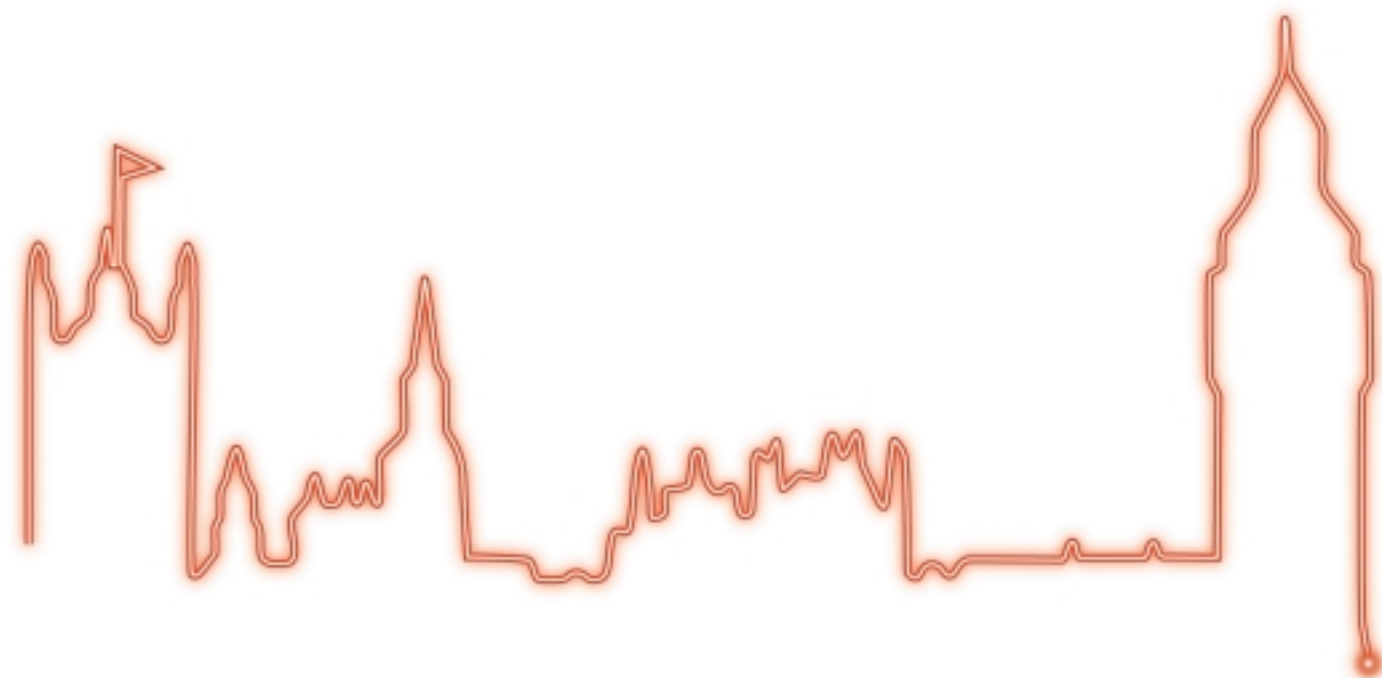


# Diabetes Dialogue



## Online consultation report – *living with diabetes in the UK*

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*The Hansard Society e-Democracy Programme is piloting innovative consultation methods aimed at increasing public involvement and engagement with Parliamentary decision-making through the use of new media tools. We are interested in ways of informing representation and facilitating the broadest democratic participation.*

# Chapter One

## INTRODUCTION

**“The launch of the consultation ... underlines the importance of involving people with diabetes, clinicians and managers in everything that we do. Our aim is to develop a service that fits the needs of service users, so it is vital that we gather their views in order to have a clear vision of what we are aiming to achieve.”**

***Rosie Winterton MP,  
Minister of State at the launch of Diabetes Dialogue,  
December 8, 2004***

At a meeting between Adrian Sanders MP and the Government and Health Policy Unit at sanofi-aventis in July 2004, it was agreed that an online consultation could be used to enable an effective and timely public discussion on several issues surrounding the management of people living with diabetes in the UK. Such issues include: goals of medical management, patient education, concordance with treatment advice, attainment of NSF outcome goals with different interventions; the burden of diabetes in terms of personal, social and NHS costs, and links with obesity. The Hansard Society, an independent organisation, was commissioned to monitor and moderate the consultation to gather evidence beyond official statistics, and widen the pool of people involved in the consultation process.

The Hansard Society has been involved in a number of online consultations, which have been widely recognised as a new way of engaging a range of relevant stakeholders. Through the domain **www.tellparliament.net**, the Society collected evidence for the Science & Technology Select Committee on Human Reproductive Technologies and the Law; and also on services for women suffering Domestic Violence for the All-Party Group on Domestic Violence; and on Flooding for the Parliamentary Office of Science & Technology.

By forming a partnership between the Hansard Society, sanofi-aventis and the All-Party Group for Diabetes, it was hoped the consultation would involve all levels of influence, including Parliamentarians, local government, health professionals, NHS managers, patient groups and patients. The online consultation would tease out which issues are of most concern at the grass roots level, and whether these differ from the focus at higher levels.

The consultation *Diabetes Dialogue* was launched at **www.tellparliament.net/diabetes** on Wednesday December 8, 2004 and ran for seven weeks until Friday February 4, 2005 with a break at Christmas.

The design of the website was simple with a focus on ease of navigation and accessibility of information. The central feature of the site was an online forum which enabled users to get involved in the consultation. In addition to the forum, there was a comprehensive information section on the site with useful links and



Left to right:  
Adrian Sanders MP,  
Dr Sue Roberts,  
Rosie Winterton MP,  
Mike Pleasant and  
Barry Griffiths

resources as well as a glossary. The site was designed with a view to encouraging people from all walks of life to take part in the online forum. This was emphasised in the welcome message from Adrian Sanders MP, the All-Party Group Chairman: "This is your space – the most important thing is to tell your story in your own words as your concerns may help shape future policy."

The online discussion was structured around four main areas:

- **Hitting the Targets**
- **Empowering people**
- **Service Delivery**
- **What's your story?**

There was also a section for **General Comments** for participants to raise any additional points and to comment about the site itself. The most popular topic among the participants was the **What's your story?** section with 35% of contributions, followed by **Service Delivery** with 22.3% of contributions to the consultation.

The *Diabetes Dialogue* generated a lively debate with over 300 messages posted to the site by 335 registered participants. The data gathered through the registration page provided us with some interesting statistics about registered users on the site:

- 76 % of participants had never previously contacted their MP before
- 60.2% of the contributions were posted by people living with diabetes
- 56 % of registered participants were female

As a matter of comparison, in our recent online consultation on Human Reproductive Technology, there was an even gender balance between the forum participants, while our recent online consultations for the



**Tellparliament.net** homepage – An umbrella title for the online consultations run on behalf of Parliamentary Select Committees and All-Party Groups

Modernisation Committee on Reconnecting Parliament with the Public was male-dominated with only 20% female participants.

The recruitment and publicity was crucial for the success of the online consultation. The Society worked closely with sanofi-aventis on building a database of health professionals, patient groups, specialist media and other stakeholders. The Hansard Society also undertook a media campaign at the start of the consultation to drive users to the site. **www.tellparliament.net/diabetes** was publicised through direct mailings, local media coverage, viral emails, web links and word of mouth. The Hansard Society established partnerships with Diabetes UK, BBC iCan and UK Online Centres to widen the net of participants in the online consultation.

In order to make this consultation as wide-reaching and successful as possible, sanofi-aventis and the Hansard Society e-Democracy Programme held two public meetings, with the participation of local MPs, in diabetes clinics in hospitals in Hillingdon and North Tyneside. The online consultation generated some press interest and was featured in various media channels. The Chairman of the All-Party Group, Adrian Sanders MP, helped with promotion of the consultation in a series of radio interviews conducted on January 13, 2005 with BBC Three Counties Radio (Beds, Bucks, Herts), CTR FM (Maidstone), BBC Somerset Sound, Mix 107 (High Wycombe), BBC Radio Leicester, BBC Radio Northampton, BBC Radio Devon, BBC WM (West Midlands), Downtown Radio (Northern Ireland), BBC Radio Norfolk and BBC Radio York. In addition, Adrian Sanders MP tabled an EDM in House of Commons which was signed by 105 MPs. To overcome problems of the digital divide, the Hansard Society also accepted written submissions to the forum which were posted on the site by the forum moderators.

The *Diabetes Dialogue* was closed on February 4, 2005. This report aims to summarise the participants' responses to the online consultation; it does not aim to interpret or evaluate the views given, or to suggest recommendations.



Left to right: Dr Anna Sörman, Milica Howell, John Randall MP, the Mayor of Hillingdon, Councillor David Payne, Mayoress Mrs Patricia Anne Payne, Dr Rowan Hillson at Hillingdon Hospital

**The following chapters contain:**

**Heading information** – The information at the top of each section was provided as background for participants.

**The keynote contributions** – A keynote contribution from an expert in the field, to start off the discussion.

**The comments** – The extracts in bold in the following chapters have been taken directly from the messages posted in the consultation and give an indication of the variety of the contributions posted. All contributions are assigned to the participants' usernames in the online forum e.g. *[Barry]*

**What did the participants think of the forum?**

Comments from the post-consultation survey:

**Thanks for holding this. It is good to see that there are others struggling with some aspect of their care, I'm not alone.** *[Saz]*

**Really enjoyed reading the discussions. Great for allowing people to be listened to and involved.** *[Watts]*

**I think it is a worthwhile exercise to continue with this sort of discussion, as it is helpful to those who take part, and, if more people are told about it and join in, it will become an effective tool in making informed decisions.** *[Steve]*

**There is a real need for a permanent online board like this – it seems to work as a cross between a chat room and an interactive website. Patients seem to have so much to offer one another! It would be incredibly helpful if Diabetes UK would consider setting one up, organised into different sections like children and parents; insulin users; work-related issues etc. It would be great if there could be regular contributions from 'experts' to point out glaring errors. A fascinating exercise and I was delighted to take part.** *[Dr Anne]*

**More cooperation is needed. We as patients must get involved to help influence decisions. Thank you for the opportunity to have our say. What happens next?** *[Jo Forrest]*

**My overwhelming feeling from being involved is that it was good to contribute and that I enjoyed the consultation very much. I guess the cynic in me thinks that all of this data will now disappear into a black hole in Whitehall, months will pass and the people that contributed won't hear what has happened as a result of this consultation. Obviously, I am hoping to be well and truly proved wrong.** *[David Simson]*

**The fact that Government 'listens' doesn't mean it takes any notice or is affected by what is said! But that doesn't mean I will stop trying to influence them! Therefore, I have to use every opportunity. Thank you for providing this one!** *[Avril]*

## Chapter Two

# HITTING THE TARGETS

### Background

“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.”

