lead to difficulties

because many type 2 patients converted to insulin in general practice are given insulin doses appropriate to type 1, and so they do not have good glucose control, at least initially. This problem is discussed further later in this chapter in relation to the current 4T study (Treating to Target in Type 2 Diabetes) which is examining the merits of different treatment regimens for type 2 diabetes.

TREATMENT FOR OTHER DIABETES-RELATED PROBLEMS

People with diabetes, particularly those with type 2 who are at increased risk of heart disease or stroke, will have their blood pressure and blood fats monitored routinely. Changes in these indicators beyond the target ranges will require treatment by one or more of a range of medical options. It has been well established, principally by the UKPDS, that all of these indicators are risk factors in diabetes (6, 101).

The primary treatment for reducing blood pressure is lifestyle changes comparable to those for type 2 diabetes: a healthy diet (with restricted saturated fats), exercise, stopping smoking, working towards a more correct weight, reducing intake of salt and alcohol, and reducing stress. However in many cases medication is also needed, and again like type 2 diabetes, a combination and then a progression of drugs may follow.

Recommendations for individual choices are made by the Joint British Societies' guidelines on prevention of cardiovascular disease in clinical practice (102). The 2006 NICE guidelines on hypertension (103) recommend treatment of younger (under 55 years), non-black patients with an ACE inhibitor, or a calcium-channel blocker or diuretic in older or black patients. Later a calcium-channel blocker or diuretic can be added for patients already on an ACE inhibitor, and an ACE inhibitor for those on a calcium-channel blocker or diuretic. The recommended third-line therapy is a combination of an ACE inhibitor, calcium-channel blocker and diuretic; and if further treatment is required, NICE now recommend adding an alpha-blocker, betablocker or further diuretic (Figure 20).

OTHER FORMS OF DIABETES

Of all the people with diabetes, between 5-15% in England and Wales have type 1, and type 2 affects 85-95%. There is also a very small proportion who have other forms of diabetes; some of which are extremely rare and can be difficult to diagnose.

“ The extra demands on the body during pregnancy can lead to diabetes - this usually resolves after the birth but may recur later in life.

Perhaps the best known of these is gestational diabetes or diabetes of pregnancy. About 2-5% of the 600,000 births in England and Wales each year involve women with diabetes (104). Gestational diabetes occurs in some women because the body is not producing enough insulin to meet the extra demands of pregnancy, and this form usually appears after the third month. In other women, gestational pregnancy can appear in the first three months, and here it is most likely that they already had diabetes before becoming pregnant. Women who were already diagnosed with type 1 or type 2 diabetes when they became pregnant (25% and 10% respectively of pregnancies affected by diabetes) will already be undergoing treatment. At greater risk, depending on how high the blood glucose has been, and for how long, are the 65% who had undiagnosed blood glucose problems before pregnancy (3). The main risk is of foetal

malformation, but there are also raised chances of miscarriage, pre-eclampsia, pre-term labour and stillbirth, and diabetic eye damage to the mother can worsen rapidly (104).

NICE guidelines for the treatment of diabetes in pregnancy are expected to be published late in 2007.

In many cases gestational diabetes can be controlled by diet and exercise, and a professional dietician will be involved, but between 10-30% of women are unable to control blood glucose in this way and need insulin injections. Gestational diabetes usually disappears after delivery and insulin can be discontinued, but 50% of women who have had gestational diabetes are likely to develop type 2 diabetes within ten years, compared to 10% in the general population. A very small percentage may develop type 1 diabetes.

Figure 20 | Treatments for control of blood pressure and blood fats

Drug type	Mode of action
Blood pressure	
ACE-inhibitors	reduce production of the enzyme angiotensin II, which results in lowering blood pressure
Diuretics	stimulate renal function and salt excretion, reducing blood pressure
Alpha-blockers	relax blood vessels
Calcium channel blockers	relax blood vessels
Angiotensin II antagonists	reduce blood pressure in a similar way to ACE-inhibitors
Beta-blockers*	reduce production of renin; involved in raising blood pressure
Blood fats	
Statins	Reduce cholesterol production and reduce triglyceride storage in fatty tissues
Fibrates	Reduce triglyceride levels
Resins	Reduce LDL "bad" cholesterol in blood
Ezetimibe	Inhibits absorption of cholesterol

Source: Diabetes UK (3)

* Use of beta-blockers to reduce blood pressure was restricted in June 2006 to a few limited situations, because of their lower efficacy than the other, newer medicines and their higher risk of stroke, heart attack and diabetes (105). However people already taking beta-blockers were advised not to stop suddenly, but to seek review at the next opportunity.

One of the rarer forms of diabetes is maturity onset diabetes of the young, or MODY (37). MODY runs in families – children of an affected parent have a 50% chance of inheriting the disease. Six types of MODY have been identified; one much more common than the others, and in this form enough insulin is produced in childhood, but it reduces with age so symptoms develop in adolescence or the early twenties (3). This form does not usually require insulin, only diet and exercise or an oral drug to reduce blood glucose. Being diagnosed with MODY does have the advantage that it can help to identify other family members at risk. Some forms of MODY do not progress to needing insulin.

Figure 21 | Rarer forms of diabetes

MODY	maturity onset juvenile diabetes
LADA	latent autoimmune diabetes in adults
TNDM	transient neonatal diabetes mellitus
PNDM	permanent neonatal diabetes mellitus
MIDD	maternally inherited diabetes and deafness
Gestational diabetes	diabetes of pregnancy

Other insulin-related disorders

Metabolic syndrome:

A collection of conditions caused by insulin resistance, which often leads to type 2 diabetes and therefore has been called pre-diabetes, although this term is not now favoured. Metabolic syndrome is characterised by high blood pressure, altered blood cholesterol and other blood lipid composition, and indicated primarily by increased waist measurement. If untreated, it can also lead to cardiovascular diseases.

Insulin resistance:

Decreased capacity for response to insulin in the muscle, fatty tissues and liver and the underlying cause of type 2 diabetes.

TREATMENT OF CHILDREN AND TEENAGERS

Perhaps 20,000 school age children in the UK have type 1 diabetes, and only a very few have type 2, although the numbers have been increasing since 2000. One current estimate is that about 200 children in England and Wales have type 2 diabetes, and in addition there are extremely small numbers with MODY (37),

Children and young people with type 1 diabetes will be referred to a diabetes specialist and treated with insulin immediately they are diagnosed. In practice the very small numbers of children now presenting with type 2 diabetes also usually go straight onto insulin although some are treated with metformin. Those with the rare forms like MODY normally respond to diet and oral drugs, especially sulphonylureas.

Apart from medication, children and young people with diabetes do need extra care because they have suddenly been given traumatic news about the strict care they need, plus the prospect of blood tests and injections, both needed several times a day. Adjusting to this level of intervention is hard even for an adult, so it represents a very big challenge for a child or adolescent, and for their families. Paediatric clinics are the focus of care, but evidence is amassing that the standard of care is very variable throughout the country, particularly in terms of frequency of monitoring, availability of diabetes specialist nurses and of access to psychological

support (18) (discussed in chapter 4). As they grow older, some patients may be transferred to an intermediate clinic for young adults, and these are the lucky ones where the uncertainties of growing up and coping with a serious, chronic disease are treated sympathetically. Depression is apparent in about 60% of adolescents with diabetes (37). This frequently shows itself in lack of interest in self-care and poor control of the diabetes. One of the actions found most helpful and effective in young adult clinics is simply taking steps to ensure they keep attending – using the sort of communications they are comfortable with including texts and emails.

“ Children and young people need extra care, separate specialist medical treatment and support structures dedicated to their particular problems in coping with a long-term disease

Young patients will eventually progress to adult clinics, and at this point many simply fail to make the transition – 50% go missing within a year (66). It is now becoming recognised that having a named care worker, probably a diabetes specialist nurse, to be their mentor through their treatment can make a crucial difference. Other steps to improve the way treatment is offered may hopefully be developed as a result of the current Children's and Young People's Diabetes Services working group set up by the Department of Health together with the National Diabetes Support Team and Diabetes UK. This aims to identify what needs to be done to enable the NHS and local care services to meet the needs of young people with diabetes, as set out in the NICE Guidelines.

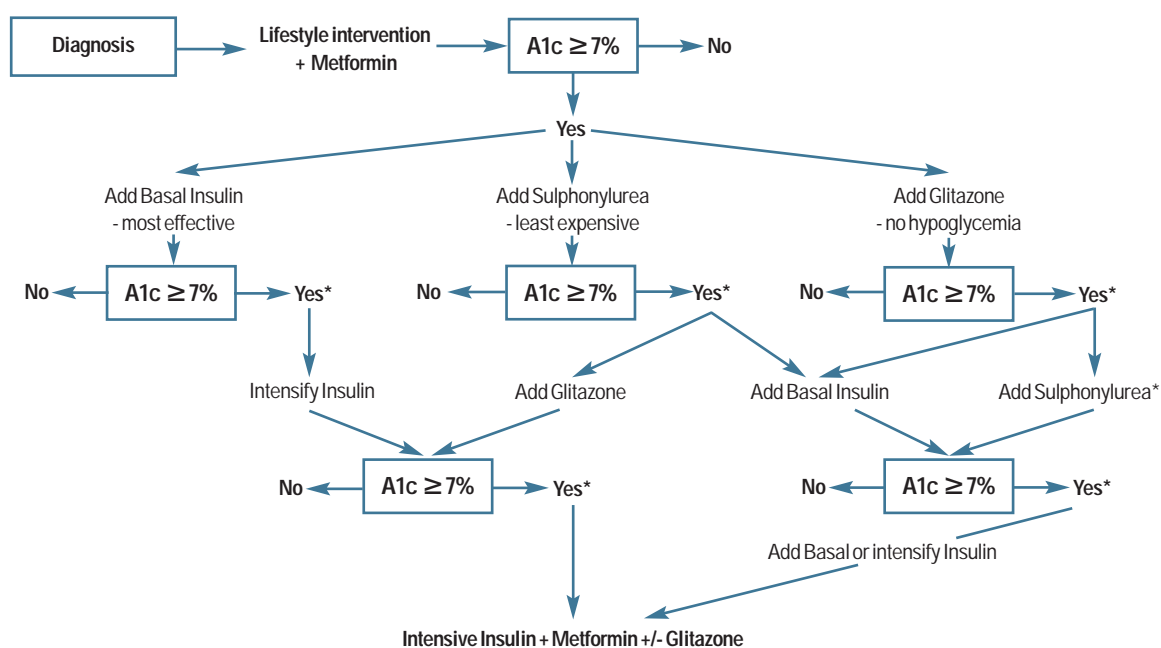
A MULTI-FACETED APPROACH

Both of the major types of diabetes show complexity of symptoms, interrelated changes in different body systems and present many treatment options. In view of this complexity, it is something of a paradox that long-term evidence on which to base treatment decisions is so scarce. Evidence of reduction in blood glucose for a few months caused by a new drug is no use to a diabetologist or his patients, because they are all involved for life (95).

For this reason, and because of the new treatments becoming available in the last ten years, it is particularly perplexing for the healthcare professional that there have been so few high-quality long-term studies to provide head-to-head comparisons of the ability of the recommended medications to achieve the recommended blood glucose levels (95). In the absence to date of such information, however, it has at least been possible to draw together from the medical literature enough information to develop a consensus statement from the American Diabetes Association and the European Association for the Study of Diabetes, together with an algorithm for coping with all the possible decisions in blood glucose management (106) (Figure 22).

What is needed for excellence in diabetes treatment is not only a vast range of medical options but also of medical facilities and skills. The quality of individual treatment rests not only on the array of medications available, but perhaps more importantly, on the expertise of a very wide range of healthcare professionals; each bringing their own specialist knowledge and skills (107). This is particularly relevant in the treatment of type 2 diabetes.

Figure 22 | Management of blood level glucose in type 2 diabetes



Source: Nathan et al.

Notes: Reinforce lifestyle intervention at every visit.

* Check HbA1c every 3 months until less than 7% and then at least every 6 months.

+ Although three oral agents can be used, initiation and intensification of insulin therapy is preferred, based on effectiveness and expense.

Figure 23 | Typical course of treatment for type 2 diabetes

Under GP Care.....

At diagnosis:

Treatments prescribed for:

- blood glucose: diet, exercise and oral antihyperglycaemic drugs
- blood pressure: up to 3 antihypertensive drugs
- blood lipids: statins, later increased, later another statin added

Six-eight years later:

- no further oral options to control blood glucose
- beta-cells down to 25%
- blood pressure often not controlled on up to 3 medications
- blood lipids usually under control

Eventual progression relating to:

- blood glucose: insulin needed
- blood pressure: GP concern at use of more than two medications
- some blood lipids resistant to treatment
- incipient complications

Under specialist care.....

Further diabetes management:

diabetologist, either alone or in joint specialist clinics in most of these areas:

cardiac failure:

cardiologist

renal failure, microalbuminuria:

renal specialist

retinopathy, laser treatment:

(screening in community), ophthalmic specialist

neuropathy, pain, ulcers:

(screening in community), expert podiatrist, vascular surgeon, plastic surgeon, orthotist

peripheral vascular disease:

vascular surgeon

erectile dysfunction:

specialist clinic

gum disease:

specialist clinic

skin disease:

specialist clinic

Source: Matthews (62)

Clearly training for the specialist diabetologist, the GP with special interest in diabetes (GPwSI), the diabetes specialist nurse and more recently the pharmacist with special interest (PhwSI) is vital to ensure that the correct decisions and optimum treatment pathways are taken at each junction. Diabetologists will have undergone training according to general and specialist curricula in endocrinology and diabetes; both set by the Joint Committee on Higher Medical Training. The general training covers the issues needed by all specialists, including good clinical care, good medical practice, communication and management skills (107). The diabetes specialist curriculum requires that specialist registrars have already undergone at least two years in approved posts in general professional training; they then undergo four or five further years before becoming a specialist diabetologist (108). Their training in that time will cover all aspects of chronic disease management, and they must be able to deal with every development which could arise for a person with diabetes during the course of their illness, including the development of any of the complications of diabetes; and to contribute meaningfully to diabetes research.

A GPwSI, according to the Department of Health guidelines for their appointment (109), should be seen as one member of the diabetes care team, as well as an individual practitioner. The aim of the GPwSI service is to enhance the quality and consistency of diabetes management throughout primary care. This could be achieved in a number of ways, for example by providing localised expertise to train other health professionals and by giving support in order to raise the general standard of diabetes care across the local community. A GPwSI service could also create some extra clinical capacity, which could alleviate pressure on specialist secondary care services. As well as organisational, communication and teaching skills, a GPwSI in diabetes needs to have a good knowledge of diagnosis, management and long-term care of people with diabetes, and of education and support practices for self-management. They need also to have spent significant time working under the direct supervision of a consultant diabetologist in a hospital setting, and training from professionals in other disciplines, e.g. podiatrists, psychologists.

New healthcare players are added to an increasingly complex mix of professionals

GPs are, of course, responsible for all other branches of general medicine as well as diabetes and so will be involved in keeping themselves informed in many other areas. Many do take on courses and workshops in diabetes (run by the BMA or offered by their PCT) as part of their continuing professional development (110).

Diabetes specialist nurses are at present mainly trained on the job, from a background of general nursing or health visiting plus training courses. Many universities are now developing courses in diabetes care for different types of healthcare professionals; notably Warwick University which runs a wide range of courses up to Master level. Warwick's courses are mapped against the Diabetes National Workforce Competence Framework; a structured framework for skills in diabetes care, developed by Skills for Health and licensed by the Department for Education and Science as the UK Sector Skills Council for Health (111, 112). Currently the Nursing and Midwifery Council (the registration body for nurses) is developing requirements for formal study which will supersede this competence framework and is likely to be in place within five years. Diabetes nurse consultants (at present only 28 have been appointed in the UK) are diabetes specialist nurses with extensive experience.

From October 2005, pharmacists in England and Wales (and the rest of the UK) began operating under the new pharmacy contract which expanded the pharmacists' role in line with the governments' policy for healthcare provision (113). The Royal Pharmaceutical Society of Great Britain had already begun to encourage pharmacists to offer services in the promotion of healthy lifestyles, and in the management of chronic conditions; both important aspects of diabetes care. The RPSGB's guidance on the care of people with diabetes (114) recommends the specific roles which pharmacists can play in the healthcare team providing services to people with diabetes, including primary prevention, detecting undiagnosed diabetes, screening campaigns and prevention of complications. In September 2006 the Department of Health released details of its scheme for pharmacists with special interests (PhwSI) (115), setting out how NHS services involving PhwSIs are to be commissioned and the role and function that can be taken by PhwSIs, plus a framework for competence.