*Standard 4, National Service Framework for Diabetes Page 24, NSF for Diabetes: Standards*

Diabetes is a major health concern in the UK, and its prevalence is increasing. Diabetes affects all sectors of the community, and can significantly affect the individual and his or her family. Diabetes has the potential to cause the NHS serious capacity problems if not tackled effectively and mismanagement will lead to a drain on NHS resources.

To address this, the Government published the National Service Framework for Diabetes: Delivery Strategy in January 2003, outlining clinical targets for reducing the impact of diabetes:

- Improving blood glucose control
- Reducing cholesterol levels in people with diabetes
- Regular recall and review of people with diabetes
- Encouraging patients to give up smoking

Two years on from the publication of the NSF Delivery Strategy, do you feel progress is being made in meeting these targets?

### Keynote Contribution

**“Standard 4 of the Diabetes National Service Framework is incredibly important in its scope. It recommends that all adults with diabetes will receive high quality care with support to optimise control of their blood glucose, blood pressure and other risk factors.**

**It should be emphasised that the major cause of morbidity and mortality by far in diabetes is cardiovascular disease. In addition, diabetes in the UK remains the commonest cause of blindness in the working population, the commonest single reason for chronic kidney failure and need for dialysis and also the commonest reason for non-traumatic lower limb amputation. We now have an overwhelming weight of evidence that improving blood glucose, targeting lipid abnormalities, reducing blood pressure and stopping cigarette smoking will dramatically reduce vascular, particularly cardiovascular, risk.**

**Progress has certainly been made in meeting these targets, although I suspect that this is just as much related to the new GMS Contract as the NSF Delivery Strategy! Indeed, it is**



*Diabetes Dialogue homepage*

clear that different PCTs have varying priorities from the point of view of diabetes management. Some have embraced the new recommendations and guidelines, but for others there is still a long way to go. Significant reductions in blood pressure and cholesterol in the diabetes population can and should be achieved within a finite period of time. Hitting blood glucose targets will be more difficult for a number of reasons. These include the limitations of current therapies, problems of polypharmacy and compliance, and difficulties with organisation and systems of care.

Overall, there is still a lack of knowledge amongst both health professionals and patients which mitigates against the above targets being met. It is hoped that with new methods of working, improved systems of care, improvement in IT links, and better education of professionals and patients, these targets will eventually be achieved. Progress has certainly been made, and continues to be made, but remains extremely patchy across the country."

*Professor Tony Barnett, Professor of Medicine,  
University of Birmingham; Consultant Physician and Clinical Director  
of Diabetes and Endocrinology at Birmingham Heartlands Hospital*

## Comments from participants

Professor Tony Barnett introduced some of the issues surrounding high quality care targets in a keynote opening to this discussion thread. Participants posted comments on issues such as the NSF, glucose control, pump therapy, education and the level of care provided.

Throughout the forum, the NSF was the target of a lot of mixed opinion from participants. A very welcome development occurred with several individuals posting words of encouragement for their

fellow participants, often sharing first hand experience or knowledge gained about aspects of their diabetes care:

**I have been extremely lucky with my diabetes care at the two hospitals I have attended. For the last few years I have attended the diabetes clinic at the QMC in Nottingham and have received the best care. Appointments are every six months and I am sent a complete copy of the results every time. I know that my cholesterol level is good, my HbA1c has improved after DAFNE and that I have no complications. I have all this information in hard copy in my possession. [jlenham]**

**I have a six-year old daughter with Type 1 diabetes. Our local PCT in Milton Keynes is failing our children and failing to get a grip of the National Service Framework. We have one diabetes nurse for over 100 children with Type 1 diabetes, no paediatric diabetologist, no psychologist and no 24-hour helpline. National Service Framework is a great idea – but only if it is implemented! [nigel hammond]**

**The Diabetes NSF document is simply an average textbook of diabetes with the added disappointment of being big on style but short on substance. What organisation (other than a Government) would launch a project as big as this with no money attached to it?? What organisation (other than a Government) would fail to even scope the existing level of service and at least ensure that all health economies were providing diabetes services at roughly the same level BEFORE attempting to improve them? [Dr Phil Coates]**

**Defining clinical targets is fine but at this stage it is pretty much like bolting the door after the horse has gone... Empowering individual diabetics to take control of their condition by education and the means to monitor their progress, though requiring expenditure, will save higher costs further down the line incurred as a result of poor control. [ctorkington]**

**Self evidently NHS care when it comes to diabetes is obviously still at best a post code lottery; at worst non-existent. [Tim Midgley]**

**Children's diabetes services tend to be a last thought by those with the purse strings (certainly smaller numbers but for every one patient there are a minimum of parents, grandparents, sibs, aunts, uncles, school staff etc to support and educate) but they are the population of the future. [gracesett]**

**I am concerned that patients with glucose metabolism disorders are not being given balanced and reasoned advice on what the optimal diet for their condition may be. If the Government really want results with diabetes they need to give patients correct information and choice of what they eat, particularly in the hospital environment. I am a general medical practitioner and mother of a 12-year-old boy who was diagnosed with Type 1 diabetes 10 months ago. [Katharine Morrison]**

**I agree wholeheartedly with Dr Morrison. The medical and health professions are woefully inept in their service for diabetics... One frequently hears in the medical world**

**expressions such as ‘the causes of diabetes have not been clearly identified’, or ‘we do not know what causes diabetes’. But this merely demonstrates their ignorance.**  
*[barrygroves]*

**If those with decision-making abilities, in charge of the NHS, will need to commission their own detailed, authoritative and conclusive clinical studies before they’ll accept the truth where diets for diabetics are concerned, then it’s highly essential that they be pressured to start the process immediately** *[nigelh]*

An area of concern for a group of posters was the level of care provided by their PCTs. Comments ranged from criticism of urine sticks to an idea that a permanent website should be established to help people living with diabetes:

**I haven’t had much support from my surgery, but my doctor actually listens to me and basically lets me get on with things... Urine sticks are utterly useless for managing BG control, simply because they tell you what was going on when it’s too late to do anything about it.** *[yankee fiddler]*

**I have suffered from anxiety attacks whenever I have a check up because there is no continuity in my healthcare – I have seen a different consultant at every review that I’ve had in the past five years, one of whom told me that I’d be dead by the time I was 30 and then wondered why I got upset. My GP should be awarded a medal – he has helped me beyond the call of duty to overcome the damage caused by hospital teams.** *[sarahinsulin]*

**We need a group website ‘Living Life with Diabetes’ and funded mobile phone link to each other. This is the only way that some of us professionals with self-induced passion and addiction for diabetes and every brave person living with this unpredictable companion can support each other, learn from each other, share our defeats and failures, but celebrate our successes.** *[lking]*

Another hot topic of debate on the forum was glucose control. Once again, the discussion and participants themselves benefited from those who were prepared to give advice and comment directly on other participants’ experiences:

**The old thinking prevails that diabetes is very simple, and it’s the fault of the diabetic if control goes awry. As a diabetic of nearly 20 years, I can confirm that this is not the case. For the last five years, I’ve used a particular system of my own devising which has proved both safe and flexible (although it requires many more blood tests) – initially I was told to stop it at once and that I was doing too many blood tests, but now I am encouraged since it turns out to be identical to the DAFNE system... The way forward is to recognise diversity and listen to the person who lives with that physiology before agreeing targets.** *[towerhil]*

**I am in agreement with most of towerhil’s observations. I have found through 30 years as a Type 1 diabetic that the wisdom of what you are advised at clinics has certainly varied. Now, in my early 50s, I am going through the peri-menopausal phase and find that it is creating a totally unpredictable impact on my control. Despite these critical comments, I**

should also say that I do receive good and sympathetic help from my GP, the diabetes nurse and the hospital clinic. *[Sarah Howard]*

You have been treated monstrously in the past. Glad to hear that people are now coming round to your level of thinking! I think that there are recommendations re treatment of diabetes in hospital and that the person should be allowed to assume responsibility for their own care if they are well enough to do this. I don't know if there are any legal issues here. *[Abi]*

I am not surprised at the comments I see in this page. I am a health professional who is Type 2 diabetic, treated with insulin four times a day. I have absolutely no problems in getting the equipment and testing paraphernalia I require to test my BM. I think I am lucky because I know what is out there and what should be available to maintain my health; there are diabetics Type 1 & 2 who have not got a clue what they should be getting free from their own GP. DAFNE is the way forward in the UK although we are about 20 yrs behind Europe, especially Germany. I advocate all diabetics should have access to all testing equipment required to control THEIR diabetes, and it is THEIRS to control. *[Tom]*

Blood glucose testing is the most appropriate tool we have at the moment to monitor what is happening. But it does need to be combined with two other aspects:

- 1) An effective testing regime (testing once a day is not an effective regime);
- 2) Education, information and empowerment to enable the person with diabetes to act on the results. *[Trefoil]*

Totally agree with Trefoil. I am a Type 2 on diet and exercise for over 10 years and urine testing tells me nothing. But blood testing has enabled me to adjust my diet, check bad habits and take charge. I have maintained good health since diagnosis with good levels because I have an excellent early warning system via the blood testing which I do, which enables me to keep in the safe zone. It also helps me feel good about my condition and means I attend my doc's diabetic clinic yearly. For me, that's empowerment. *[TG]*

I'm another healthcare professional who happens to have Type 1. Like many of the others commenting on this forum, I also believe the NSF targets have been set by professionals, without adequate consultation with those of us living with diabetes... targets should be not only quantitative but qualitative – ask us about quality of life, lack of sacrifices made because of diabetes, maintaining full brain function, good self-esteem. Not only are the targets missing qualitative factors, but so is the research. Get us diabetics involved, and not at some meaningless level to just tick another box! *[Dr Anne]*

I have met many diabetic people who allow diabetes to govern their life. Yes, of course, dealing with your diabetes is important, but I'd suggest that you get it under control and get on with your life. The importance of good diabetic control often gets lost in the volume of great advice dished out to diabetics. It is critical to prioritise the importance of good diabetic control because, above all else, if the diabetic patient achieves no other target, but achieves good, stable control of blood sugar over the long term, then all other targets are secondary. *[vince]*

Discussion turned to the allocation of money to help fund different methods of glucose control, whether participants commented on the availability of pump therapy or easy access to test strips:

**My daughter has had Type 1 diabetes since she was five years old, she is now 21... To be able to drive safely, she often tests as often as eight times a day. Her previous consultant concluded that she needs an insulin pump... her new GP does not agree and claims that there is such a long queue for pumps in Warwick area that she is not a priority... I appeal to the Parliament to take this issue seriously and enforce the Primary Care to facilitate transfer to insulin pumps in individuals who genuinely need them and will benefit from them. *[king]***

**Insulin pumps should only be prescribed by a suitably trained diabetes consultant according to NICE guidelines... What your daughter needs to do is go back to her GP and ask to be referred to a diabetes consultant who has specialist CSII knowledge and runs the local PUMP programme. *[robertE]***

**I applaud the recent announcement by Diabetes UK regarding their intention to research test strip use and improved control. If this produces the kind of evidence that I would expect from personal experience, then it may force NICE to issue specific guidelines with respect to BM/BG testing. Thanks for the opportunity to express my views. I suggest the parliamentary group also examine the NNTP UK newsgroups to locate further patient opinions on all of these issues. *[VBHo]***

**The patients, carers, health professionals and junior managers are all quite clear as to what is needed, the Government and the strategic health authorities seem enthusiastic, but the jam in the sandwich is the PCT commissioning bodies who control the funding and so far they just don't seem to get it. *[David Humphriss]***

Several participants posted comments highlighting their collective belief that structured education such as DAFNE was very important in empowering people with diabetes. One poster felt that the DAFNE course should be much more readily available in all parts of the country and another felt that what was also needed was islet cell transplants:

**I cannot state enough how valuable the DAFNE course was to me... It was also an incredible experience from a social point of view – quality time spent with other Type 1 diabetics – something I had never experienced before. I have been able to start exercising without stuffing myself with a Mars bar – and hence have slowly started losing weight instead of putting it on for the first time in YEARS. I no longer feel anxious about when and where my next meal is coming from when out and about. Most importantly my HbA1c has come down by over 1% and I know exactly what to do to correct a high blood sugar. The thing with diabetes is that you never stop learning, and there were a few misconceptions I had that were blown away – so all in all I felt much more positive about my diabetes. *[jlenham]***

**My unit was one of the first 10 units to set up DAFNE in this country. With only a few exceptions, the patients who had access to the (DAFNE) courses love it and find it hugely**

helpful, not to say liberating. Yet we and the other units involved have had to fight tooth and nail to get further funding when the initial funding from central Government expired. Neither of our PCTs has funded the programme adequately, one has at least continued the funding at the level given by the Department of Health, although the DoH always recognised their funding as a contribution rather than the full cost; the other has given around a fifth of the needed funding. Other units who wish to start DAFNE locally are receiving no encouragement or funding from their PCTs. *[David Humphriss]*

My excellent local diabetic clinic runs a local equivalent of DAFNE, with groups for both adults and teenagers. When they wanted to start me on DAFNE there wasn't a group running, so I basically learned to do it myself. I'm lucky to have a really good DSN who helped with it, but it was really DIY-DAFNE... Having learned DAFNE on so many regimes, I offered to write a self-help manual – I've never seen an official DAFNE document so I've no idea if this fits their model. If there's anyone from Diabetes UK or the Govt reading this who'd like me to get on and write the manual get a hold of me! *[Dr Anne]*

If anybody from Diabetes UK or the Government is reading this, I'd like to help Dr Anne write the manual!! *[David Simson]*

I haven't been on a DAFNE course but with the support of a dietician who gave me carbohydrate counting sheets and wired me up to a continuous glucose monitor for three days, have worked it out for myself – it's not just DAFNE we need it's islet cell transplants!!!! *[Jo Forrest]*

# Chapter Three

# EMPOWERING PEOPLE

## Background

“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.”

*Standard 3, National Service Framework for Diabetes Page 21, NSF for Diabetes: Standards*

The National Service Framework aims to empower patients and creates self-management as the cornerstone of all diabetes care. But good self-management relies on patients being confident and feeling in control of both their diabetes, and the overall management provided by the NHS. Good self-management is built upon patients having the information to enable them to make the right choices.



*Nurse Denise Dodd, a diabetes patient herself, at Hillingdon Hospital*

- Do you feel an equal partner in deciding upon your care package?
- Do you feel you are given all the tools to become an expert patient?
- Do you feel in control of managing your illness?
- Do you feel the National Service Framework contributes to improving your quality of life?

## Keynote contribution

**“Diabetes affects people from all walks of life. It is important for politicians and Government to hear your views to fully understand what people with diabetes and their carers require from the NHS. By submitting your opinions on the care you receive, the Government, along with voluntary organisations such as Diabetes UK, can work to ensure that everyone gets the care they deserve.**

**Diabetes UK is one of Europe’s largest patient organisations. Our mission is to improve the lives of people with diabetes and to work towards a future without the condition through care, research and campaigning. With a membership of over 180,000, including over 6,000 health care professionals, Diabetes UK is an active and representative voice of people living with diabetes in the UK.**

**Why are your views important?**

**Engaging and reaching people with diabetes – and the million people who have diabetes but don’t yet know it – is integral to helping them manage their condition. If diabetes is**

not sufficiently managed it can have potentially devastating consequences such as heart disease, blindness and stroke. The latest figures show 1.8 million people in the UK are diagnosed with diabetes, of which 1.5 million people have Type 2 diabetes. Although we are unsure of what causes diabetes, there are certain risk factors associated with developing Type 2 diabetes, including obesity, poor diet and leading a sedentary lifestyle. Social deprivation and poverty has been linked to these risk factors. Research has found that people from poorer communities are more likely to develop Type 2 diabetes, compared with those from more affluent areas.

Ethnic minority groups are also more at risk of developing diabetes. Raising awareness of diabetes and providing ethnic minority communities with information to manage their condition is essential. Diabetes UK actively tries to reach out to people from black and ethnic minority communities by producing information in different languages, working within these communities and targeting ethnic minority media. It is these groups that have the most difficulty accessing services.

In order to make the NHS more responsive to local needs, structures have been set up to involve patients in the design of local diabetes services. Diabetes UK has been encouraging and supporting volunteers to take part in these groups. These structures aim to get patients directly involved in the delivery of the care they receive. They also aim to mould services to local needs in the future – especially important in socially deprived areas or an area with high black and ethnic minority populations.

Engaging with people who have diabetes and those at high risk of developing the condition is incredibly important to ensure everyone gets the care they deserve. Yet it is exactly these people who often face the biggest barriers to accessing health services. To make sure that Government responds to different communities' needs we require your views about how your local NHS is performing. We look forward to hearing what you have to say about your care.

**Your response will make a difference."**

*Benet Middleton, Director of Campaigning, Diabetes UK*

### Comments from participants

In this particular discussion thread a keynote contribution from Benet Middleton was used to kick off the topic in style and help visitors feel at ease when posting messages. One of the most welcome developments throughout the forum was a high degree of experience-sharing amongst participants over issues such as education, the care they received, advice regarding treatment and financial decisions made by PCTs.