Vitaly important too is the active involvement of patients in following the treatment. There is evidence that up to 60% of patients fail to take their medications as prescribed (116), and little clinical improvement was detected from a variety of methods to encourage them to do so, including nurse efforts, pharmacy input, and adaptation of dosing (117). As patients are central to the outcome, whatever the benefits of medicine and its practitioners, the patients' commitment to the management of their diabetes is the key. Convenience and flexibility – whatever will make it easier for diabetes management to fit into a normal lifestyle, whether combination of medications in one tablet, coordinated advice from healthcare professionals or the development of new drug delivery systems – are very important in care of a long-term disease.

MEDICAL TREATMENT MUST EVOLVE FURTHER

Because the treatment goals for diabetes are so broad and complex, the idea of optimal medical interventions needs to evolve further than has been possible until now. While the current healthcare system measures the basic parameters of the disease, the full potential of modern and future medicines needs to be explored if the patient is to approach the ideal of living with diabetes, without being ill from diabetes. Society has a duty to develop treatments by research into all aspects of diabetes care; not just medication but techniques (such as islet transplantation), self-management and provision of healthcare services.

Searching for better treatments also needs to take account of the other events in the patient's life. For example, a study of different insulin injection regimens over three years with almost 3,000 adolescents with type 1 diabetes showed little difference in blood glucose level whether twice-daily or multiple injections were given (118), but a slight rise with time in both cases. The insulin doses and frequency of injections increased in all cases over the three years, but control deteriorated despite treatment. Glucose control is widely reported to deteriorate through adolescence, and the study group acknowledged that their work was observational over two time-points, with no account taken of other factors such as frequency of self-monitoring, patient education, dietary counselling and guidance on effective self-management. Weight gain was greater than would be expected for those without diabetes. There is some evidence that the apparent freedom for those on intensive, multiple insulin therapy allows excessive eating, especially if it occurs after years of dietary discipline. Prevention of weight gain at the same time as blood glucose control must be one of the major goals for future diabetes care; particularly in adolescence where overweight causes severe loss of self-esteem, then depression, eating disorders and possible cardiovascular risks.



New and long-range studies, similar to those conducted for heart disease, are needed to answer critical clinical questions in diabetes

Finding the right treatment for the individual is an area where much still remains to be learnt. It was noted earlier that type 2 patients often need a larger-than-anticipated dose of insulin on conversion, due to insulin resistance. So if a newly-converted patient is given a type1-type dose, initial blood glucose control may not be good. The 4T study of different drug delivery mechanisms (Treating to Target in Type 2 Diabetes, (119) sets out to determine adequate starting points, and incremental steps thereafter, to allow good control from the beginning that can be managed by GPs safely and with a degree of certainty (95).

For the individual, it is important to arrive at the optimal mix of medications to give the best personal outcome, while minimising side-effects. The various drugs used to alter blood glucose, blood pressure and blood lipids have different levels of effect. The statins and ACE-inhibitors, for example, are life-saving in that they reduce restriction of the arteries by fat and reduce blood pressure. In contrast, modern insulins are much more subtle in that they are able to offer insulin profiles that match glucose profiles, reducing the possibility of a hypo. This close match to the real timescale of insulin need is felt by most people to present a better quality of life. If modern insulins are measured only in terms of whether they give better absolute levels of blood glucose, their advantages are less apparent.

Hypoglycaemia can occur in both type 1 and type 2 diabetes (120). One large study found that one in 14 people with insulin-treated diabetes (of either type) has one or more episodes annually of severe hypoglycemia, requiring emergency treatment. These figures do not include hypos treated at home or in the workplace by family or friends. The problem of hypoglycaemia and its calls on the emergency services is clearly greater than previously estimated (121). Use of insulins which can match the glucose profile, avoiding or reducing the risk of hypoglycaemia, have to be considered as an improvement with economic as well as health benefits.

Evidence of the benefits of carefully tailored, multifactorial treatment also comes from the classic Steno-2 study from Denmark (122). The study found a 50% reduction in cardiovascular and microvascular events in type 2 patients with microalbuminuria who were given stepwise treatment of

- diet, exercise, metformin, sulphonylurea and various insulins toward a target of HbA1c less than 6.5%
- various antihypertensive drugs toward a blood pressure target of 130/80 mm Hg
- statins toward fasting serum total cholesterol less than 175mg/dl
- fibrates toward fasting serum triglycerides less than 150 mg/dl
- aspirin, whether or not there was a risk of heart disease or peripheral vascular disease

These benefits, like those of the UKPDS, persisted after the treatment period; and those receiving intensive treatment showed continued reduced risk of diabetic complications. The exact mixture was not felt to be prescriptive: the essential message is that early, intensive and multifactorial intervention gives significant and lasting benefits.

POINTERS FOR THE FUTURE

The best outcome will be achieved by building both new and established medical treatment options into an evidence-based, individual care plan

In 2002 the Department of Health and the Medical Research Council's priorities for diabetes research ranged from beta-cell biology and insulin secretion, insulin action and insulin resistance, genetic and environmental causes of diabetes, obesity, prevention of diabetes, screening, patient self-management and complications, to service organisation and delivery (123).

In 2007 the MODEL Group emphasises the importance of looking at individual patients, who are at the centre of all this effort. As Diabetes UK says, what works for one person does not necessarily work well for another. There are also differences in the ways that healthcare professionals treat people with diabetes, especially where there is an absence of evidence-based good practice. The end result is inequality in the care and treatment of diabetes and in the prevention, care and treatment of complications (124). Therefore Diabetes UK calls for research and improvement in care and treatment, with particular emphasis on establishment of best practice (the MODEL Group's concept of ideal or excellent care) in all aspects of the treatment of people with diabetes. The outcome of this endeavour will be not only clearer, more flexible treatments, but also that they will enable people with diabetes to live longer, healthier lives with a better quality.

Diabetes: a health system fit for purpose

Hans Csucsmi: age 73, type 2 diabetes patient

One of the things is the retinopathy - I make my own arrangements. I can still look after my feet and I don't have to go to a chiropodist, but, at the same time, these services were never offered to me. And, you know, I'm sure it happens to a lot of people. And because I was involved in all the different studies and projects, and I'm aware, I make sure that I get my annual - or fifteen months is it now - retinopathy test, and, as I say, I don't need a chiropodist at the moment. But if I do, I would obviously make my own arrangements, and so I'm reducing the side-effects, if you like, or the possible hazards.

HISTORY OF HEALTH SYSTEM CHANGE HAS LED TO INEQUALITY AND TENSION

Diabetes patients need healthcare of many kinds – acute, long-term, clinical, informative, psychological, social. Does the present system mean they all have access to all they need? Does it begin to approach ideal care?

Healthcare provision for diabetes patients in England and Wales is patchy, unequal, in many ways simply inadequate, and it compares poorly with that of other countries in Europe. For example, in Germany structured educational programmes have been implemented in hospitals and primary care for more than ten years (125). In many areas and aspects UK care is excellent; but it is far from comprehensive, both in terms of geography and quality. Part of the reason for this is historical; the legacy of the many changes to the NHS over the last 15 years. Because so many different inputs are needed, patients are suffering huge variations in the level of care on offer.

In England primary care trusts (PCTs), have the responsibility for providing local health services and administering the local healthcare budget; reporting to the appropriate strategic health authority. They are also involved in planning for healthcare provision, including strengthening the role of advisory groups and the networks of health professionals and users. Since the early 1990s PCTs have evolved through a succession of structures and organising healthcare provision has changed through many hands in 15 years (Figure 24). The consequent differences in the mechanisms and the quality of healthcare throughout the country, and the low morale of healthcare professionals, are not therefore surprising. In primary care the feeling is that healthcare teams have been drawn together, established, destroyed, reconfigured and so maintaining any sort of momentum in any long term strategy is actually quite difficult (98). In the mid-2000s healthcare providers are in a position of competing for funding, hospital against hospital and specialist services against primary services. Patients also have the choice of private healthcare.



Patchy, unequal and inadequate care for people with diabetes is the result of frequent, disruptive changes to the NHS and the complexities of the disease

Figure 24 | NHS changes, England

1991	Establishment of NHS Trusts and GP fundholding to buy healthcare from NHS Trusts. Other non-fundholding GPs provided with healthcare budgeted by health authorities and bought from NHS Trusts. Accusations of a two-tier system
1998	Launch of NHS Direct telephone advice service for patients
1999	Primary Care Groups to purchase healthcare set up with representatives from GPs, nurses, social care, health authorities, local government, lay people. GP fundholding abolished
2000-2002	PCGs become PCTs, controlling 75-80% of NHS budget. 28 Strategic Health Authorities set up to replace former health authorities. Other new trusts: Acute Trusts (hospitals), Ambulance Trusts, Care Trusts, Mental Health Trusts
2003	New consultants' contracts, aimed at fairer rewards and encouraging specialists to work in multidisciplinary teams
2004	New GP contracts, including introduction of Quality and Outcomes Framework requirements (QOF), linked to practice payments for observing them Establishment of Foundation Trusts (or Foundation Hospitals, now 52) with independence from government and Strategic Health Authority (SHA) control and freedom to raise and invest capital. Their aim: to give better access to higher quality services for NHS patients through encouraging innovation and entrepreneurialism. Accountable to local stakeholders, including staff and patients Establishment of patient choice on referral to hospital
2005	Establishment of practice-based commissioning and payment by results
2006	SHAs reduced to 10 Universal coverage of practice-based commissioning by end of 2006

In Wales the system is organised differently. As a consequence of devolution, the Government of Wales Act of 1998 gave powers over health and health services to the National Assembly for Wales, and the first elections to the Welsh Assembly Government took place in 1999. Health provision in Wales faces particular problems: it has some of the poorest people in Europe, some of the highest rates of cancer and heart disease and a high proportion of elderly people. An average of 54% are overweight or obese (126). Local health boards with the same geographical boundaries as local authorities are responsible for health service provision.

The funding for health services in Wales is negotiated between the UK Parliament and the Welsh Office. The Welsh National Assembly receives a block grant to cover all the areas devolved to its responsibility. Wales spends over £4 billion every year on its health services and this figure will continue to rise. The priorities for improvement to the health service in Wales were set in 2003 by another Wanless report (127) which called for a radical redesign for health and social care, developed capacity outside acute hospitals and greater public and patient involvement. This was amplified in 2005 by the Welsh National Assembly's 'Designed for life' review of Welsh healthcare strategy which promoted extension of primary care and an increased focus on early diagnosis and monitoring (128).

HEALTHCARE NOW

Several changes made in the past five years have had substantial collective impact on the quality, scope and level of healthcare service to people with diabetes.

- The National Service Frameworks for Diabetes and their Delivery Strategies
- The GP contract of 2004/5
- The Quality and Outcomes Framework (QOF)
- The NICE clinical guidelines on treatment of diabetes (Figure 27)

These have produced substantial structural and organisational changes within the NHS; each addressing specific NHS-related issues in its own context. However, the coincidence of these initiatives has created a strategic shift that does not always support the clinical needs of patients, the professional needs of healthcare providers and the national needs of society.

The National Service Frameworks for Diabetes (NSF, 61, 129) and their Delivery Strategies (23, 4) set out a ten-year programme to improve care for people with diabetes in England and Wales to the year 2013. The twelve national standards set by the NSF (Figure 25) spelt out the intentions to improve prevention and diagnosis of diabetes, and support for patients in decision-making and managing their diabetes. Standards of clinical care would be high, with special provision for children and young people. Care of diabetic emergencies and of diabetes patients in hospital would be managed according to established and effective protocols, involving the patient as far as possible in decisions about their care. Policies would be developed and implemented to empower and support pregnant women with existing diabetes, and those who develop diabetes during pregnancy. All diabetes patients would receive regular

surveillance, followed by timely and appropriate care, for long-term complications, and those requiring multi-agency support would receive integrated health and social care.

The NSF for Wales Delivery Strategy recommends an integrated approach, developing local diabetes service advisory groups (LDSAGs) as its main means of implementation, or setting up new stakeholder groups where LDSAGs do not exist, plus the establishment of a separate user reference group of people with diabetes for each LDSAG.

The NSF Delivery Strategy makes the point that delivering better care to everyone with diabetes will take time and that the first priority is to focus on those at greatest risk of developing complications and those newly diagnosed, where the opportunity to implement NSF standards right from the beginning is the greatest. In particular, a recommended local approach would be to offer:

- information and appropriate psychological support and the opportunity for people diagnosed with diabetes after April 2003 to participate in structured (usually group) education
- an agreed care plan, a personal diabetes record and a named contact within the local service for everyone diagnosed with diabetes after April 2003, and also for people with poor blood glucose control (i.e. those at risk of diabetes).

Early in 2007, access to structured education programmes is geographically limited and heavily over-subscribed (Chapter 2). Patients, GPs and specialists from many parts of the country report very limited or no access to psychological support (37).

There has been no real progress on the issue of the named contact beyond the general agreement that it would be of great value to diabetes patients, particularly at pivotal times e.g. at diagnosis, when changing treatment, during adolescence and at the transition to adult services. These are 'trigger' times (62) in between the periods of little change, and at these critical points decisions and changes in treatment can lead to anxiety, depression and crisis. A Diabetes UK workshop in February 2005 confirmed that a named contact would be useful because patients would then be able to ask further questions which occurred to them after they had had time to reflect on a recent consultation. The National Diabetes Support Team is currently seeking views on what would be the most useful role of a named contact and how local services could be supported to provide one for every diabetes patient.

Two key targets for 2003-2006 set by the NSF were aimed at primary care providers:

- A minimum of 80% of people with diabetes should be offered screening (and treatment if needed) for diabetic retinopathy – the retinal damage caused by weakening of blood vessel walls – rising to 100% coverage by the end of 2007
- GP registers should be kept and updated to ensure advice and treatment is in line with NSF standards. By March 2006, patients with heart disease and diabetes should be given appropriate advice on diet, physical activity and smoking; these requirements should also cover the majority of patients at high risk of heart disease, particularly those with hypertension, diabetes and a body mass index (BMI) of over 30.

Figure 25 | NSF Standards to be reached by 2013

- | | |
|--|--|
| Prevention of type 2 diabetes | 1. The NHS will develop, implement and monitor strategies to reduce the risk of developing type 2 diabetes in the population as a whole and to reduce the inequalities in the risk of developing type 2 diabetes. |
| Identification of people with diabetes | 2. The NHS will develop, implement and monitor strategies to identify people who do not know they have diabetes. |
| Empowering people with diabetes | 3. All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process. |
| Clinical care of adults with diabetes | 4. All adults with diabetes will receive high-quality care throughout their lifetime, including support to optimise the control of their blood glucose, blood pressure and other risk factors for developing the complications of diabetes. |
| Clinical care of children and young people with diabetes | 5. All children and young people with diabetes will receive consistently high-quality care and they, with their families and others involved in their day-to-day care, will be supported to optimise the control of their blood glucose and their physical, psychological, intellectual, educational and social development.
6. All young people with diabetes will experience a smooth transition of care from paediatric diabetes services to adult diabetes services, whether hospital or community-based, either directly or via a young people's clinic. The transition will be organised in partnership with each individual and at an age appropriate to and agreed with them. |
| Management of diabetic emergencies | 7. The NHS will develop, implement and monitor agreed protocols for rapid and effective treatment of diabetic emergencies by appropriately trained health care professionals. Protocols will include the management of acute complications and procedures to minimise the risk of recurrence. |
| Care of people with diabetes during admission to hospital | 8. All children, young people and adults with diabetes admitted to hospital, for whatever reason, will receive effective care of their diabetes. Wherever possible, they will continue to be involved in decisions concerning the management of their diabetes. |
| Diabetes and pregnancy | 9. The NHS will develop, implement and monitor policies that seek to empower and support women with pre-existing diabetes and those who develop diabetes during pregnancy to optimise the outcomes of their pregnancy. |
| Detection and management of long-term complications | 10. All young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes.
11. The NHS will develop, implement and monitor agreed protocols and systems of care to ensure that all people who develop long-term complications of diabetes receive timely, appropriate and effective investigation and treatment to reduce their risk of disability and premature death.
12. All people with diabetes requiring multi-agency support will receive integrated health and social care. |

Source: Department of Health (2001): National Service Framework for Diabetes: Standards

The Quality and Outcomes Framework (QOF, 130) was set up as part of the new General Medical Services GP contract in 2004-5. Through it GPs and other primary care providers are financially rewarded for delivering care to patients based on observance of 146 care indicators, of which 19 relate specifically to diabetes. The practice earns points through meeting clinical and organisational targets; also some relating to additional services, patient experience and holistic care. The clinical targets are by far the predominant, with holistic care only earning up to 20 points out of a possible 1,000. In the QOF for 2006-7, greater emphasis has been allocated to testing for blood glucose (HbA1c) and for blood pressure (which means more points).