Responding to questions posed at the start of the thread a large majority of participants certainly did not seem to feel empowered. Comments ranged from those individuals who seemed very angry about their care to those who offered constructive advice which could help empower diabetes patients:

**I am heartily sick of being patronised by the medical profession. In no way is anyone attempting to create a partnership with me in order to manage my diabetes better!** *[moxeyns]*

**I believe the medical and health professions are woefully inept in their service for diabetics. Helping diabetics to manage their condition involves giving them truthful and accurate advice. This is not happening.** *[barrygroves]*

**I help to run a local diabetes support group (not Diabetes UK) and we all have different experiences but generally feel we are 'given' medication without being told of the possible side effects, what its effect will be, how it works or why. [Trisha]**

**I believe that the most important issue for diabetes management is in empowering the patient in his or her own treatment. This requires the patient having the knowledge about their illness, and the data to use that knowledge. [nag]**

**People with diabetes in my experience need time invested at specific points of their diabetic career, they need to be listened to, and for the professionals to understand what it is like for them as individuals to live with diabetes, there is no one size fits all remedy. [J Carpenter]**

**Earlier this year when my pens became obsolete I had to contact the pharmaceutical company direct who were most helpful and sent me a brochure... My opinion is that whilst great advancements in the treatment/control of diabetes have been made, the care provided by hospital clinics is sadly much worse than 25 years ago. [Heather]**

**Doctors seem to have a fetish about pills. They don't discuss exercise and interesting ways to get fit without joining a gym. They are not much good at diets or how to cut down drinking. This is preventative medicine not pill oriented medicine. [Phoenixpr]**

**In industry people have to be accountable but it would appear that many health professionals and the hospital administrators do not. [brian moore]**

**The NHS love to use sound bites like 'accountability' and 'accessibility' but that is pure obfuscation that hides their inaction for those of us with conditions like diabetes. [Tim Midgley]**

**The NHS is now such a complex system to access, with so many managers and departments to get through that many people give up. It seems that the hospital management are aware of the need for certain areas of improvement; they are then faced with a brick wall from the PCT who are answerable to the Department of Health. Their only priority is to make sure that all the relevant boxes are ticked and that all the relevant targets as set out by the Department of Health are met. There is little room for negotiation with these people. They are completely out of touch with both patients and medical team requirements. [joanne downen]**

A school of thought existed in this thread that highlighted the importance of education in helping individuals to feel empowered. Some users have found through their own personal experience that one of the best ways to gain more understanding about diabetes is to educate themselves; whilst others commented on the knowledge they gained from taking DAFNE and expert patient courses:

**I believe a large part of empowerment is about education. In my case I have educated myself, mostly through experience and partly through studying specific subjects. The internet, though it must be treated with caution, is clearly an invaluable source of knowledge these days. [David Simson]**

**One important bit of information that I WISH the media/health professionals would get across is that Type 1 and Type 2 are very DIFFERENT. As a kid with Type 1, there was nothing more upsetting than being constantly told that I was never going to eat sugar again! [Jlenham]**

**I totally agree with jlenham, being a Type 1 diabetic for 22 years and not actually knowing anything useful about my condition until I took the DAFNE course. I only ever got five minutes with a doctor prior to DAFNE, and I learnt more about my diabetes in one week than in the 20 years prior to DAFNE. [kevin roe]**

**This is very interesting. DAFNE is unavailable in Worcestershire. I have written to my MP Julie Kirkbride and the Chair of the PCT Eamonn Kelly to get it funded. I am being told by Eamonn Kelly that DAFNE is not proven and expensive. [Val Snow]**

**I think Eamonn Kelly should get in touch with the DAFNE team at the Leicester Royal Infirmary or even better, the patients who have taken the DAFNE course; I think without exception this course helped every one of us. [kevin roe]**

**As an example of excellent empowerment practice, can I also recommend the Expert Patients' course. I have just completed this and I can't praise it, and my two tutors, too highly. It has enabled me to build friendships with other people with different chronic diseases, I have benefited from their thoughts and I think they have benefited from mine. It will more than repay its costs, both for me personally and in encouraging a more efficient use of medical professionals' time by patients. [Lchanney]**

As with other discussion threads on the forum the process of financial decision-making amongst Primary Care Trusts (PCTs) was a bone of contention with lots of messages posted on the topic. These ranged from a participant who purchases personal test strips and lances, to participants discussing how difficult it was to get insulin pump therapy and a participant referring to a lack of funding in paediatric services:

**I am determined to control my condition as well as I can, and so I am left with the only option of having to purchase my own test strips and lances. This costs me, but I consider it worthwhile because it has enabled me to work out the best routine to time my meals and medication to achieve the lowest and most consistent blood sugar levels that suit me. [AJ]**

**I was able with much persuasion and letter writing to change to insulin pump therapy 18 months ago... My control is now fantastic, I feel completely empowered, the pump enables me to exercise spontaneously and well, continue to work in an unpredictable sometimes stressful neonatal unit and precisely be able to calculate insulin doses and eat so freely. [fionastoate]**

**I have had Type 1 diabetes for 36 years. I have been very disappointed by the level of care and support I have received from the NHS over the years. The use of an insulin pump was never mentioned to me by any consultant, yet I researched this myself and managed to persuade my consultant to 'agree' to my trying it. The pump has allowed me significantly to improve my control. [catalpa]**

**I have been campaigning tirelessly for the past year to get improvements to paediatric services both at my local hospital and nationally. I am currently working alongside my Diabetes UK regional manager and have the support of many other parents in the area to address the situation. I also wrote to my local MP Henry Bellingham, who has been very supportive.** *[joanne downen]*

**I wholeheartedly agree with everything Joanne has written. I too have a child with Type 1 who was diagnosed four years ago (now six years old). The Government needs to look at urgently recruiting paediatric diabetic specialist nurses.** *[A Participant]*

The National Service Framework (NSF) was the focus of debate for some registrants, who criticised the initiative as they had not heard of it before. One proposed an idea to increase awareness of the NSF and the empowerment model of diabetes care:

**I do not perceive the NHS as a partner in my 'care package' – I keep myself informed, I get the insulin and test strips I ask for, I exercise and I get on with my life. And that's fine by me. As for the last question, 'Do you feel the National Service Framework contributes to improving your quality of life?'; this is the first time I have heard of the National Service Framework.** *[vince]*

**1st time I've heard of the NSF as well. Not well publicised is it? However, even if it were well publicised, there's no escaping the fact that the overwhelming majority of diabetic care is the responsibility of the person with diabetes.** *[David Simson]*

**I believe there should be a coordinated campaign involving the National Clinical Director for Diabetes, the PCTs, Secondary Care Trusts, Diabetes UK and others to raise the public's awareness of the NSF and the empowerment approach to diabetes management.** *[Trefoil]*

Several participants used the forum to ask for specific improvements which will help improve the quality of their lives, one by a mother on behalf of her son about classroom assistants and one about the inadequate labelling of drink:

**My son was diagnosed with Type 1 diabetes when he was 19 months old...he is a healthy, happy and clever little boy who is now in Year 1 at school and who feels confident about his diabetes... in Sweden a diabetic child entering school is classed as two children. The class numbers then allow the teacher a little, not much, but at least a little extra time. Along with having a full-time classroom assistant in each class, as should be the case for all children in any primary school, this seems very sensible.** *[Jacqui]*

**Food labelling gives information on carbohydrate and sugar content – excellent. Drink labelling gives only alcohol % – hopeless.** *[paulcope]*

# Chapter Four

# SERVICE DELIVERY

## Background

“The National Service Framework for Diabetes will set out the actions to be taken by local health and social care systems, milestones, performance management arrangements and the underpinning programmes to support local delivery.”

*Page 12, NSF for Diabetes: Standards*

The National Service Framework pledges to ensure patients receive a consistently high quality service. Do you think that your local NHS services currently have the resources to offer an all-round service for people with diabetes, their families and their carers?

- Is the infrastructure in place to deliver improved services?
- Are there adequate levels of resource and staffing to ensure improvements to diabetes services can be delivered?
- Are local services and processes sufficiently developed to ensure delivery of the NSF's targets?
- Do you feel services have improved?

## Keynote contribution

Welcome to the [www.tellparliament.net/diabetes](http://www.tellparliament.net/diabetes) website. This provides a unique opportunity for healthcare professionals, people with diabetes, their carers and, indeed, anyone with an interest in diabetes to contribute their views on how the National Service Framework (NSF) is being implemented.

The announcement of the NSF in December 2001 marked a significant point in the development of consistently excellent diabetes services within the NHS. For the first time national standards were laid down that provided guidance and inspiration for local services to aspire to. Standards that would, if fully achieved, enable the NHS to provide a world-class diabetes service for England. The vision was of a service that would make existing unacceptable disparities of treatment and outcomes a thing of the past.

The NSF broke new ground with its major focus on developing a true partnership between health care professionals and people with diabetes. It recognised that enhancing the level of personalised care and promoting self-management are key to improving diabetes services. As are also developing effective networks of service providers to bring together the considerable skill, dedication and experience that exists in the NHS.

The NSF is a 10-year journey however and we are just at the beginning but perhaps now is the right time to start asking, 'Is it working?' The Hansard Society, the All-Party Parliamentary Group (APPG) for Diabetes and sanofi-aventis, who are co-ordinating and



*Dr Sue Roberts with patient P Wilkes in North Tyneside Hospital*

**organising this online consultation, want to hear how the NSF is delivering change and improvement in diabetes services and any other issues raised. The aim is to create an informed discussion that will eventually lead to a short report to the APPG in Parliament.**

**Thank you for your interest and contribution to this radical new approach to consulting with service users and providers. One that I am sure will provide much valuable information and debate.**

*Dr Sue Roberts, National Clinical Director for Diabetes*

### **Comments from participants**

This discussion thread began with a keynote contribution from Dr Sue Roberts who asked participants if, amongst other things, the NSF was working at the beginning of a 10-year journey. A huge raft of comments from participants were directed at the NSF, some stating that care is worse now than before the framework was introduced, others offering advice on how the NSF could have had more impact:

**I hate the term 'People living with diabetes' with a passion – maybe you could help point us to where we can see how the national standards have provided inspiration to those within the NHS? [Beav]**

**Thank you for setting up this consultation. It is only to be hoped that it leads to some much needed changes in the thinking of the decision-makers! I fear that no initiative, such as that contained in the Diabetes NSF, will have much chance of succeeding... So my response to Sue Roberts' keynote is: no, it isn't working and it cannot work as long as these essential underlying issues aren't properly dealt with. [nigelh]**

**Before you put together something like the NSF, go and talk to the people it really affects, I mean, of course, us diabetics, have a read of the newsgroups (NGs) and go into the**

internet chatrooms and talk to real people about the problems they have had with GPs, nurses and dieticians, then you might be able to put together something that will actually benefit us. *[IanB]*

As a Type 1 diabetic and a member of a group looking at diabetes services in our local hospitals, I have been appalled at the deterioration in diabetes services in our area. The National Framework for Diabetes Services has not improved the situation of diabetes care – it has added to the growing problems. *[Wendy]*

The NSF is an aim or a target level of service, one presumes. When has the NHS achieved such targets and had enough resources in place to achieve them and carry out the wonderful statistical and reporting exercises? There appears to be a lack of knowledge and understanding amongst those who profess to be the professionals. *[iso8655]*

In the run up to the introduction of the NSF as a Type 1 diabetic I felt that the services I experienced had hit rock bottom in terms of quality and delivery. Since the introduction of the NSF things have not improved, at best they have stayed the same and in most cases have worsened – so from a patient's perspective the NSF has been a waste of money. *[adrianmiller]*

I have spent five years of frustration, as a hospital consultant, at inadequate funding and resources – no funding would be forthcoming pending the NSF... It is simply not seen as a must-do by those that have the money. The only consolation from browsing this website is that we are clearly not alone. *[David Humphriss]*

The NSF has been beneficial in focusing the mind for all involved in delivering care. It has really only reinforced what has been known for some time. *[Nigel Taylor]*

Good diabetic care is possible but requires teamwork. I worked in the community while Sue Roberts ran the local service and provided the support and education we needed. Patients are the ones who live with the condition and must be equal partners in decision-making. Although good care is costly, poor care is even more so. *[judithholmes]*

I have three chronic conditions for which I rely on the NHS for treatment. One factor which ties them all together is the lack of specialists available to treat patients. Seven minutes every two or three months leaves little time to educate me or deal with my symptoms. Thank god that I go in prepared with a great deal of research from the internet. Still, I am concerned that something may be missed simply due to the time constraints on my doctors. *[Aridland]*

Under the NSF I should be seen at the hospital once a year. My appointments kept being cancelled... It is never going to work unless the resources are aimed at the right place. How can we, as responsible adults, manage our condition when we do not get the support the NSF says is our due? *[Grannyjan]*

Service provision seems to depend on what part of the country patients live in and was clearly a very important topic judging by the number of comments made by a wide variety of participants. There were complaints as well as praise:

**I'm the parent of a 12-year-old, who has been diabetic for over two years. Reading some of the comments here, I realise we must be very lucky. The care my daughter receives from St Mary's Hospital in Manchester has been first class, from the excellent consultant, DSN and all clinic staff, I could not praise them highly enough. What I don't know is whether they provide this level of care despite the system or with it! [Steve]**

**Our local system in Portsmouth involving secondary care clinics, probably organised by Professor K M Shaw, is working extremely well in my experience. The specialisms required for particular complications are to hand when needed and can be brought to bear with the minimum of administrative formality. [paulcope]**

**I can only compliment the service I receive from the John Kilner Diabetic Unit in Epsom and my local GP is very understanding and supportive. The people on the LIT are all enthusiastic and dedicated. However, our main frustrations are:**

**1) The lack of finance – Why was money for the NSF not ring fenced? Could Parliament please advise on why this ludicrous decision came about and what they can do to help remedy the problems this has caused?**

**2) Having to reinvent the wheel. We have just written protocols for diabetes management in the PCT. It has taken many people many hours to write and is now fantastic. But why, oh why, is something like this not available centrally? Perhaps Sue Roberts could respond? [Jo Forrest]**

**I feel I have received excellent attention at Burton Queens Hospital, especially since visits to the specialists moved to the diabetic clinic. Over the past three years my blood sugar has been at a very good average circa 7.3. This is on metformin and other BP & bladder control tablets. Staff are helpful e.g. retesting and replacing the blood sugar meter. The clinic waiting facilities are excellent and waiting time is reasonable – I don't get much time to read any of the magazines or a book I might take with me. [A Participant]**

**I am a member of the Salford Diabetes Care Patients Forum. We are consulted by the healthcare professionals at Hope Hospital, Salford on a regular basis and doctors and nurses involved in diabetes care attend our meetings. We have been asked to comment on a variety of issues such as the community diabetes team's education booklet before it was issued to new patients, the hand held patients record and research projects being undertaken by a research consultant. [maggieJones]**

**This is still patchy, but slowly improving. Training of professionals in all primary care outlets is now ongoing. Many are now taking the Warwick University's 'Certificate in Diabetes Care' course. That is good. [Geoff Aitchison]**

**Based on the diabetes care received by both myself and my husband I would say that what is on offer in this county of Gloucestershire is rather like the curate's egg i.e. good in parts! The best I can say, based on some 12 years' experience, is that it is adequate. [Veracity46]**

**Medical professionals at my hospital clinic seem to think the NSF is working. They are oblivious to what patients want and what patients need. They assume too much and don't communicate to patients in the right way. The medical team at my clinic need to stop thinking they are right all the time and listen to what patients want. I feel the medical team think they have implemented the NSF, yet in reality they are so far away. [robertE]**

**I understand that my local Diabetes Centre at Hillingdon NHS Trust has recently axed its walk-in diabetes clinic held on a Friday due to a shortage of resources – I presume that patients' diabetes complications will wait until there is sufficient resource for HbA1c levels and control to improve? [adrianmiller]**

**I live in the country and for 35 years I have had a few hypos but over the past three or four years I have not been able to contact a doctor after 5pm in the evening – the time that hypos usually occur. The service at evening weekends and holidays is worse now than it was 35 years ago. [Mike]**

**Judging by the comments in my support group, as well as the various postings here, 'development ... of excellent diabetes services' is hardly consistent. Good, or even adequate, services seem to depend largely upon where you live and the luck of the draw insofar as what sort of GP you end up with. [yankee fiddler]**

**Have been diabetic for some 38 years. Eastern board (N Ireland) has been prepared to fund up to 20 pump users – however, the evidence to date is that knowledge and recommendation of this treatment method (which undoubtedly offers better HbA1c levels and life flexibility) on the ground is scarce; at a local level much depends on groups like INPUT to inform prospective patients. [j twigg]**

**I'm seriously worried about the quality of service and level of advice given to diabetics through the NHS. I am 32 weeks' pregnant, and three weeks ago a routine check found glucose in my urine.... I have not been offered any counselling whatsoever or any dietary/health advice. [ElunedP]**

On the issue of better education for diabetics one participant summed up the plea echoed amongst other users that education programmes are made more readily available, and another felt that a version of the DAFNE course should be made available online:

**Diabetes information and education has to be one of the biggest areas that needs to be addressed. Structured education programmes like DAFNE and DESMOND have been recently introduced but their introduction appears to have been sporadic and is based on whether the PCT has either the funds or the resources to implement these or other structured education programmes. While structured education programmes are being introduced, they are not universally available. [Trefoil]**

**Appropriate education can be seen as a two-fold approach. Firstly to ensure those who educate need to be up-to-date themselves, but also to have teaching skills to make education more interesting. Some of these skills are being taught by the more well known**

**approaches such as DAFNE and other structured education initiatives. We all know if we are explained something once, we would remember very little, however, being explained and supported frequently, and also by using different methods, will allow for more memory retention. This all takes money and time. Do we have these resources? Could a forum of this nature be used to share good practice? [Surinder]**

**I was lucky enough to go on a DAFNE course, and I understand that these are incredibly expensive to run. However, I cannot believe that there is not a cheap way to keep up the education for diabetics. In this day and age couldn't there be some sort of online education programme? [Jlenham]**

The financial decision-making process came under scrutiny from numerous posters; some were left frustrated trying to gain funding for their own insulin pump while another participant welcomed the new incentive for GPs:

**The new GMS contract for GPs provides a financial incentive for them to do something about diabetes, which has to be welcomed. However a lot of the GMS contract centres around maintaining registers, collecting information i.e. test results etc. [Trefoil]**

**I'm a diabetic medical student, diagnosed in 1996. In Jan 2003 I began pump therapy, having found it impossible to control my blood sugars. When the NICE guidelines were published I was reassured that my funding would be back-dated – I was advised not to hassle the PCT but to await their decision and I eventually received funding. However, when I asked whether back-dating was possible I was told that it would not be as I am funded by the hospital (due to its status as a foundation hospital) rather than the PCT. It strikes me that this is yet another example of healthcare by postcode – I'm certainly not impressed and find it somewhat frustrating that I was not kept informed about events. [Sarah]**

**The NHS does not have services or resources in place to help people with diabetes. According to NICE guidelines, I was expecting to receive 'pump consumables' through the NHS. I have yet to see any consumables. [Nicole]**

A group of participants made up of doctors, consultants, specialist nurses and patients wanted to air their concerns about care in general but also identify changes they would like to see. These range from requests for a new sugar-testing device to an idea that the NSF should set national standards:

**I read tellparliament and immediately identified with comments by people with diabetes. I'd like to see changes such as:**

- 1. Independent outpatient and GP surgery clinics for people with Type 1 and 2 diabetes to enable more focused care and generation of separate specialities.**
- 2. Structured education available for all and not the few, designed with greater emphasis on self-management skills to more closely match patient needs, including regular interactive updates and support.**
- 3. Greater degree of responsibility, clinical expertise and problem solving by health professionals.**
- 4. Improvement in partnerships by agreement between patients and health professionals**

to combat fragmented systems of care by using patient-held notes for instance.

**5. Wider access to information easily available for patients possibly directed to problem solving.** *[Joanwalker]*

As a hospital consultant... the NSF for diabetes places the emphasis on primary care to manage the majority of patients with Type 2 diabetes. Most of us feel like we are fire fighting most of the time and this is obviously reflected in much of the frustration found on these forums. As with most tasks, we need the tools to carry it out properly and in the case of diabetes, the DOH seems to be willing to allow 10% of the NHS budget to be wasted mainly on diabetes complication management, rather than invest a fraction of this in ensuring high quality care is available both in hospitals and the community. *[Dr Phil Coates]*

I agree with the sentiments expressed by Dr Phil Coates. To succeed in winning the war against the diabetes epidemic we need active programmes on three major fronts.