The QOF indicators for diabetes are what would be normally checked in an annual patient review. The GP practice does not have to carry out all the checks itself – e.g. retinal screening is usually done by an optometrist – but the practice is responsible for making sure they have been done. Similarly it has responsibility for making sure that checks on type 1 patients have been done, although their care is shared with a specialist.

“ The QOF indicators achieve high compliance but are only the basics of an annual review with the GP

The NSF and the introduction of the QOF approach have coincided with improvements in diabetes care. For example between 1998 and 2003 key indicators recorded by Campbell (131) showed improved control of serum cholesterol in 21.5% rising to 52% of diabetes patients, and control of blood pressure in 21.8% rising to 35.8%, plus a small (non-significant) improvement in blood glucose control. Significant improvements were also made in recording of creatinine (which indicates progress of kidney failure), weight and blood glucose level (HbA1c). Dr Clare Davison, diabetes lead in Newham PCT, London reports that the whole emphasis of the incentive scheme and the enhanced service has been to increase the proportion of patients under the care of the GP - in her area from 75- 85% (from 47% in 2000), with a consequent reduction of those under specialist care. It has also raised the basic level of care for a large cohort of type 2 patients (98).

In its 2006 report (132) the Healthcare Commission reported a high degree of overall compliance with the QOF diabetes indicators – both England and Wales showed scores of 93% of the total possible. However, there were some disturbing factors:

- for diabetes, as for all other conditions, the scores for general practices in poorer areas tend to be lower than those for richer areas, especially for single-handed practices
- 23% of the people predicted by epidemiological studies to have diabetes are not recorded on GPs' registers of patients with diabetes (133)
- 61% of people with diabetes receive eye checks; the target for 2006 is 80% (133)
- data is checked by PCTs but not independently audited

The Healthcare Commission also found that almost 20% of PCTs were not sure that they were taking proper account of guidelines published by the National Institute for Health and Clinical Excellence (NICE) when treating patients. For example, where mental health patients were cared for by outreach teams, many were not receiving recommended health tests. Only 26% had received blood pressure checks and only 17% had been tested for obesity, so many cases of diabetes and high blood pressure were not being identified (134).

The Audit Commission in Wales noted in 2003 that although the importance of prevention and diagnosis of diabetes had been recognised

in Wales, there was at that time only limited evidence of a strategic approach across local health boards to identify people with undiagnosed diabetes (126, 135). The lack of developed primary care services for diabetes in some Welsh areas was also noted by the Audit Commission. This had given rise to concerns, as expressed by some GPs and nurses, about the capacity of primary care in Wales to identify and manage those at risk of diabetes (136). These concerns highlighted lack of resources and the perceived low motivation of patients to modify their lifestyle.

Figure 26 | Patients' experiences on access to and quality of care

Diabetes UK's 2005 survey of patients examined their access to key priority services in the year to July 2005:

- 86% had been offered an eye examination for retinopathy but only 56% given digital retinal photography
- 8% had attended a structured education course in the last five years
- 35% had received emotional support in recent years
- 44% had been diagnosed with diabetes as a result of another condition
- Only 18% had been diagnosed through a routine test in primary care
- 97% of those involved in children's services had been referred to a children's specialist diabetes team
- 90% felt confident in managing their child's diabetes
- 45% were satisfied with their current diabetes service provision.

Source: Diabetes UK (137)

A particularly bleak picture is provided by Farooqi (138) who compiled a baseline analysis of the diabetes service provision in Eastern Leicester. Half of its 180,000 population is South Asian; the average for England and Wales is 6%. The Eastern Leicester PCT has a high number of single-handed practices, and a poor population. Analysis of the diabetes care provided showed many shortcomings, most notably only 10% of practices offered any structured education, and 76% were unable to produce a practice protocol for diabetes. Also inadequate training, access to nurse hours and dietician support were evident. The comparison between the 6% diabetes prevalence reported by the best-organised practices and the Trent regional estimate of 4.3% suggests a gross underestimate of diabetes care needs for the whole region.

However primary care is much more effective in other parts of England. In affluent Guildford, Surrey, primary care services have been bolstered to take on most routine diabetes care. A network of diabetes clinics operate from general practice, and the GPs and practice nurses who run them have all completed Warwick University-validated diabetes training courses. None are GPs with Special Interest in diabetes (GPwSIs; see later in this chapter). The more complex cases are seen by specialists in hospital but about 350,000 patients are looked after in primary care. Patient services are good: a psychologist is available one day a week and patient education is offered by GPs and practice nurses who have completed teaching training (139). DESMOND (see Chapter 2) was considered too expensive.

The QOF has been criticised as focusing on easily-measured elements such as pharmaceutical intervention, which has risen substantially. Patient-focused elements such as information, education and empowerment have been largely ignored (140). The extra income from the new GP contract and QOF have enabled practices to invest in staff and resources; non-participation in the non-mandatory QOF would have meant a loss of about a third of their income. The outcome for diabetes is the substantial and not always appropriate change to managing the majority of diabetes interventions in primary care.



Welcome and necessary reforms have some unforeseen and counterproductive results, reducing availability of necessary expertise, increasing primary care costs, and under-delivering for patients.

The Association of British Clinical Diabetologists (ABCD – diabetes consultants in secondary care) welcomes the improved monitoring of patients by GPs, especially those with type 2 diabetes. But it points to the unexpected consequences of the requirement to improve blood glucose control to meet the target value of 7.5% for HbA1c – the increased referral for possible insulin conversion of patients who have formerly been treated satisfactorily by oral medication. The move of most diabetic care from secondary to primary care has resulted in some PCTs actually downsizing specialist diabetes units (141). The ABCD reports that this has led to discontent, a decline in recruitment of diabetes consultants and a threatened loss of specialist services which will be hard to re-create.

While much excellent care can be provided in general practice, many patients will still need the expertise of specialists to address their complications. So secondary care for diabetes should not lose its resources; rather it should receive more investment. GPs need the support of diabetologists and their multidisciplinary teams, the ABCD believes, and access to specialists for patients with complicated diabetes-related conditions should not be reduced. Specialist care is also essential for establishing centres of excellence, and providing education to those providing standard care (62).

It is essential to maintain the delicate balance between standard care and specialist care, because an inappropriate shift may not yield the anticipated cost savings and can also result in loss of expertise and service. The rise in costs is linked with the heavier burden on general practice and the need for more specialist nurses and GPs, as shown in the Leicester evidence. More patients are expected to be diagnosed and monitored in general practice, with an associated rise in the number of patients needing to be referred to secondary care for treatment of earlier-detected complications (142). The ABCD believes that to reduce the burden of complications would need a process of intensive care such as provided by the UKPDS, which would exceed the capacity of most primary and secondary care centres (143).

While the majority of care can be offered in the community, there is still a clear need for increasingly specialised services for the more challenging problems of type 1 diabetes, and for type 2 complications. What is needed is a concerted approach, built on mutual respect, to span both primary and secondary care, with an effective information system to cover overall treatment in both. The patient should be empowered to contribute effectively to the management of care, and be able to move without difficulty – seamlessly – between primary and secondary care.

It is widely agreed that effective clinical networks are essential for the organisation of the care of people with chronic conditions like diabetes. This is specifically recognised in the NSF Delivery Strategy, which recommends that PCTs should consider using them to reach the NSF standards and deliver its targets. Diabetes care networks should ideally link all the varied inputs with a view to enabling planning and delivery of diabetes care services, taking full account of integrated care, improved clinical outcomes, cost-effective service, better patient experience and equity of service provision. It follows that they will be fully involved in commissioning and delivery of care, with the patient at the centre (144).

Currently about 150 diabetes networks are operating in England, bringing together healthcare professionals and managers in both primary and secondary care, social care and patients. So as well as GPs and diabetes specialists, they involve PCT representatives, service commissioners, diabetes nurses, podiatrists, dieticians and private service providers. The setting up and continued working of diabetes networks is supported by the NHS National Diabetes Support Team (NDST).

The NDST has been heavily involved in developing guidance for networks on the effects of the present NHS reforms – principally practice-based commissioning and payment by results. Examined more fully below, the key role of the networks and local health teams will be to translate national policy into a system to fit local needs and meet local priorities. The networks will be increasingly important in coordinating service design and delivery. It has been seen that sources of difference are already apparent between the various components, despite the widely held view that integrated care is the top priority for diabetes (145, 146, 147)

Several good examples of networks functioning well come from the north of England. The South of Tees Diabetes Network has been able to coordinate development of a retinal screening programme and obtained funding from PCTs for this and for patient education programmes, insulin pump therapy and a paediatric diabetes specialist nurse. Every PCT in the network has completed its diabetes service assessment and produced an action plan with priorities for continuous improvement. The network has also held public awareness events on diabetes and general good health (148).

A more specific example comes from the Eastern Wakefield and Wakefield West PCTs, which have developed an integrated care pathway for diabetes foot. The key is that patients will have access to foot care at a frequency and from a healthcare professional appropriate to their needs, and appropriate referrals to specialist care. The team involves primary and secondary care including podiatrists, plus a vascular surgeon, microbiologist, orthotist and tissue viability specialist, all consulting with a patient focus group and patient information group. Routine foot care is provided in the primary setting, with referral to podiatrists and specialists as needed according to specific triggers. The care pathway incorporates a training package for the primary care teams, and patient education leaflets (148).

Achievements in secondary prevention through diabetes networks have been shown by the Derby PCT, particularly in the area of diabetes foot care. An annual rate of 54 amputations was reduced by 37 in a year, and to 8 after five years, through development of a new care model involving two podiatrists to educate practice nurses to treat feet problems urgently. The reduction in hospital costs was well over £400,000 in the first year (149).

CHILDREN AND YOUNG PEOPLE WITH DIABETES - IN THE GREATEST NEED

Dr Sue Roberts' report on the first three years of the NSF (9) acknowledged that standards of diabetes care services for children and young people are inconsistent, despite the specific requirements for them set by the NSF. The Department of Health, together with the National Diabetes Support Team and Diabetes UK has therefore set up a Children's and Young People's Diabetes Services working group to identify what needs to be done to enable the NHS and local care services to meet their needs as set out in the NICE Guidelines. The group has not yet reported (January 2007). Among the possibilities it may recommend are the establishment of young people's clinics, staffed by diabetes specialist nurses and other healthcare professionals, involving rigorous attendance monitoring for adolescent patients and a named care worker, probably a nurse, to ensure that they complete the transition to adult diabetes care.

Figure 27 | NICE Guidelines relating to diabetes

TYPE 1

Diagnosis and management in children, young people and adults

Requiring multidisciplinary, patient-centred care. Clinical control of blood glucose, lipids and assessment for onset of complications; provision of education. For children and young people with type 1 diabetes: in-patient or home-based initial management from diagnosis; care package designed to keep HbA1c below 7.5%; treatment for ketoacidosis and screening for other complications including coeliac disease, thyroid disease and retinopathy; timely psychosocial support to patients and families

Insulin pump therapy

This is recommended as an option for people with Type 1 diabetes provided that multiple dose insulin (MDI) therapy (including, where appropriate, the use of insulin glargine) has failed; and the patient has the commitment and competence to use the therapy effectively. Insulin pump therapy should only be initiated by a trained specialist team and all patients starting the therapy should receive specific training.

Pancreatic islet cell transplantation

This may be able to replace insulin injection, by replacing non-functioning pancreatic islet cells with others from the patient or a donor which can produce insulin normally. The procedure requires special arrangements for consent and for audit or research.

TYPE 2

Retinopathy – screening and early management

Requiring eye examinations at diagnosis and at least annually thereafter for retinopathy screening

Renal disease - Prevention and early management

Requiring annual review and determination of urinary albumin and serum creatinine; to be repeated if microalbuminuria is present

Managing blood glucose levels

HbA1c should be measured at 2-6-monthly intervals depending on various parameters; for each individual a target HbA1c should be set between 6.5% and 7.5%, based on the risk of complications. Other areas covered in the guidelines include: lifestyle, patient education, general therapy, drug treatments including metformin, insulins and anti-obesity drugs.

Management of blood pressure and blood lipids

Requiring a full clinical history to be taken at diagnosis, including any history of coronary heart disease; this to be estimated at least annually thereafter. Clinical management of blood pressure and blood lipids.

Prevention and management of foot problems

Requiring annual review for risk factors for foot ulceration

Glitazones

The use of a glitazone in addition to either metformin or a sulphonylurea (as an alternative to treatment with a combination of metformin and a sulphonylurea) is not recommended in type 2 diabetes except for those who are unable to take metformin and a sulphonylurea in combination because of intolerance or a contraindication to one of the drugs.

Obesity

The guideline covers assessment of the overweight and obese conditions; how people can be helped to lose weight; care for people whose weight puts their health at risk; helping people to ensure they and their children stay at a healthy weight, and how health professionals, local authorities and communities, childcare providers, schools and employers should make it easier for people to improve their diet and become more active.

TYPES 1 and 2

Long acting insulin analogues

Insulin glargine is recommended as a treatment option in type 1 diabetes. It should only be considered for those with type 2 who require insulin therapy and either need help from a carer or healthcare professional to give their injections, if their lifestyle is significantly restricted by recurrent hypoglycaemia, or if they would otherwise need twice-daily basal insulin injections in combination with oral antidiabetic drugs.

Patient education models

Requiring that structured education is made available to all people with diabetes at diagnosis and then as required, based on formal assessment of need. Education should be given by an appropriately trained multidisciplinary team. Group sessions should be accessible to the broadest range of people and use a variety of techniques to promote active learning. The Dose Adjustment for Normal Eating (DAFNE) programme may be a suitable option for individuals with type 1 diabetes.

Inhaled insulin

Inhaled insulin is not recommended as a routine treatment for people with either type 1 or type 2 diabetes. It should only be used for either type where the blood glucose is not being controlled by other methods including diet, oral glycaemic drugs or insulin, AND the person is not able to have insulin injections before meals or to increase their current level of injections because of a confirmed phobia or because of persistent and severe problems with injection sites.

Source: NICE (150)

“ Children and young adults are the most underserved group of people with diabetes, even though this has been well known for years

Evidence for the inadequacies of care for children and young people until now is plentiful. The NDA report on the quality of care for children and young people for 2004-5 (65) quotes the following:

- The rates of carrying out care processes varied significantly between specialist units [in England and Wales]. 81% of children and young people (aged 0 – 24 years) had their blood glucose level recorded at least once in the audit period 2003-4 (it should be done at least three times a year in children). However this indicator was by far the most frequently recorded

Figure 28 | Proportion of children and young people receiving various care processes (% of patients of 12-15 years, 2003-4)

Care process	Males	Females
HbA1c	80	81
BMI	53	56
Blood pressure	46	48
Urinary albumin	20	21
Creatine	21	23
Cholesterol	19	18
Eye examination	19	19
Foot examination	17	20
All care processes	2	2

Source: National Diabetes Audit (2006) (65)

- Not all care processes are recommended for all ages, but it is of concern that only 17-19% of 12-15 year-olds received eye and foot examinations or had their cholesterol level checked
- Only 16% of children and young people under 16 years achieved the HbA1c target of <7.5%, while 72% of under-16s achieved the HbA1c target of <=9.5%. The benchmarks set in the previous year's audit, not met, were 20% and 76% respectively
- Only 54% of PCTs have guidelines for the management of children and young people with diabetes, but 80% refer all on the day of diagnosis to a paediatrician with a special interest in diabetes, and 98% of children and young people have their diabetes managed by such a paediatrician
- As age increases, the proportion of patients with blood cholesterol in excess of the target 5mmol/litre increases: 66.7% of 16-24 year olds achieved the target; compared to 79.8% of 12-15 year olds
- The National Diabetes Audit received data on 7,841 children and young people from paediatric units in England (7,073) and Wales (768), and on a further 10,265 from primary care registers in England. A further 846 were submitted from other sources, making a total of 18,952.

Even more worrying information comes from a 2005 survey conducted on behalf of Diabetes UK (151). While the Royal College of Nursing recommends that paediatric diabetes specialist nurses attending clinics for children and young people should have a caseload of not more than 70-100 (152), the average caseload found in 165 clinics surveyed was 147. 61% of clinics had a specialist nurse (WTE): patient ratio of <1:100.

Of the responding clinics, the survey noted with concern that 11% were run by general paediatricians, with no specialist training or interest in diabetes. The clinics run by consultants with a special interest in diabetes achieved significantly better HbA1c levels than those run by general paediatricians.

Further, support from a psychologist or psychiatrist (required by the NICE Guideline, (Figure 27) was reported from only 22% of responding clinics, while 28% had access to another form of counsellor or nurse therapist. 87% reported that they could refer to a psychologist and 90% to a psychiatrist but waiting times for these could be as long as 18 months. The difficulty was commented on by respondents as the greatest area of concern, particularly in view of the increasing incidence of diabetes, especially in young children where expertise and emotional support are needed.

The same survey reported that only 61% of clinics received regular attendance from a paediatric dietician with diabetes expertise – of great concern in view of the advent of modern insulins requiring multiple injections and sophisticated dietetic management. From this survey it emerged that the average whole time equivalent dietician:patient ratio was 1:830 – representing an impossible task.

Similar findings came from the Diabetes UK survey on access to and quality of care (137). Here Diabetes UK members reported that the help they were able to receive between visits to a specialist clinic came mainly from diabetes specialist nurses (63%), the specialist children's diabetes team (28%) or the GP (27%). Only 3% had access to a paediatric psychologist between clinic visits and only 1% to a general psychologist. One member commented that the worst experience was "Not being able to contact anyone when my child has a problem".

Transfer from children's diabetes care services to an adult clinic is recognised as a difficult transition, and clearly Diabetes UK members found this less than ideal. Of those who had been transferred, only 35% said that specialist staff of both children's and adult clinics were available during the transfer and only 29% had both children's and adults' services available at the same clinic. This means that the transfer involves going to a different physical location – an ideal chance for treatment to begin to lapse because of uncertainty and unfamiliarity. Again, at this critical transition time, 2% were offered support from a psychologist or counsellor.

Figure 29 | Are we investing in the wrong things?

This comment from a member of a children's sub-group of a London PCT poses the question:

"... the response I get for pointing out the need for increased resourcing at (my hospital) is appalling – simply saying that any increase in provision would mean cuts elsewhere because of the overall NHS funding problem.

"There are monthly clinics, three of which have just been cancelled for 100 children. There is very little patient education possible, no dietician, and an average HbA1c of 10 – is this the highest in the country? But all of this is delivered in the most beautiful, state of the art new hospital costing mega millions."

Source: National Diabetes Support Team

“ Of the current NHS reforms: patient choice and payment by results are largely irrelevant to diabetes patient needs and clinical realities, and benefits from practice-based commissioning depend on diabetes networks

SYSTEM REFORM – THE KEY FUTURE MECHANISMS

Cultural as well as structural changes in the NHS represent a fundamental shift in its traditions and practices, impacting on the delivery of diabetes care. The three key mechanisms of the current system reform - patient choice, practice-based commissioning and payment by results - aim to change the service from a provider-driven to a commissioner-driven service.

These changes attempt to respond to perceived patients' need for more control over their health, for an informed choice of high-quality local services, and for care to be conveniently and locally offered. Patients also were calling for more support from the NHS in preventing illness, and if they were ill, for staying out of hospital (145). The reforms aim to take account of rising obesity in the UK and related health problems; of the low health standards in the poorest communities, and also the extensive new possibilities in terms of drugs and other therapies.

Patient choice: Since the beginning of 2006, patients in England have had the right to choose between at least four hospitals for their non-emergency treatment. This is intended to act as an incentive for healthcare providers to offer the highest quality services, as patients have the freedom to choose to be treated by a practitioner or a hospital further away from home because of some advantage, e.g. shorter waiting lists. Because of this, payment for the services follows the patient; i.e. the better centres will attract more patients and therefore more funding. 'Choose and book' is the practical application of the concept, introduced in mid-2004 and available from 2006. When a GP agrees that a patient needs to see a specialist, they will offer the choice of at least four hospitals or clinics and the patient will be able to choose the date and time of the appointment. However this approach has been criticised for diabetes as it does not fit well with long term conditions, although it does with cataracts, hip replacements and hernias (98).

Commissioning of healthcare services is intended to ensure that the NHS budget for a location is spent as effectively as possible. The PCTs lead in primary care commissioning, but will also involve strong partnership

with other relevant bodies like clinical networks, local authorities and general practices. Practice-based commissioning (PBC) is designed to give GPs more control over their resources, and follows the idea of a primary-care-led NHS. Practices are paid through a scheme of incentives per registered patient to encourage them to take part in PBC, and are entitled to use savings made on more efficient choices for the benefit of the practice (153).

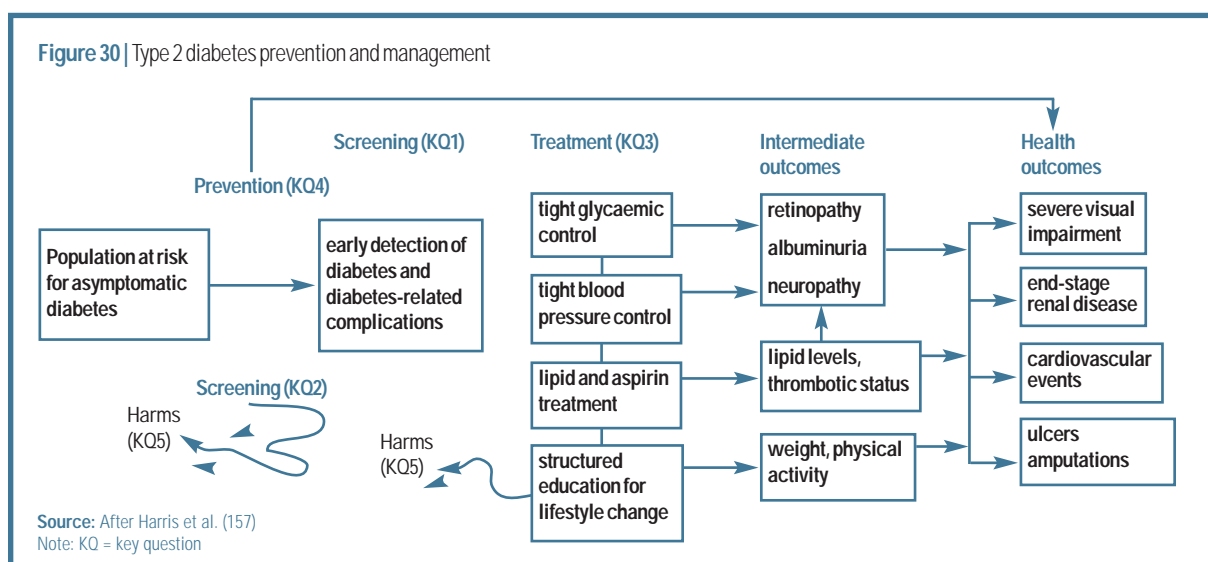
In relation to diabetes services, PBC will give increased importance to the networks, especially in assessing local needs, agreeing an ideal model of care for the specific community, and also monitoring performance including setting appropriate quality standards (138, 154).

Practice-based commissioning may have the effect of stimulating preventive care and developing better care for chronic conditions, reducing clinical deterioration and emergency hospital admissions. Early evidence for this, from the few practices which are already using PBC is showing some examples of significant reduction in admissions. The use of extra training to generate GPs with special interest in diabetes (GPwSIs), more training for nurses and more initiatives from pharmacists all contribute to the ability to provide more primary care for the large majority of patients.

The commissioning process involves finding a way to implement national objectives in an appropriate way to meet local needs (155). Four levels of care have been described – levels one and two set national aims with overall requirements for every diabetes service and then further detail of each component.

Level three is concerned with describing how the national requirements will be delivered locally, and this is where the various organisations involved with diabetes care, ideally the networks, will define the local model of care. Level four gives a detailed account of how the model of care will work in practice. Local care pathways will be developed once the model of care has been agreed.

In early November 2006 a specific commissioning toolkit was published for diabetes services to provide advice for all commissioners of diabetes services (157). It describes how to carry out a health needs assessment for a local diabetes population and specifies diabetes care, using recognised quality markers and suggesting key outcomes for the services. It also suggests how the quality of the current service can be monitored and improved. The toolkit can help diabetes networks in developing their model of care. Because it was developed specifically with the multifactorial nature of diabetes care in mind, this should offer sound guidance for the structures charged with commissioning.



Payment by results (PbR) is the other current major healthcare system reform. It sets a national tariff to be paid to service providers by the PCTs or practices commissioning their services. This means that the payment will follow the patient's choice of provider, so that efficiency should be rewarded financially. The tariff for consultant appointments for diabetes, first set for 2005-6, will be revised annually and has already risen significantly. It applies to all NHS trusts. By March 2007 it is estimated that £22 billion worth of services will be covered by PbR.

PbR is not totally appropriate for diabetes care. It does not apply readily to treatment of people with diabetes, because it is based on consultant episodes, and only applies to pre-booked consultant-led appointments. Diabetes clinics have a high level of follow-up compared to most other medical specialties, with services provided by a wide range of healthcare professionals. In renal, antenatal and other specialist clinics there are often joint consultations involving multiple professionals, but only recorded as one episode of care. Many diabetes services such as outreach clinics, nurse-led appointments and patient education are not covered by the tariff, and must be funded separately through local agreements between the PCT and Acute Trust. The effect of PbR on these vital services is a cause for concern.

FINDING THE RIGHT BALANCE ON BEHALF OF THE PATIENT

Perhaps 85% of interventions in the care of people with diabetes occur at the primary care level. One study of 108 practices in two English health districts showed that nearly two-thirds of the people with diabetes were being followed up solely in general practice, the remainder in hospital or both. The proportion managed in primary care varied from 5.6% to 94.6% (158). This survey revealed large variations in the quality of delivery of diabetes care.

The multiple changes within the NHS have undoubtedly sharpened the focus of general practice on diabetes care, possibly in a way which could be echoed for other chronic diseases. However, the resultant shift of patients from secondary care can place considerable demands on primary healthcare teams – in terms of preventive care, diagnosis, monitoring, treatment, referral and liaison with secondary care. Increased emphasis on pre-diagnosis screening and lifestyle advice will inevitably result in more diagnoses, and therefore more patients for continuing care, and more and earlier detection of complications.

GPs are on the one hand satisfied in that they are treating more diabetes patients and fewer are going undetected; but on the other hand these greater demands for diabetes care are paralleled in relation to many other medical conditions.



Today's NHS promotes competition rather than collaboration between diabetes specialist services and primary care professionals. Is the right balance being struck?

The rise in prevalence of diabetes in the late 1980s led to the establishment of hospital-based diabetes centres and the introduction of diabetes specialist nurses. The idea was that these centres of excellence would complement and support the broader and more locally available capabilities of general practice, offering all-round care for patients. However the market structures of GP fundholding and the establishment

of the NHS Trusts introduced the competitive edge which has remained ever since, and has been accompanied by progressively increasing demands in terms of both standards and patient numbers. Instead of mutual support between the primary and secondary sectors, there is competition. Instead of shared responsibility there is a tug of war over compliance with targets and the numbers of patients in care. Specialist diabetes units in hospitals are facing a great challenge to their ability to provide excellent care, because of the healthcare reforms. GPs are taking on multiple, demanding roles for diabetes: early warning system, source of preventive advice, triage point, coordinators of care, providers of good standard care and decision makers on referral to specialists. They are equipping themselves with more training and more specialist nurses able to deliver high quality routine care. Primary care clinics are now monitoring and advising on many aspects of blood glucose, blood pressure and blood lipid control.

In contrast to the intensive, multiple activities in a diabetes centre is the new role of the diabetologist acting as a community consultant. This is an attempt to support GPs with 'intermediate care' – services designed to bridge the gap between primary and secondary care, to relieve the pressure on specialist services and support diabetes care in general practice.


This type of care can include the employment of 'practitioners with a special interest'; not only GPs but also other professionals such as diabetes specialist nurses, optometrists, podiatrists, dietitians, community pharmacists and healthcare assistants working within primary care. An intermediate care team can offer support to the system in terms of expert triage, appropriate and up-to-date treatment, and development of skills in patients and primary care personnel (159).

The options available for intermediate care include a GPwSI working with a diabetes specialist nurse, or a primary care clinic run by a consultant physician. A GPwSI would provide support for other GPs and leadership to integrate services between primary and secondary care. The intermediate care model has yet to prove its effectiveness in terms of use of resources. Additionally, adequate flow of information between the primary, intermediate and secondary sectors is even more vital in order to avoid overlap or duplication.

Intermediate care also raises the question of appropriate training for personnel. There is as yet no formal training or accreditation for GPwSIs, so their quality is variable. Similarly consultants normally have had no training for working in the community, while they were specialist registrars. Demand has been high for a new diabetologists' development programme developed through the group of consultants from Diabetes UK and the ABCD (Specialist Service Liaison Group, SSLG). In two years, 50 consultants will pass through the programme (160). A current study under the National Clinical Director for Diabetes, Dr Sue Roberts, is looking at the difficulties in finances and in medical manpower, involving detailed interviews with 92 consultants. Another SSLG study is due to report in spring 2007 on the present and future role of specialist diabetologists and their teams in relation to PCTs and the system reform.

Definition of roles in intermediate care is as yet indistinct; not only for the GPwSI and the community consultant, but also for the diabetes specialist nurse. Early experiences are showing that particularly the consultant and the specialist nurse are being used to cover work beneath their capabilities by general practices (98). Questions have been raised about whether taking part in an intermediate clinic is the optimum use of a consultant's time, in comparison with the multiple activities which are possible in the specialised treatment centre.

This also raises other questions about moving most of diabetes care into the primary care sector. Diagnosis of diabetes is not always straightforward – some childhood diabetes does not need insulin, although most does; insulin is difficult to administer in exactly the optimum dose range for each patient (GPs would convert only a few patients to insulin each year), and the progressive complications of diabetes are not simply those that will need emergency hospital treatment. While routine care of people with diabetes is ideally not too far from home, there is still a continuing need for specialist centres to offer expertise in more challenging circumstances. Few patients would want to find that there were no specialist services available to support their long-term condition until or unless they needed emergency hospital admission. Also the approximately 15% of diabetes patients now receiving secondary care are a changing population – some will stabilise and move back easily into primary care, while others will progress to needing specialist treatment. Those needing specialist expertise are not just a simple minority.

 **What is needed is seamless and flexible care, provided by any and all partners in a multidisciplinary team as needed, depending on the patient's changing circumstances**

In October 2005 Diabetes UK and the ABCD reported their joint concern that the effect of PCT reorganisation of diabetes services involved in some cases the block transfer of diabetes patients' care from secondary to primary care facilities, with little or no consultation with the primary or specialist services, the patients or their carers. This lack of involvement is not consistent with the care diabetes patients should expect, and contradicts the government recommendations to involve all members of the diabetes community in service redesign (161).

Early in 2007, the situation is even worse because of the financial pressures in the NHS. In some areas GPs have taken over the care of all their diabetes patients, including some who may have complications. Concern has been expressed by the SSLG that although these patients continue to have annual checks, the QOF requires only assurance that checks have been made; it does not make requirements on the quality of care (160). This concern has been expressed in the MODEL group by diabetes specialists, GPs and diabetes specialist nurses (39, 98).

So instead of the mutual respect which is the basis of effective diabetes care networks, there are barriers and breakdowns in communication between specialists and GPs. Instead of collaboration and communication, both vital to an integrated system of care, the mood is one of competition and resentment - all of which is counter-productive for the health professionals and more so for the patient.

The system should surely fit the patient; the patient should not be forced to fit the system. To the patient, the title of the care provider is not so important as the level of knowledge and empathy provided. Patients need to know that they are being given consistent, good information by people who are experts, appropriately trained, emotionally committed and driven by the pursuit of excellence. (39).