**1. More money to provide adequate training for existing staff.**

**2. Training for additional staff to meet the confidently predicted doubling of cases in the next 10 years.**

**3. A major campaign to educate the nation to the dangers of our current lifestyle. The man in the street needs to understand the certainty of blindness, amputations and heart attack if he continues with the modern lifestyle.** *[malcolmwhitmore]*

Diabetes is the leading cause of blindness in adults in the working age group and it is a leading cause of end stage renal failure. Diabetic patients are at greatly increased risk of cardiovascular disease and life expectancy is significantly reduced mainly due to coronary heart disease. In addition, diabetic patients have a substantially increased risk of lower limb amputation. This results in substantial disability and is a very expensive complication in terms of NHS and Social Services resources. Already at least 10% of acute hospital beds are occupied by diabetic patients, many with foot problems requiring multiple surgical and radiological interventions leading to prolonged inpatient stays. Much of this is preventable with good management specialist podiatric care.

There is now abundant evidence that the careful control of diabetes can prevent or greatly reduce the severity of many of these complications. The landmark Diabetes Control and Complications Trial (DCCT) in patients with Type 1 diabetes showed that a reduction in glycosylated haemoglobin (HbA1c) by, on average, 2% over seven years substantially reduced the development, progression and severity of retinopathy and nephropathy.

The Association of British Clinical Diabetologists (ABCD)... has major concerns about current NHS reforms. ABCD recommendations are:

**1. Every district should have an adequately resourced specialist care service**

**2. Specialist services should be provided with sufficient resources to allow the introduction of complex therapies**

**3. Education programmes such as DAFNE and DESMOND have been shown to be of value in improving patient empowerment**

**4. ABCD supports the provision of adequately resourced primary care services**

**5. ABCD supports the effective integration of local primary and secondary care diabetes**

services in order to provide 'seamless' care for all patients

**6. ABCD supports the provision of comprehensive and effective screening services to detect complications such as retinopathy at an early and treatable stage**

**7. ABCD would like to emphasise that most, if not all, of these changes will need adequate and effective IT support to improve communication and facilitate quality monitoring and audit of clinical outcomes. [Dr Richard Greenwood FRCP, On behalf of ABCD]**

**Surely the National Health Service and the National Service Framework should set out national standards e.g. national protocols (not every consultant writing his/her own); national standards on frequency of check-ups (not every GP deciding him/herself); national education programme; national web-based information; national ways of patients monitoring their blood sugar. Then the NHS could also know national costs, and fund those costs. [Janda]**

**I have great ideas as a diabetes specialist nurse and I have been involved in a structured education programme for the Asian community. I feel MPs need to work at a clinical setting to understand the hardship and commitment health care professionals have but more and more nurses are leaving to work for pharmaceutical companies. [kmarwa]**

**The most difficult part of diabetes is testing your sugar levels. When this is improved then diabetes control will improve. Just like a gauge in a car you should be able to look at an instrument and tell what level your blood is. [Patrick Lyne]**

# Chapter Five

## WHAT'S YOUR STORY?

### Background

Tell us about any aspect of diabetes treatment, your experience and thoughts. Whether you want to tell us about your local services, give us your perspective as staff, relative or policy maker, talk about how you manage your diabetes, or what treatment works best for you, let us know.

### Comments from participants

This thread was left very open and the participants posted a huge variety of interesting messages. These ranged from discussion about dietary advice, the financial implications of methods of care, the importance of structured education to some varied examples of care across the UK:

**I am very fortunate to be able to attend the Hillingdon Diabetes and Endocrine Unit, which in my view is outstanding in its delivery of care and support. I found the support and advice of diabetes specialist nurses invaluable in teaching me the basics of living with the illness. [lan]**

**I contacted my GP (after the morning surgery had finished) who told me to come straight to the surgery. Within two hours I had been seen at the blood clinic at the local hospital for blood glucose/cholesterol testing; was booked in to see the specialist diabetic dietician, optician and chiropodist (all who saw me within three days); received the results back from the hospital; seen by the specialist diabetic nurse with a further appointment**

**in three days' time; had my blood pressure checked (way up), and in receipt of a prescription for blood glucose testing equipment, metformin, lisinopril and atavastatin for my blood pressure and cholesterol problems. After seeing my optician, who diagnosed an early cataract attributed to the diabetes, I was immediately referred to a consultant ophthalmic specialist and added to the annual retinal scan programme. All the professionals I visited gave me a very good education on how diabetes affects the body, how my medication helps and how best to help myself. When I first heard the dreaded words of 'diabetes' I envisaged that my life had come to an end. The reality is, with the continual support and**



A typical example of messages posted by participants in the 'What's your story?' thread

**wonderful understanding given to me of my condition by the very dedicated professionals who work here, I am living life to the full and having a ball. Even my eyesight has improved over what it was six years ago. I am extremely grateful to my PCT and in particular to my GP practice who are absolutely wonderful. [rogerslimprs]**

In contrast however, the youngest participant at 11 years old had something negative to say about her local diabetes care:

**I was diagnosed with Type 1 diabetes when I was seven years old. I am now 11. My parents had to move my diabetes care from Dudley to Birmingham Children's Hospital 18 months ago because the care in Dudley was not geared to children. Please help Dudley to improve their services to children. [millie]**

A large amount of debate on the forum centred around the difference of care depending on where participants lived and on the NSF in general, and made specific suggestions:

**The NSF is an excellent document covering all aspects of care but there is insufficient money to implement it. The care and treatment available is still too widely variable – depending on the attitudes and interests of the PCTs and the GPs. [Avril]**

**My own experience has been good, but I am lucky with the primary care practice with which I am registered. [Geoff Aitchison]**

**My doctors, nurses and optician are all excellent. My surgery operates a triage system and if I am ever feeling unwell, whether it be related to the diabetes or not, I can generally get a same-day appointment. [Dawn]**

**At first the care was adequate and then I was lucky as it changed because they had a diabetic clinic at my GPs with a very good doctor looking after us and also a terrific nurse who looks after diabetics. [Elenor]**

**Due to the help and support of my consultant and the rest of the team I have been able to control my diabetes fairly well; my HbA1c has always been below 7.5%**

**The main reasons why I have been able to achieve this are:**

- 1. The initial education and support I received after diagnosis.**
- 2. Most importantly to me my consultant has always wanted to listen to my side of the story and has treated me as an equal.**
- 3. I have been able to test my blood glucose four times a day. Anything less than this makes it virtually impossible to keep a good average. What some people do not realise is how sensitive glucose control is and how rapidly levels can fluctuate. There is a very fine line between good control and going too low. [Ian]**

**The comments on this website echo what I hear from my patients. What I feel is needed from Government is a co-ordinated policy to delivery diabetes care, with standards, deadlines and dedicated funding. Yes I know you gave us the NSF but without the most significant part – the ring-fenced dedicated funding. [Bonnie]**

**Having a National Framework is an excellent idea. It provides a national target for the sort of service that should be provided.** *[Ian g Baldwin]*

**I was living in France, when I was diagnosed with Type 1 in 1992... the level of individual tailored support I received was far superior to that which is available in this country.** *[vince]*

The financial implications of different methods of care were a topic of hot contention from several participants, whether it was urine-testing strips, insulin pumps or a talking blood monitor:

**I am told by my GP and also by the hospital diabetes clinic nurse that I should not test by any other means than urine strips. I am convinced the only reason my Dr will not prescribe the test strips is financial and not medical.** *[ErnieHastings]*

**I am fortunate in that my GP is excellent so that I never have any problem obtaining blood strips. However, that's not to say that it has been easy as I have had to convince my GP of the merits of what I do but, bless her, she is very far-sighted and recognises that money spent today on blood strips will save much more money longer term by avoiding complications.** *[David Simson]*

**ALL diabetics should get free prescriptions. Whether you test by urine or blood, this is an essential part of managing the condition and I therefore feel that all prescriptions should be free.** *[Dawn]*

**My GP practice are excellent at supplying as many test strips as I require but the diabetic clinic at the hospital leaves a lot to be desired. I finally managed to get an appointment last week and had to take a copy of the NSF for diabetes with me to obtain the required level of service.** *[Jenny Henderson]*

**I have also been fighting for an insulin pump for nearly three years but I have been constantly bombarded with excuses and criteria that I have to meet in order to receive one.** *[Aimee]*

**Why isn't there a talking blood monitor for blind diabetics in the UK? From the web they are available throughout Europe, Ireland and the US. I am totally blind but desperately want to be able to independently control my own blood sugar levels.** *[DiabeticFor52years]*

**Surely it must make better financial sense in the long run for blind diabetics to be given the equipment they need to manage their diabetes correctly, than to become a drain on NHS resources through the need for dialysis, amputations, coronary and/or stroke care in the future.** *[ChrisP]*

Some participants used the forum to complain about their care and more specifically that they felt they were not being treated as individuals:

**I've been diabetic for 34 years...I feel like a statistic who is patronised if her blood sugars aren't perfect – despite living a full life and after 34 years of diabetes the only directly related complication is some slight retinopathy that hasn't required treatment.** *[A Participant]*

**There is no doubt from the comments here that the diabetic NSF is not working very well. One of the main culprits appears to be the PCTs in their never relenting drive to save money, instead of vision, limb and life... After all, diabetes is for life, not just for a parliamentary session.** *[rogerslimprs]*

**Some of the ignorance that comes from 'specialists' is amazing – yes they have all the facts and figures to hand – but they do not have the experience of 'living' with diabetes.** *[UKKati]*

**I have benefited from the forum as it has made me look further into my daughter's rights and led me to contact other parents in order to ascertain that the points I put forward were not just specific to my daughter. There is great ignorance within schools as to the needs of the diabetic child, it is unreasonable of the Government to hope PDSNs could train teachers, the geographic and time frames involved would make this impossible. Which leaves parents to educate the schools and that is not something the heads will entertain. The legal guidelines given to heads/ governors are, if read, then ignored. Even armed with the knowledge my daughter is entitled to a care plan, the headmistress still will not renew one drawn up almost three years ago.** *[Jennyrobyn]*