THE IDEAL CARE MODEL FOR DIABETES

Competence, ability to deliver and willingness to cooperate within a team are the basis of an ideal model for diabetes care:

Resources

- Healthcare professionals with competence and confidence in managing patients throughout the progress of their disease, with its stable periods and times of need for acute intervention
- GPs providing a large volume of care to a large number of patients; based on sound knowledge of local needs of the community and insight into personal needs
- Specialist diabetologists in centres of excellence, supported by specialist nurses and a multidisciplinary diabetes care team, providing
 - expert input to model care development
 - continuous support for patients in high clinical need or periods of transition, e.g. diagnosis, transfer from childhood to adult, onset of complications
 - emergency support in complicated cases
- A mechanism for all healthcare providers and users to communicate with each other with robust IT infrastructure – possibly (but not necessarily) the diabetes network
- The more active participation of an informed patient who acts more purposefully as a partner in managing the care resources
- Possible support provided by health professionals in intermediate care, depending on the local needs assessment conducted by the network

Actions

- Prevention of diabetes – by providing good lifestyle advice and facilitating diet and exercise, especially among high risk patients
- Early diagnosis, aided if possible by screening of high risk groups
- Care in communication with the patient and family or carers providing proportionate information on the disease and the medical options, complications and disease progression
- Evidence-based treatment according to need and events in the life of the patient, progressing seamlessly between primary and secondary diabetes care - and back to primary care if possible
- Seamless referral to specialists in other disciplines, e.g. cardiovascular, renal
- Regular monitoring of clinical indicators, allocating enough time to discuss patients' concerns, and surveillance for early signs of complications
- Intensive management of blood glucose, blood lipids, and blood pressure
- Provision of structured education in primary or intermediate care on lifestyle factors including diet, exercise and smoking (type 1 and type 2), and for type 1, in secondary care, on practical skills
- Provision of psychosocial support as needed
- Seamless flow of patient information to all members of multidisciplinary team
- Integrated multiple interventions: medical, psychological, behavioural, social and familial.

In short – the prescription is for a 'Schengen Agreement' for both healthcare professionals and patients. As it is for international travel within the Schengen area (where passport checks are not required), so it should be for progress in managing diabetes: free flow without delay because of organisational and professional barriers that are unrelated to the duty and commitment to care.

Collaboration should be the essential point; not competition.


Diabetes: investing in excellence

Francis Andrews: age 76, type 1 diabetes patient

My feet get looked at by the jolly chiropodists over at Henley; they're very good. I go over there about once in three months, and they provide me with nice insoles. They haven't been able to do it for the last six months, because as an economy measure, the health service in Reading is not providing insoles. I can't quite see how much money gets saved by insoles, if you then find that people develop ulcers on their feet that take a long while to heal and take up a lot of in-patient time, but then that's their choice, and if they're barmy, I can't do anything about it. I have got neuropathy which affects the feet, and the peripheral pulses in my feet are not awfully good. When I go to the diabetic clinic, they also assess the feeling in my feet.

COST OR INVESTMENT?

The economic impact of a disease such as diabetes, with onset, progression, treatment options and outcomes all influenced by multiple factors, deserves to be measured with an equally diverse approach. Diabetes is far more complex than an acute condition which requires straightforward interventions. As for all chronic diseases, sophisticated methods are needed to estimate the economics of treatment. The mismatch of secondary care of diabetes patients with the limitations of payment by results, based on specialist consultations but not taking account of all the other health professionals' input required, is just one example. Estimating the cost of diabetes care needs a much more subtle and finely-tuned approach than is currently used.

 **The costs of treating diabetes must be estimated using a complex approach, relevant to epidemic chronic diseases rather than acute medical conditions**

For diabetes, as for other chronic diseases the return on investment in treatment and education may take ten years or more. It is difficult for policy-makers to maintain long-term objectives; most political initiatives have a much shorter timeframe and inconsistencies arise. For example, in August 2006, funding from the Department of Health was withdrawn from a 12-year study on links between childhood obesity and diabetes; despite the government's pledge two months earlier to prevent diabetes through diet and exercise (162). As another example, Northampton has provided the largest DAFNE course in the UK and has trained some 400 people with type 1 diabetes across the UK. In July 2006 its funding was withdrawn with the loss of 45 people, some of whom were specialist nurses who were then re-employed as healthcare assistants on general medical wards. The funding appears to have been restored following some controversy.

Maintaining and improving public health is a worthy, but to some extent, unexciting political objective, and it is equally difficult to convince the public of long-term aims until a certain critical mass of public opinion is clear. Smoking is now out of favour in England and Wales and many have been able to give it up despite its addictive nature; but the health risks of smoking were known for many years before the collective efforts of many different interests were able to turn the tide of public opinion.

With diabetes many of the present consequences to public health are known, and projections have been made on the future impact on the public purse of the disease and its complications. Much is known on the benefits of controlling type 2 diabetes in order to prevent or delay complications and much also has been demonstrated on the ideal of primary prevention – preventing the onset of the disease in the first place. Identifying risk factors and targeted prevention has been shown to be effective in Finland, India and the USA, reducing the incidence of cases of type 2 diabetes by 58%. But given the extent of this epidemic chronic disease relatively little has been achieved in the UK despite an accelerated policy agenda and many medical and organisational innovations.

Although hard, it is not impossible to measure the benefits of excellent treatment for diabetes, and it should be regarded as an investment for the future rather than a current cost. As diabetes has no cure, the financial benefits are

- For the health service: savings in future treatment costs and potential savings to overall healthcare provision needed / release of resources for other needs
- For the individual: avoidance of loss of productivity and earnings, and reduced outlay on treatment
- For the economy: avoidance of productivity loss through time off work, early retirement and social care costs

plus - the unquantifiable enhanced quality of life for the patient. Studies indicate significant financial savings, both direct and indirect, result from focused investment in primary and secondary prevention. The savings in human suffering are undoubtedly greater.

WHAT ARE THE COSTS OF DIABETES TO THE NHS?

Many attempts have been made to estimate the cost of treating diabetes – both direct treatment costs and the indirect cost to the patient and society.

The basic facts:

- Diabetes accounted for 5% of total NHS expenditure in 2002; estimated as rising to 10% in 2006. It accounts for 9-10% of NHS hospital expenditure (9)
- Total annual cost of diabetes to the NHS is estimated as
 - £1.3 bn in 2002, rising to £1.9bn in 2010-2011 (11) or
 - £1.28bn - £1.36bn in 2007 rising to £1.46bn – £1.54bn in 2012 and £2.08bn – £2.21bn in 2027 (163)
 - although another well-founded study estimates £1.77bn – £2bn in 1998-9 for type 2 alone (188),
- Annual cost of diabetes care per patient, per year is estimated as £1,021 for type 1 (165, 166) and £1,505 – £1,738 for type 2 (167, 188)
- 30-65% of type 2 care costs are due to hospitalisation (168), annual type 2 drug costs are in the region of £300 for oral antidiabetics and insulin, plus another £273 for other drugs (188)
- 30-65% of type 2 care costs are due to hospitalisation (168)
- If the NSF were fully implemented in England, an annual saving of £200 million would result in ten years' time (2012) from the extra £600 million spent (11).

Costs of treating patients presenting both micro- and macrovascular complications are more than five times those of patients without complications

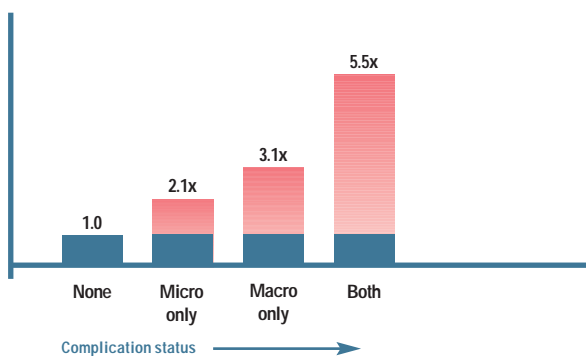
Drugs prescribed for people with diabetes are the second largest cost on the national drugs bill. Between 2004 and 2005, the cost of drugs used in diabetes rose by 11% and the number of items prescribed by 10%. Over the five years to March 2005, the number of items grew by 77% and the cost by 55% (169). These increases are partly because of the increasing prevalence of type 2 diabetes and partly because of the growing use of intensive treatment regimens. The drug types showing the greatest increase are the intermediate and long-acting insulins and the newer oral antidiabetic drugs pioglitazone and rosiglitazone (169).

The PCTs in England show a seven-fold variation in spending on oral drugs for diabetes; higher spending corresponds with a higher proportion of non-white patients. The differences are reflected in the estimated prevalence of diabetes within the local authorities of England, and the striking increase predicted by the Yorkshire and Humber Public Health Observatory for 2010 (14). Prescribing of metformin, traditionally the drug of first choice for type 2, has increased over the last five years by 138% to 1.9 million items (£5.9 million) in the quarter to March 2005.

More basic facts – on hospitals:

- Between 1999 and 2004 the number of in-patient bed days resulting from diabetes rose by 5% (170)
- Between 2000 and 2005 the number of out-patient attendances rose by 23% (171)
- Hospitalisation costs of type 2 patients are double those of type 2 patients with no complications if microvascular complications are present; triple with macrovascular complications and 5.5 times as great, if both are present (172) (Figure 31)
- The length of hospital stay of a diabetes patient for treatment of problems unrelated to diabetes is 2.5 – 3 times than for treatment of the same condition in a patient without diabetes (172)

Figure 31 | Effect of complications on hospitalisation costs



Source: Williams (2005)

The hospital treatment of the complications of diabetes in type 2 patients is clearly a major component of the overall costs. A significant level of hospital resources could be freed if these complications were prevented or delayed (172).

The costs of these complications were estimated in detail by the UKPDS (92) (Figure 32). If a patient develops just one complication the costs of treatment rise significantly, and many patients will develop more than one. Everyone who dies from diabetes will also experience one of the main complications during their lifetime (62).

Another complication (affecting type 1 or type 2 patients) which should be taken into account is serious hypoglycaemia, which causes a low but constant level (1-2%) of diabetes patients to need hospital admission or emergency paramedic treatment. As well as resulting from mismatching of insulin dose and/or timing with food intake, hypos can also be triggered as a side-effect of treatment with sulphonylureas, (especially in the elderly), or ACE-inhibitors (173).

Hypoglycaemia is one of the most feared adverse events related to diabetes. The fear of a hypoglycaemic episode has been shown to be linked with increased anxiety in patients with diabetes (175, 176). The risk of hypoglycaemic events can also give rise to reluctance to prescribe insulin to patients with type 2 diabetes (177), and up to 30% of type 2 patients are unwilling to take insulin even when prescribed (178). Although hypoglycaemic events are a frightening experience for the patient, the majority can be treated by the patient or a family member without the need for healthcare services. However, the costs associated with severe hypoglycaemic events, requiring admission to hospital, are significant being reported as £776 rising to £2,171 per episode if complications are involved (179). Drug treatment for hypoglycaemia is estimated at about £4m per year (46).

It should be noted that hyperglycaemic events in type 1 patients can also require emergency hospital admission for treatment of ketoacidosis and coma. Significant costs are also involved here: £1,292 rising to £2,426 per event if other complications are involved (179).

An estimate of the cost to the NHS for treating these conditions could be obtained by combining the unit cost of each condition with the proportion of diabetes patients expected to develop it. However each step of such a calculation involves assumptions on the costs of treatment, standard practice and complications which, combined, generate such a wide margin of error that the outcome would be only indicative.

A sounder approach is the concept of the quality-adjusted life year (QALY) which is now widely used by health economists and allows comparison to be made between the outcome of very varied interventions and combines survival and quality of life in a single measure (180). QALYs are estimated by assigning every life-year a weight between zero and one, where a weight of zero reflects the worst health state, usually death, and one reflects full health.

“ Does the NICE definition of QALY values tell the whole story?

The use of QALYs in cost-benefit studies indicates improvements in both life expectancy and quality of life through prevention or delay of complications. The key practical importance of the QALY is that it quantifies cost-effectiveness judgements and provides a more tangible basis for NICE to decide if an intervention – e.g. a new drug treatment or a new procedure – represents good value for money. NICE makes its decisions on the basis that if the cost per QALY is higher than £30,000, the proposed treatment is unlikely to be cost-effective. If it is between £20-30,000 a judgement must be made on the basis of other tests, and an intervention costing £20,000 or less per QALY is cost-effective (164, 181, 182).

It is worth noting that the NICE assessments of cost-effectiveness (and therefore value) of specific interventions do not address the potential savings to economic productivity. Such complete assessments are extremely complex, but this dimension should not be ignored.

Cost-effectiveness ratios have been calculated for intensive blood glucose control with sulphonylurea or insulin, intensive blood glucose control with metformin for overweight patients and tight blood pressure control of hypertensive patients. At 2004 prices, the cost per QALY gained for intensive blood glucose control was £6,028 and for blood pressure control was £369 (93). Each of these treatments therefore shows a much lower cost per QALY than many other accepted uses of healthcare resources. The additional costs of the intensive treatments are at least partly offset by the savings in costs of hospital care over an approximately ten-year follow-up period (Figure 20).

The diabetes treatments which are already known to be cost-effective, representing costs per QALY of less than £20,000, were summarised in 2004 by Wanless (183):

- Tight control of blood glucose and blood pressure for all people with diabetes (cost per event-free life year gained is about £1,200 for blood glucose control (184) and for blood pressure control is £400, or £720 (185)
- ACE inhibitors for people with diabetes with one other risk factor not otherwise quantified, e.g. for tight control of blood pressure. Tight control of blood lipids is probably cost-effective especially if used in combination with blood glucose and blood pressure control. It is almost certainly cost-effective for patients with a history of heart disease, but less so for those without - one UKPDS estimate for those with high levels of blood lipids but no history of heart disease is £22,000 per QALY (164)
- Retinopathy screening for all people with diabetes – very cost-effective for all type 2 patients, at £1,400 per QALY, (164)
- Foot screening for those at high risk – cost-effective: about £4,000 per QALY for those at high risk but not cost-effective if untargeted at £38,000 per QALY (164)
- Screening obese people for impaired glucose tolerance, and related treatment
- Multiple risk factor management
- Self-care including patient education, and
- Reduction of obesity and physical inactivity in high risk groups.

(no data is available for the last four categories)

Assuming the prevalence of type 2 diabetes in the general population is 1.0 – 1.9% (in 2000; prevalence and costs are higher in 2007), a practice with 10,000 patients will have 100-190 type 2 patients. The UKPDS group estimated that intensive blood glucose treatment costs an additional £1,435 per patient, or £14-27,000 for the practice; but that these costs would be offset by £10-18,000 in savings on complications (184). Applying the estimates of intensive blood glucose and blood pressure control to the general population, UKPDS derived additional management costs for type 2 diabetes in England at £132m (1999 prices) plus an additional £73m in oral drugs and insulin. The consequential reduction in hospital costs for treatment of complications was estimated at £104m – for intensive treatment of £100m per year. Although based on data several years old, this does demonstrate an important principle.

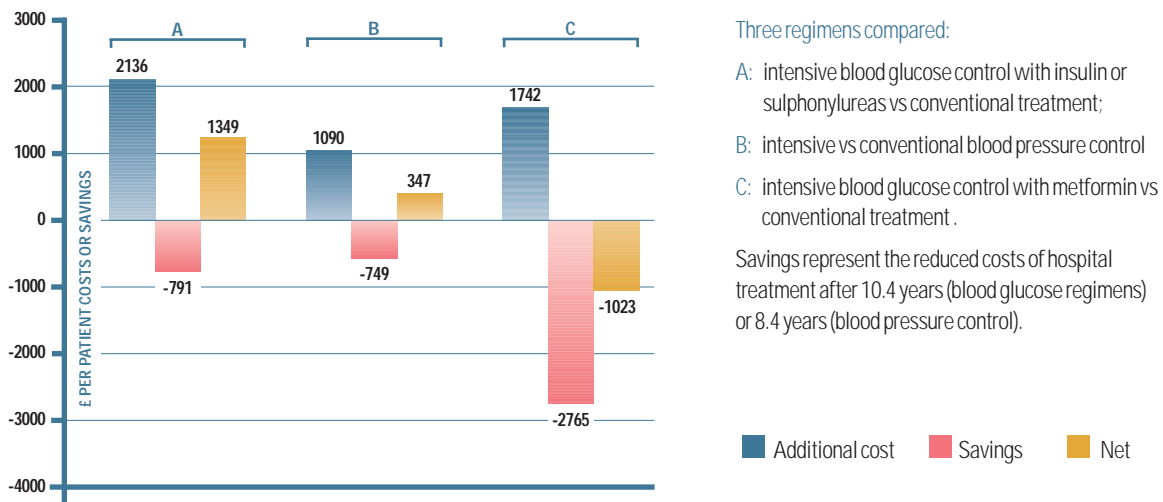
“ Cost of intensive management of blood glucose for type 2 patients can be offset for the most part by cost savings through the reduction in complications

Figure 32 | Cost of treating type 2 complications

Complication	Average cost, £, 2002 (92)	Range, £, 2002 (92)	2004 data where available, £ (93)
In-patient:			
Amputation	8,459	5,295 – 13,200	10,029
Non-fatal heart attack	4,070	3,580 – 4,722	4,825
Fatal heart attack	1,152	941 – 1,396	1,366
Non-fatal stroke	2,367	1,159 – 3,274	
Fatal stroke	3,383	1,935 – 5,431	
Ischaemic heart disease	1,959	1,467 – 2,541	
Heart failure	2,221	1,690 – 2,896	
Cataract extraction	1,553	1,320 – 1,855	
Blindness in one eye	872	526 – 1,299	
Renal disease	20,902*		
Out-patient, year of main event:			
Macrovascular complications	315	247 – 394	373
Microvascular complications	273	215 - 343	324
Out-patient, subsequent years:			
Macrovascular complications	258	220 - 297	306
Microvascular complications	204	181 - 255	242

Sources: Clarke et al (92), (93), * Lamping (174).

Figure 33 | Costs and savings associated with intensive blood glucose and blood pressure control



Source: Clarke, P.M. et al (93)

The UKPDS cost data has been used as the basis for projections of costs for conventional and intensive treatment for the next 20 years (163), on the basis that the number of people with diabetes will increase by 25% over that time (163). One of the main savings in intensive treatment is the saving in hospital bed days to manage the complications. The absolute values in Figure 34 must be viewed with caution, however, because indications are that the prevalence of diabetes has already exceeded these estimates: the latest estimate of total diabetes patients in the UK (including those undiagnosed) is 2.35 million in 2007.

Diabetes and its complications are a significant and growing problem for the NHS and the economy. Cost-effective interventions can significantly reduce the cost pressure on healthcare systems by offsetting the cost of treating complications – and can also reap important health benefits in terms of both quality of life and life expectancy (164).

WHAT ABOUT THE INDIRECT COSTS OF DIABETES?

As well as the direct financial costs involved in treating diabetes and its complications, the other costs are related to the individual person with diabetes – and to the economy as a whole. People with diabetes have lower incomes, lower productivity, higher healthcare costs including travel to clinic appointments. They may also be forced into premature retirement, reducing the length of their economically active life, receiving a reduced pension and eventually dying in typically ten years less than the general population. A small but significant proportion (6%) of type 2 patients are unable to work at all because of diabetes – in most cases because of the presence of complications (163).

Quality of life for people with diabetes is affected not only by dietary restrictions, limited mobility and pain, but by the limitations of fewer job opportunities due to employers' reluctance to commit *a priori* to a perceived risk of lost working time. The main problems that can affect work are impaired sight and diabetes foot-related problems, but these only affect a small minority of people of working age. Although well-managed diabetes does not pose a problem for the vast majority of workplace activities, those with diabetes suffer a higher rate of unemployment, especially young people (186). Sickness absence is between two and three times the rate for the general population, with a larger number of absences and of a longer duration (163).

The costs to individuals of living with diabetes have been estimated as £500 million per year in the UK (187). Where patients with type 2 diabetes report lost earnings, their average loss is £14,000 per person per year, with carers also standing to lose up to £11,000 per year if they are unable to work because of their caring duties (188). Estimates of social services' costs vary between £128 million - £230 million (188, 187). Although only one in 20 people with diabetes use social services for assistance, their costs are £2,450 per year, the bulk of which is accounted for by residential or nursing homes, but also includes home care and day centres (163, 188).

Evidence is scarce on working time lost in England and Wales by people with diabetes, but indications are that it is between two to three times that of the general population. On that basis, the cost to employers in the UK of an extra 6 million working days (total 10 million), in excess of the absence expected in the general working age population (~4 million days) cost £418m in 2002 (189). Calculating on the basis of the CBI estimate of £476 per employee (average for all employees) and the projections of UK population of working age with type 2 diabetes, the excess cost to UK employers caused by time lost through diabetes could reach £650m by 2027 (163).

This direct cost to employers includes the cost of salary and replacement. Employers' costs almost double if their indirect costs – maintaining the quality of service and customer satisfaction – are taken into account.

COMBINING DIRECT AND INDIRECT COSTS

It is extremely difficult to get an exact idea of all the costs involved and how they will change over the next twenty years. What is known clearly is that:

- the number of people with diabetes is expected to rise by between 15-25% (9), but possibly by less if primary prevention measures could take effect
- therefore the number of complications will increase: possibly by the same percentage but possibly by less, given more intensive care after diabetes diagnosis
- the average cost of treating a complication is £2,900 (2003 prices, (92))

The total cost of treating complications is likely to rise (Figure 36).

It is also known that:

- drug costs may rise, and new drugs will become available but are likely to be more expensive. Some costs of existing drugs will fall as patents expire, so the drugs bill will not necessarily rise in line with inflation
- incomes will rise and therefore spending power will also rise
- hospital treatment costs will rise but not necessarily proportionately to the increase in patient numbers, because of the increased proportion of treatments delivered at the primary care level
- structured education, where available, can mitigate the rise in treatment costs for complications, e.g. DAFNE pays for itself in four years; DESMOND is reporting on a 3-year cost-effectiveness study in March 2007

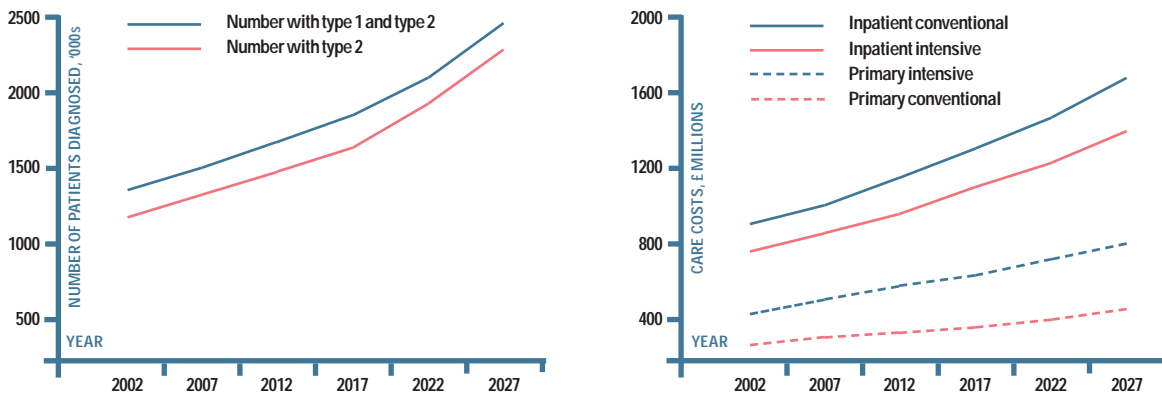
and that:

- intensive drug treatment can reduce or delay the onset of complications
- treatment costs for complications could rise less than expected from simple extrapolation
- intensive drug treatment can offset a significant part of its own extra costs by reducing the costs of treating complications
- structured patient education should reduce the unnecessary costs resulting from non-adherence to prescribed treatment.

This thinking shows that although absolute numbers are difficult because many interrelating factors are at play,

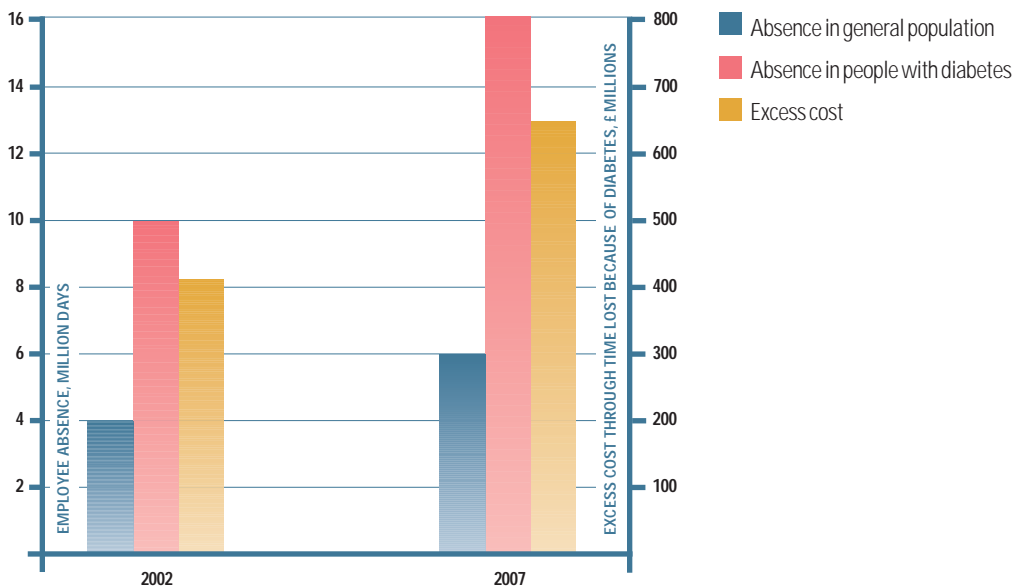
- diabetes costs will continue to escalate
- using more intensive treatment regimens will cost more, but their net cost rise is less because of their benefits
- the resulting savings would release resources for other healthcare needs.

Figure 34 | Projections of number of diabetes patients and care costs to 2027, UK



Source: Bramley-Harker (163), after Gray et al (184)

Figure 35 | Costs to UK employers of lost working time



Source: Bramley-Harker (163)

Figure 36 | Direct annual costs of treating complications, UK*

Year	Number of complications ¹	Average cost per complication (range) ³	Total annual cost to treat complications (range)
2006	864,000	£2900 (£2000 - £4000)	£2.5 billion (£1.7 - £3.5 billion)
2026 ²	993,600	£2900 (£2000 - £4000)	£2.9 billion (£2.0 - £4.0 billion)

* Assumptions:

- Number of complications: 48% of people with diabetes will have one or more complications (190); number of people diagnosed with diabetes 2006 is 1.8 million (13)
- Diabetes prevalence will increase by 15% between 2006 and 2026 (31)
- Cost of treating complications: based on unweighted UK price for treating a diabetic complication for 2003, therefore probably an underestimate (92)

Source: Abacus (191)

A summary of the overall annual cost implications of diabetes gives an indication of the outgoings in hospital and drugs costs and social care, the costs to industry and the economy (Figure 37). It must be used with caution because of the large number of assumptions, but it does indicate the alarming extent of damage done by diabetes to the individual, the healthcare system and the national economy.

Figure 37 | Overall annual costs of diabetes, UK *, **

	2006	2026 ¹
Number of NHS bed days (10)	1.1 million	1.265 million
Cost of treating complications ²	£2.5 billion (£1.7 – 3.5 billion)	£2.9 billion (£2 - 4 billion)
Average drug costs ^{3,4}	£592 million	£681 million
Total healthcare costs	£3.09 billion	£3.581 billion
Costs of social service care (187)	£230 million	£265 million
Costs to industry through lost working days (163)	£418 million	£650 million
Cost to industry through premature death (166)	£113 million	£130 million
Total industry costs	£531 million	£780 million
Total costs	£3.851 billion	£4.626 billion

* excluding costs to the individual in lost earnings and out-of-pocket expenses; also excluding costs to families or carers

** Assumptions:

1. Diabetes prevalence will increase by 15% between 2006 and 2026 (31)
2. From Figure 36
3. Average annual drug costs have been derived from prescription cost analysis data (192, 195); drug costs from the British National Formulary 2005-6
4. It is assumed that the same antidiabetic drugs will continue to be used at the same costs; this may not be so (see text)

Sources: adapted from Abacus (191)

In the context of the whole economy, investing a little more in intensive treatment for diabetes and structured education makes an overall cost saving, because it can so effectively reduce the costs to industry and business, and to the individual.

Saving or spending is not just a matter of drug costs or hospital days. Addressing the effects of an epidemic chronic disease needs careful evaluation of all its effects.

SAVING THROUGH INVESTMENT

Mathematical models using data from existing trials now make it possible to predict the economics of the progression of diabetes. The Cardiff type 2 diabetes model, for example, can predict the economic gains to be made by delaying the onset of the disease, and can accommodate the effect of improvements in treatments of blood glucose, lipids and blood pressure. The model predicts that 5,000 heart attacks will occur in the UK over a 20-year period (from 2005) in people with diabetes, compared to 1,000 in those without diabetes. Treatment of these heart attacks costs £21 million, so if type 2 diabetes were removed as a precursor, the cost of treating heart attacks could be cut by 85% to £3 million (24). Delaying the onset of type 2 diabetes by five years would result in a 6% estimated reduction in costs, and by 10 years in an estimated 17% reduction. This model has been used in conjunction with the Steno study (122) to predict the cost reduction associated with intensive treatments to control blood glucose, blood lipids and blood pressure, and found the savings were additive – much more successful together than individually (24) (Figure 38).


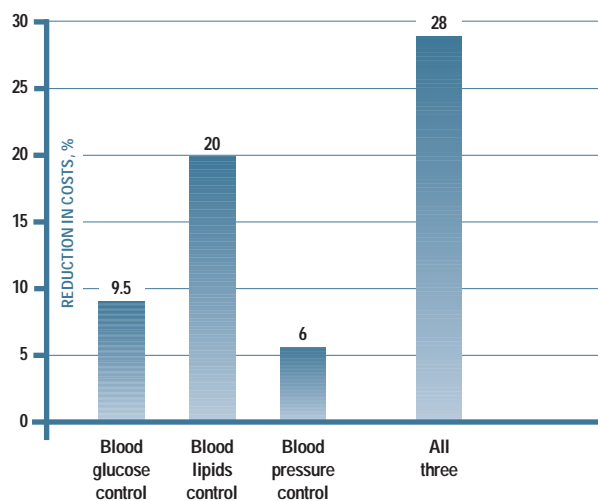
 The cost savings derived from intensive treatment of blood glucose, blood lipids and blood pressure are additive

Figure 38 | Costs and savings associated with intensive blood glucose and blood pressure control



Source: after Williams, R. (24)

Hopefully savings will also be made as a result of development of new and future advances in therapy at the financial level as well as savings in human suffering. One of these areas of advance is intensive insulin treatment, where it is becoming more widely accepted that treatment is far more effective if insulin is started earlier in the treatment of type 2 diabetes rather than waiting until oral treatment fails, and if it is started at an adequate starting dose likely to be effective and increased by effective increments (95, 37, 62, 185). A number of new drugs will become available in the UK during 2007, notably the GLP-1 agonists.

Another area of promise is the development of pancreatic islet transplantation, which, if developed further, has the potential to make type 1 patients free from insulin treatment, and will therefore obviate the need for conventional treatment.

If intensive intervention is cost-effective, is primary prevention also a worthwhile investment? The NSF Delivery Strategy recommends screening of people who are identified as being at high risk of developing diabetes and a number of examples of initiatives to enable earlier diagnosis have been quoted earlier in this report. In particular, screening for retinal damage has been shown to be highly cost-effective (164, 196). Untargeted screening would not be cost-effective. Screening does need to be approached carefully. It would be naive to assume that it offers a complete answer to the public health problem of increased incidence and missed diagnosis. More evidence is needed on the absolute value of screening, and current randomised trials are comparing the implications. It is first necessary to quantify the benefit of early detection, and to evaluate it in comparison with the benefit of intensive treatment of those diagnosed early. If the benefit of early detection is not great, then intensive treatment would offer a more cost-effective option than screening (197). However this approach does not appear to take into account the benefit of early treatment in relation to delaying or avoiding the onset of complications.

The evidence from the societal approach taken in Finland and from the work of the US Diabetes Prevention Research Group (Chapter 1, (34, 52)) indicates a highly successful reduction in diabetes incidence through lifestyle changes, especially if targeted towards those with impaired glucose tolerance. So it is possible through positive policies for a healthier lifestyle to achieve reduction in diabetes treatment costs. Is it probable in England and Wales?