**I would rather be alive with diabetes than not alive at all and that is what influenced my decision to have children.** *[Hampton]*

A group of posters wanted to emphasise the power of self control and that the introduction of new tools such as an online support service could help improve diabetic control:

**I have been a diabetic for 26 years and have never been able to stabilise my blood glucose over all these years. I have tried to monitor my control on spreadsheets, which I take to the nurses if I see them, which is infrequent. Good control needs to be supported by an online service that could be monitored by nurses who read the results and then contact the diabetic person to discuss how to improve the situation.** *[anne]*

**What I have learned is that I need to take responsibility for my health, do my own research, and come up with my own diabetes management plan. I can do this, but sometimes I feel really worried by the people out there who will still accept whatever a doctor says as truth, and may be suffering because of it.** *[Saz]*

The topic of patient-centred research was raised by a group of posters, who felt this could be another avenue of opportunity to exploit:

**A decent clinical service nationwide is clearly what everyone posting comments wants! Why isn't the Government funding a research programme into the long-term safety and qualitative measures associated with synthetic insulins? A plea: we need funding for research designed by patients, monitored by patients, around patient-centred outcomes.** *[Dr Anne]*

**I agree wholeheartedly with Dr Anne. I think legislation needs to be brought in to force the pharmaceutical companies to show the ongoing test results of all their products so that**

**the side effects of so called 'synthetic human insulins' can be brought to the attention of prescribers in order for them and the patient to gauge what is going to be best for the patient and not what is best for the companies' profit margins.** *[Barrie Morgan]*

One poster asked the Government to make all research on GM insulin readily available and another said that a small minority of their outpatients were on 'animal' insulin:

**Will the Government please insure that: All the research about the effects of GM insulin is published and made available to diabetic patients? Medics who prescribe insulin and care for diabetics have available to them information about all the side effects of GM insulin?** *[Roger]*

**I have been in post (consultant) nine years and see an average of 3,500 people a year in my outpatient clinics. 0.01% of these are on 'animal' insulin.** *[Dr Phil Coates]*

Discussion turned to diet and several participants had some very interesting views on dietary advice and problems they would like addressed by the Government:

**The only real thing that bothers me with my diabetes – being limited to what I can drink when in public houses. I would be nice to be offered more diet drinks to choose.** *[kez]*

**Unfortunately slimming down will not cure you of diabetes; it will only help to control your blood sugar results. Diabetes is a progressive condition. By slimming down you will help all the 'nasties' that go with diabetes.** *[gappygap]*

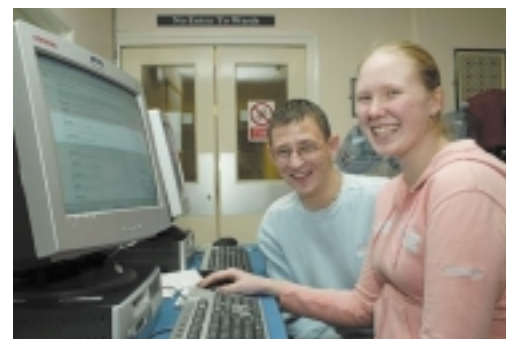
A specialist dietician posted a note of cautious encouragement to those people who have to change their diet as a result of diabetes:

**Making changes to the food you have eaten all your life takes time, and I certainly allow for this time. Also changes are agreed with the person with diabetes and not enforced.** *[Surinder]*

Throughout the forum many participants felt that DAFNE education courses were perhaps part of the solution:

**Following the DAFNE experience, I realised how little I did actually know. The C course was so informative and covered all aspects of life with diabetes. Everyone should get the opportunity of going on the course.** *[Stevertcliffe]*

**I have found it most interesting reading all that has been written, it is certainly good to find out how other people deal with diabetes, and also the way the system supports them. Many people have mentioned DAFNE which from the little I have found out about it seems to be a good idea and seems to give confidence to people.** *[Delia]*



*Patient Donna Holt with partner Scott Parker*

## Chapter Six

# FINAL COMMENTS

**“As National Clinical Director for Diabetes I am delighted that this excellent initiative has been such a success. I was at the launch and have read the contributions each week with great interest.**

The Diabetes NSF was launched two years ago in response to three things: The increase in the number of people getting diabetes as the population gets heavier and less active. The very significant burden of ill health caused by diabetes, for those with diabetes themselves, the NHS and society as a whole. But the main purpose was to deal with unacceptable variations in treatment and outcomes

There is good evidence of how the health of people with diabetes can be significantly improved. The aim of the NSF was to ensure that everyone has access to the very best care based on the knowledge, skills and experience of the diabetes community.

This dialogue comes at the end of the first two years of our 10-year plan. It has shown that a great deal of unacceptable variation remains. I have been saddened to read the accounts of people with distressing problems which have not been addressed, when others have described how similar issues can be dealt with quickly. We cannot put up with this.

I have been encouraged by the many examples of good practice, some of which I know have been put into place in the last two years. The dialogue has also confirmed that people with diabetes themselves are an excellent source of support and information to each other.

One of the things that remain most variable, but most important for people with diabetes, is access to consistent information and education. So I am pleased that high quality education programmes such as DAFNE and DESMOND are now available for PCTs and diabetes communities to provide.

But much more needs to be done. The first year or so of the NSF was about putting building blocks in place and we now need to build on these. For instance I have particularly noted the concerns around services for young people. We will be looking at the final report with interest and ensuring that the ‘sound bite’ at the centre of the NSF becomes a reality ...’ to make the best the norm’...”

***Dr Sue Roberts, the National Clinical Director for Diabetes***



*Dr Sue Roberts (second left) and her National Diabetes Support team*

**“People with diabetes have clearly engaged with the online consultation to express their opinions and frustrations. While some people are clearly getting good care, many of those who have contributed are not. Meanwhile, many health professionals feel frustrated at being unable to deliver the standard of care they would like to. In particular, education and support are essential to help people understand their diabetes and empower them to manage their condition effectively. It is through education that we can build a true partnership between people with diabetes and the health service.**

We hope that this excellent response will be used to understand and learn from people with diabetes and their healthcare professionals. It gives a clear indication of what is actually happening on the front line of diabetes care. If diabetes care is to improve, decision-makers and policy leaders should take these comments on board and look at how they can build a truly patient centred service that supports people to manage their diabetes effectively.

***Benet Middleton, Director of Campaigning, Diabetes UK***



*Benet Middleton: “... many health professionals feel frustrated at being unable to deliver the standard of care they would like to.”*

**“Sanofi-aventis is a research-based pharmaceutical company which provides medicines in a range of important disease areas, including diabetes. However, we go beyond that and are committed to delivering improved outcomes for patients through a range of ethical partnership initiatives, including: educational programs for nurses and GPs; awareness projects that reach out to the public about the risks and optimal management of diabetes; and events which link people living with diabetes with their healthcare professionals and policy-shapers.**

This Diabetes Dialogue online consultation has been a radical new approach in linking service users, providers and policy-shapers. Focusing on the standards and targets set out in the National Service Framework for Diabetes, which map out the optimal steps to improving health outcomes, the consultation

has highlighted many areas where real progress has already been made.

Sanofi-aventis is pleased that there has been so much interest in this opportunity for people to ‘have their say’. We thank our partners and lead contributors for their active involvement in this initiative. Most particularly, we thank everyone who participated by logging on and contributing their views and experiences. We trust that the opportunity to hear directly from ‘the grassroots’ will contribute positively to the delivery of optimal care for people affected by diabetes.”

***Dr Anna Sörman, sanofi-aventis***



*Dr Anna Sörman (second left) with Milica Howell, Rosie Winterton MP and Adrian Sanders MP*

## Afterword

# ADRIAN SANDERS, MP

**“I am delighted to have been involved in this timely and interesting online consultation, and thank everyone for taking the time to participate. Ministers, parliamentarians and officials must learn from the experience of grassroots stakeholders to understand how policies developed in Westminster and Whitehall are being translated into front line service delivery.**

This consultation has given hundreds of people with diabetes and their carers, health care professionals, and patient representatives the opportunity to inform and shape policy. The All-Party Parliamentary Group for Diabetes and Department of Health have been closely tracking the consultation, and this report is a blueprint of grassroots opinion that I hope will drive future policy-making in diabetes.

When the Government published the National Service Framework (NSF) on Diabetes Delivery Strategy in 2003, emphasis was placed on empowering patients to support their care management and set national standards for diabetes services. The NSF aims to make best practice the norm: ensuring high quality of care wherever people live and reducing the burden of diabetes and the associated health inequalities. However, the NSF also recognised that this demands real change in the way that the NHS delivers care to people with diabetes. Reading through the comments, I was encouraged by the many experiences of people with diabetes who have received excellent and valuable care by highly dedicated professionals. There is real and concrete evidence that, when implemented well, the NSF has enabled people to manage their diabetes effectively. Regrettably, evidence also suggests that there are patient experiences that fall far short of the aims and expectations of the NSF, and therefore areas for improvements in the provision of care exist in many parts of the country.

I know the Department of Health is committed to ensuring that best practice becomes the norm across the UK. The All-Party Parliamentary Group for Diabetes will, I am sure, help to facilitate further dialogue, thus enabling the Department of Health to build on the successes of the last two years.

As Chairman of the All-Party Parliamentary Group for Diabetes, I am pleased to suggest some priorities based on the report and call upon the Government to:

- Continue the excellent progress that has already been made in developing diabetes services in line with the standards and targets contained in the Diabetes National Service Framework, ensuring that this is adequately resourced for maximum health gain.
- Continue to focus on the importance of reaching and maintaining control of blood glucose levels, and in particular the target of HbA1c at or below 7%, in order to reduce the serious and debilitating medical consequences of diabetes – frequent blood glucose level testing like HbA1c needs to be encouraged by all care services.