THE COST OF NOT TREATING DIABETES IS MUCH GREATER THAN THE COST OF PROPER TREATMENT

The choices to be made by policy-makers and healthcare providers can be reduced to the scope of initiatives to be offered and financed in primary prevention, in treatment of diabetes once diagnosed, and in treatment of complications once developed. The appearance and progression of type 2 diabetes is strongly linked with (but not entirely dependent on) personal lifestyle choices. Intervention therefore involves something of a conflict with individual freedom of choice. But it must be in the interests of everyone, even the very young, to encourage the avoidance of long-term, chronic suffering – and at the same time to avoid healthcare spending on treating conditions which were preventable, and the related wastage and reduced productivity in business and industry.

“ A robust, evidence-based model based on healthcare and social indicators is needed to assess the financial impact of primary prevention

Making these choices inevitably involves financial criteria. Clearly a more robust evidence base than presently available is needed, particularly for the cost-effectiveness of primary prevention activities. The quantification of value for money adopted by NICE is a useful rule of thumb. The massive data collected from the UKPDS (some 55,000 patient-years of information, with all the risk factors and complications) have given rise to a most useful

model which can be used to predict the long-term impact of health interventions for people with type 2 diabetes (198).

The UKPDS Outcomes Model is designed to assess the total burden of disease over a lifetime for populations with type 2 diabetes. It will enable economic evaluations by estimating the changes in life expectancy and QALY in relation to changes in risk factors like blood glucose level, blood pressure, blood lipids and smoking. Use of such a soundly-based model will be of great value in health service planning for populations with diabetes, and is already being used under licence in the UK and other countries.

One further study, from Denmark, illustrates the comparison between three alternatives: the Danish treatment for diabetes current in the year 2001, an ‘improved’ case with intensified insulin treatment and appropriate drugs to control associated complications, and a hypothetical ‘ideal’ case where diabetes does not confer any complications or reduced life expectancy (199). The results from the model (Figure 39) indicate the costs of treatment for the three alternatives, and their implications for life expectancy and productive time gained. They indicate, on the basis of data from 152,800 patient-years with diabetes, that the benefits to society outweigh the investment in improved treatment.

Figure 39 | Costs and benefits of intensive and ideal treatment: the Danish evidence

All costs in US\$	Denmark, 2001	‘improved’ case	‘ideal’ case
Costs of treatment for 152,800 patient-years	1.55 bn	0.883 bn (reduction of 0.67bn)	0.176 bn (reduction of 1.37bn)
Gain in patient-years	Baseline 152,800	+ 16,000	+ 36,000
Gain in productive value to economy	Baseline 1.49 bn	+ 0.57 bn	+ 1.09 bn

Source: Green (199)

Treating diabetes is costly, but any assessment based on healthcare costs alone does not give an overall view of diabetes as a societal problem – it must take into account the chronic effects on productivity and wellbeing.

Diabetes: a model for other diseases

Kushira Hackett: age 45, type 1 diabetes patient

I think it's important to be aware that if diabetes is in your family, the best thing you can do for your children is to actually give them a healthy diet. Make sure they have a reduced sugar and salt diet with reduced fat. Get them used, from a very early age, to eating healthily, then they won't be as tempted by the sweet stuff and the fizzy drinks. We have no fizzy drinks in our house - all our drinks are sugar-free or fruit juice or flavoured water. We only have fresh fruit. It's really nice for me, if I take the children out and give them an option at McDonalds, and they actually ask for a salad! That is really, really good, you know - it's a bit of a boost. But that's the best thing you can do for your family as a diabetic parent.

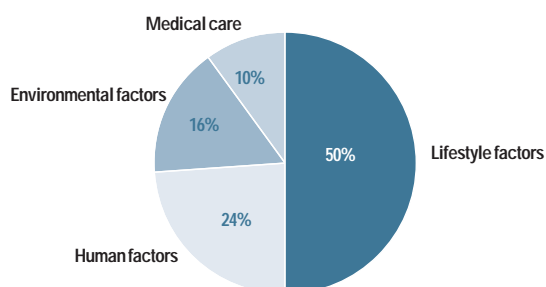
THE NATURE OF CHRONIC DISEASE

Studying diabetes, which will be one of the main health problems of this new century, is useful in relation to the care of other chronic diseases. Having addressed many of the major infectious diseases, the medical profession, public health authorities, education and social services should urgently turn their attention to the chronic diseases which will debilitate and eventually kill, but not before they have caused long illness and expense to healthcare systems.

“ Epidemic chronic diseases kill twice as many people worldwide as HIV/AIDS, malaria and tuberculosis combined. Much of this is preventable.

This is a major problem facing healthcare provision in the developed world, but even more dramatically in developing countries, which will shoulder 80% of the burden of diabetes by 2010. More than 230 million people (almost 6% of the world's adult population) now live with diabetes and this number will grow to 380 million in less than 20 years if action is not taken. Today diabetes kills more than 3 million people per year (200). Looking at chronic diseases together, type 2 diabetes, cardiovascular and chronic respiratory diseases and cancer, are responsible for 60% of deaths worldwide.

Figure 40 | What matters most in healthcare



Source: Hinkle et al., CDC 1997 (201)

These chronic diseases are characterised by their long duration and multiple impacts, and are largely caused by unhealthy or impoverished diet, lack of exercise and smoking. Lifestyle factors are far more influential than human biology, environment or medical care.

Because chronic diseases go on so long, and manifest themselves in many different symptoms, the patient takes on a key role in self-management. The input from many different health professionals will be needed and ideally long-term relationships should be built with the members of this diverse healthcare team. Provision of information, properly structured and professionally delivered education and support to the individual is essential to enable effective self-management.

All of these issues apply equally to any of the chronic illnesses as well as to diabetes. And in many respects they are all preventable, or at least their impact can be reduced or delayed. The major risk factors are lifestyle-related and are within the power of society and the individual to control and manage. If these risk factors were eliminated, at least 80% of heart disease, stroke and type 2 diabetes, and 40% of cancer would be prevented (202). Sadly type 1 diabetes cannot be prevented at the present time although this area continues to be researched, but people with type 1 diabetes also need education and long-term support.

DEALING WITH CHRONIC DISEASE IS A MAJOR PRIORITY OF THE 21ST CENTURY

In a 2005 editorial, Lancet editor Richard Horton said the reduction of chronic disease called for by the WHO should be made a Millennium Development Goal. Without concerted and coordinated political action, he said, the gains achieved in reducing the burden of infectious disease would be washed away as a new wave of preventable illness engulfs those least able to protect themselves (6-1). The burden of chronic disease is certainly carried disproportionately by poorer people, who are constrained from being able to adopt a healthier way of life because of their diet, education and available time, money and space. On 20 December 2006 a United Nations General Assembly resolution recognised diabetes as a chronic, debilitating and costly disease with major complications that present severe risks worldwide.

Other chronic conditions that contribute to the overall chronic disease burden are visual impairment and blindness, hearing impairment and deafness, oral diseases and genetic disorders. From a projected total of 58 million deaths worldwide from all causes in 2005, it is estimated that chronic diseases accounted for 35 million, which is double the number of deaths from all infectious diseases (including HIV/AIDS, tuberculosis and malaria), maternal and perinatal conditions, and nutritional deficiencies combined (Figures 41 & 42).

FIREFIGHTING OR PREVENTION?

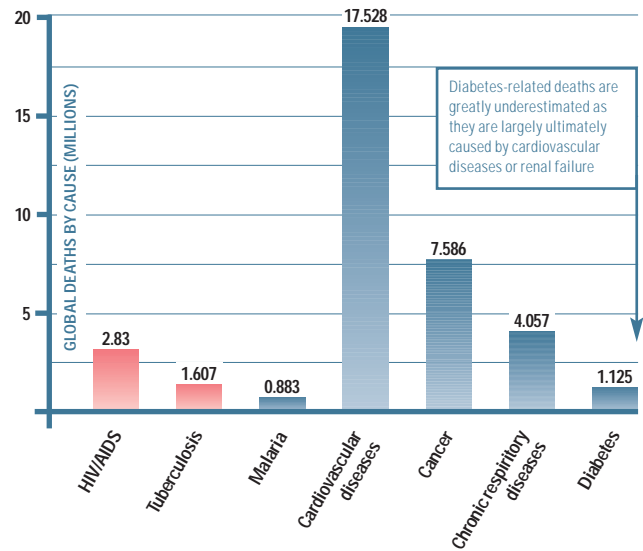
In many ways the present healthcare system in England and Wales engages in firefighting rather than prevention. It offers a response to illness but has few resources for addressing what leads to major medical conditions, rather than their effects. Putting it bluntly, inactive people are eating too much of less than ideal types of food, and then taking 20 or more tablets a day to counteract the effects of their lifestyle. At the same time, while they exercise this choice, they are not offered the information they need to be able to make a better choice (2-33). While obesity and inactivity are much more in the news than even two years ago, no-one is making a concerted, coordinated stand - involving government, the professions, employers, the education system and the media - to really make people aware of the damage they are needlessly doing to themselves and to their children.

Tackling the problem at an earlier stage - by investing in primary preventive care and lifestyle changes - could make a significant difference.

A systematic review of the evidence shows that primary prevention of type 2 diabetes is cost-effective, particularly in high-risk groups and even at low levels of effectiveness (204). A range of studies reviewed indicate that primary prevention programmes are highly cost-effective, and involve low costs to the provider which are sufficient to offset the theoretical cost of treating complications (205, 206). The first large-scale study of lifestyle intervention, the Finnish Diabetes Prevention Study (207) showed a 58% reduction in the incidence of diabetes through dietary and exercise advice. Patients who met 80% of their diet, exercise and weight loss goals did not develop diabetes.

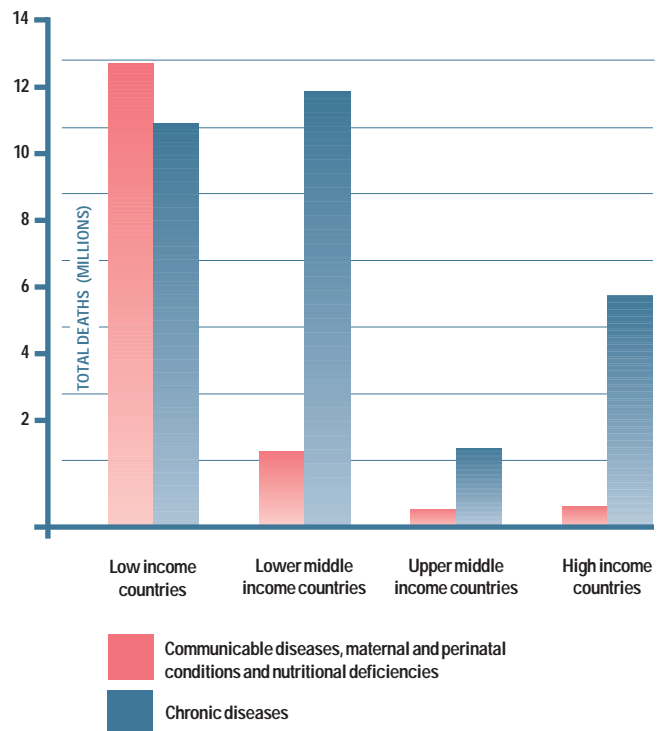
Advice and encouragement to people at high risk of diabetes should be paralleled with stronger advice to the general population on benefits of healthy diet, exercise and smoking cessation. We need more supportive environmental conditions like making healthy food more affordable. Once again an example can be taken from Finland, where employers are obliged by law to provide preventive care for their employees, while treatment for illnesses is optional. The Finnish Type 2 Diabetes Prevention Plan, 2003-2007, is part of the national diabetes programme and is the first large-scale type 2 diabetes prevention programme in the world. It is putting into practice the evidence that type 2 diabetes can be prevented by lifestyle changes. The Finnish project has elected to assess the general population, to identify the individuals at high risk and those with impaired glucose metabolism by use of a very simple questionnaire, and they are then referred for preventive health care.

Figure 41 | Deaths from chronic and infectious diseases



Source: WHO 2005: Preventing chronic diseases: a vital investment (202)

Figure 42 | Deaths in the developed and developing world




Source: WHO 2005: Preventing chronic diseases: a vital investment (202)

The evidence shows that lifestyle intervention in people at high risk for type 2 diabetes resulted in sustained lifestyle changes and a reduction in diabetes incidence, which remained after the active lifestyle counselling was stopped (47). A comment from the US Diabetes Prevention Program concludes: 'while we wait for hard evidence that lifestyle change delays diabetes-related outcomes in the face of the deluge of diabetes that threatens to overtake us, the evidence for sustainability of lifestyle benefit presented by the (Finnish) investigators supports their argument for urgent widespread establishment of community-based diabetes prevention programmes, such as those developed by the Finnish Diabetes Association' (208).

While it is probably unrealistic and not warranted in England and Wales to screen the whole population for diabetes or other chronic diseases, it could well be cost-effective to screen those at risk. The evidence on screening for type 2 diabetes is less conclusive than that on primary prevention, and more economic analysis is needed (204). The obvious difficulty is in the long timescale required to track the progression of disease and complications. On the basis of the evidence available, opportunistic screening (assessment of diabetes indicators as and when the opportunity is presented, rather than due to presentation of symptoms) is relatively cost-effective. This is particularly true for younger age groups, as these patients have the most quality-adjusted life-years to gain; and also in BME groups as these have a higher incidence of the disease.

Diabetes UK has been campaigning for many years for early identification of people with type 2 diabetes to reduce the impact on both them and on NHS resources. They stress the benefits of early diagnosis because many people have had diabetes for several years before they know it and have already developed some complications which could have been delayed or avoided. The current Measure Up campaign has the aims of raising awareness of the risk factors of diabetes and motivating those at risk to be tested. It urges primary care trusts to be active in ensuring that all people with diabetes are diagnosed early, to help prevent life-threatening complications. Detecting diabetes must also be linked with detecting cardiovascular disease, as they share many risk factors and their incidence overlaps significantly.

A UK policy on screening for diabetes has emerged since the National Service Framework recognised that there was good reason for a more systematic approach (61, 129, 23). As a result the Diabetes, Heart Disease and Stroke (DHDS) Pilot Prevention Project was developed under the National Screening Committee (209). Its aim was to assess the feasibility of screening for type 2 diabetes in primary care, and the pilot project, involving eight English regions selected to cover mainly deprived, inner-city communities, ran from October 2003 to September 2005. These included single-handed and large group practices representing predominantly white, predominantly Indian or Pakistani populations, and very deprived communities or those with high turnover, refugees and asylum-seekers. The pilot established that screening is feasible and was generally felt by participating practices to be worthwhile. Out of the 25,356 patients screened, 358 new diabetes cases were diagnosed, representing 0.2% of the total practice populations (210).

 Evidence on cost-effectiveness of preventive screening results in the new Vascular Risk Management Programme, recommending early identification of diabetes risk markers

The UK National Screening Committee decided in July 2006 that general population screening should not be offered to adults. However the pilot prevention project did raise the idea of considering screening in terms of a 'vascular syndrome' rather than individual diseases like diabetes or heart

disease. The reason for this is the extent of overlap: people with diabetes almost always have some form of vascular disease, and people with coronary artery disease also tend to have diabetes. It is now also becoming more usual to focus on people at risk, rather than tackling risk factors – in other words, diabetes itself can be viewed as a risk factor for vascular disease.

For this reason, in January 2007 the National Screening Committee has recommended the introduction of a Vascular Risk Management Programme, in which the whole population aged over 40 should be offered risk assessment that could include, as a subset, measurement of diabetes risk factors such as blood pressure, blood cholesterol and blood glucose. The Department of Health, NICE and the National Screening Committee are currently examining the options to achieve this, which include self-assessment, assessment of patient records to identify those at highest risk who are not receiving risk advice and management, or primary care population-based risk assessment. Guidance is now being prepared and will be presented to the National Screening Committee in March 2007 to be followed by advice to primary care in April 2007.

Primary care trusts with high mortality rates and lower than average life expectancy through cardiovascular disease and cancer are considered as 'spearhead' PCTs within the terms of the Public Service Agreement for the NHS. These PCTs are subject to targets and are required to implement appropriate action plans to improve their morbidity and mortality. For example, cardiovascular mortality and the inequality gap between the best and the worst PCTs are both to be reduced by 40%, by 2010. Failure to meet these targets is regarded very seriously, so spearhead PCTs are working hard at their action plans.

One such plan is in the London borough of Newham. The cardiovascular diseases action plan, which views diabetes as a key component, focuses on three key medical interventions – smoking cessation, cholesterol reduction and control of hypertension – backed by organisational changes to develop the infrastructure to help undiagnosed patients. Dr Rida Elkeir, public health consultant estimates that the diabetes population in Newham could be as high as 20,000, although only 14,500 are registered and treated. The action plan will cost about £240,000 per year (half from the PCT plus half from the neighbourhood renewal fund supported by the Department of Health and other sources). The plan will save an estimated £1.5 million per year, out of the £6 million per year currently spent on acute hospital care for cardiovascular disease (40).

A word of caution about the broad rationale for screening comes from work supported by the National Prevention Research Initiative. This multidisciplinary body was launched against the background of the 2004 Wanless report (183) which emphasised the need for evidence-based interventions, which are both effective and cost-effective, in preventing disease through informing personal health behaviour and public health policies. The NPRI supports an extensive programme of prevention research, supported by the British Heart Foundation, Cancer Research, Diabetes UK, the Department of Health, the Wales Office of Research and Development for Health and Social Care, and other medical organisations. Dr Simon Griffin of the Medical Research Council, Cambridge, has been developing the evidence base toward identifying people at high risk of diabetes and vascular disease, and evaluating means of changing their behaviour, like encouraging more exercise. He warns that it may be naive to adopt the idea of screening wholesale, and that what is needed is better quantitative evidence before assigning a larger budget to screening. Trials at Cambridge are indicating that targeted screening is the best option, but even so, a careful balance should be evaluated between the cost of screening (which will be negative for the majority screened) and the benefit of earlier diagnosis for the few, who can then be given intensive treatment at an earlier stage in their illness (211)

Figure 43 | Finnish Type 2 diabetes risk assessment form

Participants are asked to add up the points for each answer:

1. Age

- 0 under 45 years
- 2 45-54 years
- 3 55-64 years
- 4 over 64 years

2. Body-mass index

- 0 under 25 kg/m²
- 1 25-30 kg/m²
- 3 over 30 kg/m²

3. Waist circumference (cm)

	Men	Women
0	under 94	under 80
3	94-102	80-88
4	over 102	over 88

4. Do you usually have at least 30 minutes of physical activity at work or in leisure time, including normal daily activity?

- 0 yes
- 2 no

5. How often do you eat vegetables, fruit or berries?

- 0 every day
- 1 not every day

6. Have you ever taken antihypertensive medication regularly?

- 0 no
- 2 yes

7. Have you ever been found to have high blood glucose e.g. in a health examination, during an illness, during pregnancy?

- 0 no
- 5 yes

8. Have any of the members of your immediate family or other relatives been diagnosed with diabetes (type 1 or type 2)?

- 0 no
- 3 yes: grandparent, aunt, uncle, first cousin
- 5 yes: parent, brother, sister, own child

The risk of developing type 2 diabetes within 10 years if your score is:

under 7	low	1 in 100
7-11	slight	1 in 25
12-14	moderate	1 in 6
15-20	high	1 in 3
over 20	very high	1 in 2 will develop type 2 diabetes

Interpreting the results:

- under 7 no action needed
- 7-14 referral to healthcare assistant for retesting within three months. If risk still at this level, background information on this individual recorded on database and information given on lifestyle, diet and exercise; plus local organisations to help reduce risk and events promoting physical activity, and helpful websites
- 15-20 referral to nurse or doctor within three months for further testing and treatment
- over 20 referral to nurse or doctor within one month for further testing and treatment

Source: Finnish Diabetes Association (212)

It appears that screening for diabetes and other conditions within the 'vascular syndrome' will become a reality in England and Wales. This does, however, raise another problem which was quoted by Dr Elizabeth Goyder in her report on the DHDS pilot programme in the form of a comment from a participating GP (210):

"... there's no point in screening if you're then not doing anything about it. It goes hand in hand; if you go into screening we need the extra resources to deliver the care to those patients."

POLITICAL CHANGE AND HEALTH SERVICE PROVISION

For many years, government healthcare policy has focused on improving access to elective care. The introduction of the national service frameworks in England and Wales for coronary heart disease, diabetes, cancer and other diseases has improved the management of specific conditions, but without an agreed overall approach for managing chronic diseases. One model that has gained wide credibility in the US is the chronic care model, which considers chronic disease management in a broad frame involving healthcare provision and organisation, community support, self-management, clinical decision-making that is evidence-based and allows for patient preference, and fast and effective clinical information systems (213). This wider context is not accommodated in the NSFs, nor in the management of multiple conditions. Developing an overall approach could also be helpful for patients with chronic conditions not yet covered by NSFs.



Health service resources must be invested against the growth of chronic diseases. Evidence-based structural change should not threaten stability, but enhance integrated care provision, support self-management, and embrace effective information flow.

Some of the NHS policy changes of recent years will improve NHS management of chronic diseases, and these include the NSFs themselves, the new GP contract and investment in information technology. But other aspects of change could actually hinder chronic care, for example the financial payment flows and the focus on waiting lists rather than long-term support (213).

Quite simply, the ability of the health service to provide adequate care for chronic conditions cannot be threatened by political decisions which bring short-term or narrowly-focused change. Clearly overall political objectives will be to improve the standard of healthcare, but the myriad of organisational changes to the NHS over recent years and the all-time low morale of health service professionals cannot fail to be counter-productive.

To reduce anxiety in the essential medical profession, a much higher degree of stability is needed. Structural change and improvement are important, but clear evidence should be available to support them. Future system changes should be tested, piloted and reviewed to develop an adequate evidence base before any decision is made to continue, extend or modify them.

And most important of all – changes to the healthcare system should be considered in the light of future trends of disease – principally the well-evidenced epidemic of chronic disease.

DIABETES – THE SILENT DISEASE

If, like diabetes, avian flu affected 5% of the population, the government would be forced to bring it to the top of the political agenda. Avian flu kills almost exactly half of the people who get it, so the threat of a pandemic caused by mutation of the viral strain that causes avian flu has rightly caused concern and preparedness initiatives. But diabetes also kills 50%. In contrast to the very limited numbers of people infected with avian flu, the fact that well over two million people in this country have diabetes, which will kill every other person who has it, attracts little attention.

One of the main differences between diabetes and avian flu is the speed at which the diseases progress. While avian flu will kill within a week, the progress of diabetes takes many years. Because it kills so slowly, many people fail to see it as particularly dangerous. But without expert care, diabetes progresses steadily over the years, with appalling morbidity and mortality. Diabetes patients are not vocal campaigners and statistics of comorbidity are often under-reported (39).

In a sense, the low profile of diabetes is an example of the general unawareness of the public and unpreparedness of the health service to deal with the chronic disease epidemic.

Many people prefer to keep quiet about diabetes because they see it as a low-intensity, chronic condition which is going to need some management but is basically tolerable. In some ways it can be viewed as a little like having psoriasis or eczema – annoying, troublesome, but manageable given some medication. Further down the road the complications of diabetes appear, but many patients are able to accommodate their worsening condition and continue to cope. By this stage the complications tend to require care from cardiologists or other specialists, so the focus moves away from the diabetes itself. Death involving diabetes is often not reported as such. The reason for death is more likely to be the last medical event, such as a heart attack, so deaths from diabetes are generally agreed to be under-recorded.

THE BOTTOM LINE

The true impact of diabetes in the next twenty years will be a shock to many, because it has been developing silently for so long.

We need to:

- wake up to the reality of the epidemic of chronic disease
- make people aware that lifestyle advice is not boring – it's vital

and recognise that:

- medical science must make politicians shoulder responsibility for future wellbeing and not act solely for short-term political advantage
- confronting chronic disease can only succeed if it is undertaken on many fronts:
 - information (on food, diet, exercise, medicines, tobacco)
 - prevention (monitoring, risk assessment, targeted screening)
 - environment (advertising, architecture)
 - education and training of patients and healthcare professionals
 - early diagnosis and treatment (medications, procedures, healthcare systems)
 - support (psychological, social, public)
- research and development must continue to uncover new and more effective medications and procedures, not only to resolve conditions but to improve quality of life. Doing that will enable the individual to retain normality and a positive attitude to controlling chronic conditions in the long term
- the healthcare system and its budgetary framework must take into account the long-term realities of chronic diseases. This involves:
 - an overall approach to the scale and the potential of the growth of chronic disease
 - availability of appropriate levels and types of care throughout the course of the disease, and flexibility in procedural guidelines, structures and teams to accommodate different life stages
 - special attention, especially in terms of psychological support, to the transition periods throughout life, when crises are more likely
 - a systemic overview of the entire care pathway to ensure that change in one area is not allowed to generate chaos in other parts of the system
 - an individualised care plan for each patient and a lifestyle / wellbeing prescription for those able to avoid chronic disease.

Finally, we must acknowledge responsibility to the next generation, and not choose to do nothing.

In conclusion: 'if we can't sort out diabetes, which has very clear diagnostic criteria, and where there is a lot of evidence on how it can be prevented and treated, then we might as well pack up and go home' (98).

Glossary

Blood glucose	Glucose, mainly derived from food after meals and from the liver when fasting, is carried in the bloodstream to the cells of the body where it is used to provide energy
Blood lipids	Fats are needed as a food and as essential components of cells. They are carried in the bloodstream, but high levels can lead to damage to the blood vessels
Blood pressure	A measure of the pressure inside the arteries. It consists of two measurements: the higher (systolic pressure) is that after the heart has contracted, and the lower (diastolic pressure) is the pressure when the heart dilates
BME	Black and Minority Ethnic communities
BMI	Body Mass Index; a measurement of the ratio of body weight (in kg) to the square of the height (m ²)
Cholesterol	A fat transport particle produced in the body (see blood lipids above). HDL cholesterol (high density lipoprotein) has beneficial actions but high levels of LDL cholesterol (low density lipoprotein) lead to arterial thickening and heart disease
Diabetes	The usual abbreviation of the full name 'diabetes mellitus'. The disease in which the body is unable to produce enough insulin. In type 1 diabetes (T1DM) the cause is an immune reaction in the body, and in type 2 diabetes (T2DM) the cause is a relative insufficiency; often in cases where the insulin works less well (see Insulin resistance)
Diabetic Complications	The complications which can arise from diabetes: these can be divided into acute (hypoglycaemia, dehydration and ketoacidosis) and long-term tissue complications. The tissue complications include damage to the retina, damage to the kidney, damage to the nerves, erectile dysfunction, hardening of the blood vessels, heart disease, stroke, peripheral decrease in blood supply, and foot ulcers
Erectile Dysfunction	Failure to maintain an erection due to diabetic effects on the nervous system
Gestational Diabetes	Diabetes that occurs in pregnancy. It usually subsides after the birth but may recur later in life
HbA1c	(full name haemoglobin A1c) The test used to measure the amount of glucose that has been in the blood over the last few weeks. It measures how much glucose is attached to the haemoglobin of the red cell
Hyperglycaemia	Blood glucose level is too high
Hyperglycaemic Event	If blood glucose levels rise too high because of lack of insulin, dehydration and drowsiness result. Left untreated it is fatal
Hypertension	Blood pressure is too high
Hypoglycaemia	Blood glucose is too low. This can occur in diabetes when the person has injected too much insulin or done too much exercise for the amount of food eaten. May cause a sudden loss of consciousness. At best embarrassing, it is always dangerous because it causes accidents. Left untreated, it is fatal
Hypoglycaemic event or 'hypo'	Causes the person to feel anxious, weak and have a headache, blurred vision and confusion, possibly leading to loss of consciousness. Mild events are resolved by taking a small amount of glucose; more serious events need hospital treatment
Impaired glucose tolerance	A condition which often precedes diabetes and is a risk factor for its development: blood glucose is higher than normal but not high enough to indicate diabetes
Incidence	The number of new cases of a disease arising in a given population in a specified time period
Insulin	The hormone which enables the body cells to use glucose to generate energy. Insulin is normally produced in the beta-cells of the pancreas
Insulin-dependent	People with type 1 diabetes are insulin-dependent as they cannot produce insulin themselves and need to inject it. Those with type 2 diabetes can also be insulin-dependent if their treatment has progressed

Insulin resistance	People with type 2 diabetes have insulin resistance - the insulin they produce (or are given) works less well than in people without diabetes
Juvenile onset Diabetes	A former name for type 1 diabetes; which mainly arises in children and young people
Ketoacidosis	A condition which can occur in type 1 diabetes if levels of insulin have been completely insufficient. Energy cannot be obtained from glucose so the body starts to use fat as an energy source, releasing fruity-smelling ketones. These accumulate in the blood, resulting in dehydration, an excess of acid, coma and if left untreated, death
Late-onset Diabetes	A former name for type 2 diabetes; given because it mainly occurs in later life
Macrovascular	Relating to damage to large blood vessels, leading to heart disease (including heart attack, angina and heart failure), stroke, peripheral vascular diseases (damage to the blood vessels supplying the legs, resulting in poor circulation, which may lead to amputation)
Metabolic Syndrome	A combination of conditions predisposing to type 2 diabetes and cardiovascular diseases. Key features are high blood pressure, insulin resistance, high blood lipids and obesity
Microvascular	Relating to damage to small blood vessels, in the eyes (diabetic retinopathy, which may lead to visual impairment and blindness) the kidneys (nephropathy, which can lead to renal failure) and neuropathy (damage to the nerves)
MODY	Maturity onset diabetes of the young – a rare form of diabetes in young people
NDA	National Diabetes Audit; sponsored by the Healthcare Commission, to support the implementation of the Diabetes NSF and to improve the quality of patient care for people with diabetes in England
NDST	National Diabetes Support Team, set up to support the implementation of the National Service Framework for diabetes
Nephropathy	Damage to the kidneys; a possible late complication of diabetes
Neuropathy	Damage to the nervous system: usually in the feet, and lower limbs, where it can lead to amputation. In other nerves it can lead to postural hypotension, abnormal sweating, gastrointestinal problems, difficulties with passing urine, erectile dysfunction
NICE	National Institute for Health and Clinical Excellence
NSF	National Service Framework for Diabetes, the ten-year plan begun in 2003 to improve the standards of care for people with diabetes
Obesity	A level of the amount of body fat, defined as body mass index (BMI) over 30 kg/m ²
Overweight	A level of the amount of body fat, defined as body mass index (BMI) between 25-30 kg/m ²
Prevalence	The number of people in a given population reported to have a disease
QALY	Quality-Adjusted Life Year; a measure of the improvements in life expectancy and quality of life resulting from a treatment
QOF	Quality and Outcomes Framework; a set of indicators introduced by the 2003 GP contract, to ensure that a full range of checks and treatments is provided to patients in primary care
Retinopathy	Damage to the small blood vessels of the retina of the eye, leading to blurred vision and sometimes blindness
Type 1 diabetes	The body is unable to produce insulin, leading to high blood glucose levels. Insulin treatment is essential
Type 2 diabetes	The body produces insufficient insulin or cannot use it effectively. Type 2 diabetes can often be controlled with diet, exercise and oral drugs but it is progressive so insulin is often needed sooner or later
UKPDS	United Kingdom Prospective Diabetes Study, the major 20-year study of intensive treatment of blood glucose and blood pressure in type 2 diabetes

Methodology

METHODOLOGY

The MODEL Group came together as a group of health professionals with a wide range of knowledge and experience in the care of diabetes. This report, which represents its views on diabetes care in England and Wales, was prepared between September 2006 and February 2007. It was compiled on the basis of a series of roundtable discussions between group members held throughout that time. Interviews with 26 expert witnesses were also conducted on various aspects of the study, according to their particular expertise. The report also draws on extensive desk research in the relevant medical and healthcare literature.

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The MODEL Group Secretariat is Kissmann Langford, a healthcare strategy and communications consultancy. Interviews, research and preparation of the report were carried out by Dr Vivienne Kendall.

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We are a healthcare company and a world leader in diabetes care, manufacturing and marketing medicines, devices and services that make a significant difference to patients, the medical profession and society. We focus our resources on finding better methods of diabetes prevention, detection and treatment. Throughout our history we have also supported efforts to improve diabetes care through research, development of education programmes and encouragement of patient groups. In this, we work actively to promote collaboration between all parties involved in this disease, harnessing their respective expertise to achieve the common goal of defeating diabetes.

We have the broadest diabetes product portfolio, including the most advanced products within the area of insulin delivery systems. We also have a leading position within haemostasis management, growth hormone therapy and hormone replacement therapy.

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Where no reference is cited the material has been developed by Dr. V. Kendall in consultation with the MODEL group.

Patient stories:

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