- Continue to support the delivery of systematic and adequately resourced care, which places emphasis both at care delivered in the community by primary services and in hospitals. Services need to be integrated to achieve maximum outcome for patients.
- Continue to establish comprehensive and effective screening services to detect complications from diabetes – the national eye screening programme is welcome and will prevent people from going blind or having their sight impaired. This service needs to be available nationally as soon as possible.
- Ensure local NHS service providers maintain regular dialogue with their diabetes networks: as they champion the views of people affected by this disease and determine local services and priorities.
- Continue to improve paediatric services and services for young people, and place greater emphasis to address specific needs by patients.
- Continue the advances in patient education and provide additional resources for education to support self-care for people with diabetes, including web-based education. Programmes such as DAFNE and DESMOND have been shown to be of value in improving patient empowerment and should be extended.
- Encourage more training amongst healthcare professionals to provide a patient focused problem solving care package, by adopting further multi-disciplinary approaches to providing specialist care.
- Publication of regular local and national audits to ensure the NSF is being implemented, that objectives are being met, and that standards are being maintained

The NSF has put self-management and personalised care at the centre of diabetes care, and sets standards which should drive forward the quality of care. We need to strive to achieve its full implementation and the online consultation gives a clear mandate to make national best practice a reality across the whole of the UK.

Finally, may I thank those who took the time to participate and help shape the future of diabetes care and support, those who made the dialogue possible, and those who will now take this agenda forward.”

**Adrian Sanders MP**

**Chair, All-Party Parliamentary Group for Diabetes**

# Appendix

## GLOSSARY OF TERMS

**Adipocytes:** Fat cells

**Antibody:** Protein made by the B cells of the body's immune system that is specific to an antigen. It can bind to the antigen, allowing it to be recognised by the body as friend or foe.

**Antigen:** A molecule found either inside or on the surface of a cell that can induce an immune response. Antigens are used by the body's immune system to recognise whether the cell is a dangerous foreign intruder or a harmless part of the body. They are like molecular labels.

**Anti-rejection drugs:** The drugs that people who receive a transplant have to take to prevent their immune system from attacking the new cells.

**Autoimmune:** Conditions caused when the body's immune system antibodies (the system that normally protects us from foreign germs like bacteria and viruses) start to attack some of the body's own cells. Type 1 diabetes is one example of an autoimmune condition, which is caused when antibodies (the immune system's chemical weapons) attack and destroy the insulin-producing islet cells.

**Auto-immune conditions:** These are caused when the body's immune system (the system that normally protects us from foreign germs like bacteria and viruses) starts to attack some of the body's own cells. Type 1 diabetes is one example of an auto-immune condition, which is caused when antibodies (the immune system's chemical weapons) attack and destroy the insulin-producing islet cells.

**Autonomic neuropathy:** A complication of diabetes that results from damage to the nerves that function automatically such as those that control the bladder and digestion.

**B cells:** Specialised cells of the immune system which help to fight infections by making antibodies. They are also called B lymphocytes. In Type 1 diabetes, they help the T cells to kill the beta cells by making antibodies targeted specifically at the beta cells – these are called autoantibodies.

**Beta cells:** Beta cells are the individual cells that produce insulin. Beta cells are stored within the islets of Langerhans in the pancreas.

**Beta cells (b cells):** Specialised cells found in the Islets of Langerhans in the pancreas. Their job is to produce insulin. They are destroyed by the immune system in Type 1 diabetes.

**Blood glucose levels:** The amount of glucose being carried in the blood.

**Cells:** The body is made up of many tiny biological units or cells – they are the building blocks of the body. They all carry out special jobs such as making insulin (beta cells), carrying oxygen (red blood cells) or transmitting messages (nerve cells).

**Chromosomes:** We each have 23 pairs of chromosomes that contain all of our genetic information (DNA). Cytokines – Molecules produced by cells of the immune system to help them to communicate with each other. They help to orchestrate the activities of the immune system.

**Complications:** Complications are problems that arise as a result of a medical condition. In the case of diabetes, complications include eye disease (retinopathy), kidney disease (nephropathy), nerve damage (neuropathy), coronary heart disease and stroke.

**COBE:** A special piece of equipment which helps separate out islets from donor pancreases.

**Cryopreservation:** A process for preserving tissue for transplantation. Tissues are stored at a low temperature to prevent damage being caused by bacteria or chemical changes.

**Diabetes:** Diabetes (or diabetes mellitus) is a condition in which the amount of glucose (sugar) in the blood is too high because the body is unable to use it properly. This is because the body's method of converting glucose into energy is not working as it should – either because the body is not producing enough insulin (the hormone which controls the amount of glucose in our blood) or because the body's cells are unable to use insulin effectively. There are two principal types of diabetes, Type 1 diabetes and Type 2 diabetes.

**Donated tissue:** Tissue used for transplantation, which comes from living donors or people who have been classified as clinically brain dead. In the case of islet cells, tissue can not be taken from living donors because the process for retrieval would involve destroying the pancreas. This would mean that the tissue donor would develop diabetes.

**Donor:** Some tissues for transplantation may be donated by living donors, such as kidneys or bone marrow. Islets can only be retrieved for transplants from people who have been classified as clinically brain dead. They cannot be transplanted from living donors (see Donated tissue).

**Edmonton protocol:** The procedure for retrieving, purifying and transplanting islet cells pioneered by James Shapiro, Jonathan Lakey and the team at the University of Alberta, in Edmonton, Canada. The protocol also involves giving transplant recipients a cocktail of drugs to prevent their bodies rejecting the new islets. The key innovations of the Edmonton protocol, which is the most successful protocol for islet transplantation so far, include:

- a new technique for purifying and isolating the islet cells before transplantation
- the use of larger numbers of cells than used in previous transplant protocols (each transplant requires on average the islet cells of two donor pancreases)
- the drugs used to prevent rejection do not include steroids (which can damage the islets and may cause insulin resistance), and includes sirolimus (Rapamune), which has never been used in islet transplantation before.

**Encapsulation:** A technique for protecting transplanted islet cells from being attacked by the recipient's immune system. Researchers have experimented by packaging the transplanted islets in a capsule – a kind of molecular tea bag that allows the insulin to diffuse out into the blood stream and allows nutrients into the cells, while at the same time protecting the cells from attack. In theory this technique could minimise, or even overcome entirely the need for drugs to prevent immune attack. However, so far a successful balance between letting insulin out of the capsule and blocking entry by hostile cells has eluded scientists.

**Enzyme:** A specialised type of protein that controls chemical reactions in the body. They are very important; their activities range from controlling the breakdown of food in the gut to helping to send important messages to the inside of cells.

**Gene:** A region along a large molecule called DNA, which is found in every cell, that carries inherited information from parents to their offspring. A gene carries the recipe or code for a particular protein. Proteins are essential components of the body.

**Genetics:** The study of inherited information.

**Genome:** The complete set of chromosomes. In humans the genome involves around 30,000 genes.

**Glomerular mesangium:** Contracting cells in the glomerular structure that help regulate blood flow through the glomerular capillaries and prevent any foreign debris getting stuck in the glomerus.

**Glomerulus:** The main filtration unit of the kidney. Each kidney is made up of thousands of these tiny tubes through which the blood passes. Water and soluble waste are filtered out as urine.

**Glucose:** A type of sugar.

**Glycogen:** The storage form of glucose.

**HbA1c or glycosylated haemoglobin:** This blood test measures your long term blood glucose control over the previous 8-12 weeks. Your diabetes team will advise you on the level which is best for you. For most people this will be 7% or lower.

**Hyperglycaemia:** Hyperglycaemia occurs when the body is unable to process glucose effectively, leading to raised levels of glucose in their blood. If somebody has diabetes, the glucose in their body is not turned into energy, either because there is not enough insulin in their body, or because the insulin that the body produces is not working properly. People with diabetes need to control their blood glucose levels either by diet alone, a combination of diet and tablets or with diet and insulin injections. Left uncontrolled, high blood glucose levels can lead to a dangerous condition called diabetic ketoacidosis, and also greatly increases the chances of developing complications such as eye disease or coronary heart disease.

**Hypoglycaemia:** Hypoglycaemia (or 'hypo') is the medical term for when the level of glucose in the blood falls too low, usually under 4 mmol/l. Treatment is very simple and requires taking some fast acting carbohydrate, such as a sugary drink, followed by a starchy snack such as a sandwich. Left untreated, hypoglycemia will eventually result in the person becoming unconscious.

**Hypo unawareness:** For some people the warning signs that usually accompany hypoglycemia may be lost. This may be as a result of keeping very tight control of blood glucose levels, and research has shown that as people experience hypos more frequently they begin to lose their ability to recognise the symptoms. Although rigorously avoiding hypos can be very effective in reversing problems of hypo unawareness, for some people whose blood glucose is prone to dramatic fluctuations, the problem can prove more intractable. Hypo unawareness was one of the selection criteria used by the team in Edmonton when choosing participants for the islet transplantation research trial.

**Hypo warning signals:** When the level of glucose in a person's blood falls too low the person often experiences 'warning signs', which occur as the body tries to raise the blood glucose level. These warning signs vary from person to person, but often include feeling shaky, sweating, tingling in the lips, going pale, heart pounding, confusion and irritability.

**IDDM:** Insulin dependent diabetes mellitus. Now more commonly known as Type 1 diabetes. The majority of beta cells in the pancreas have been destroyed by the immune system and the person needs regular insulin injections to survive.

**Immunosuppression:** The suppression of the body's defence system against foreign bodies (the immune system), which is necessary in transplantation procedures to protect the transplant from being rejected. This is achieved using drugs.

**Incubator:** A piece of equipment that can be used to contain tissues or organisms in a controlled environment. Incubators can be used in experiments to help grow new islets.

**Insulin:** A hormone produced by the beta cells in the pancreas. It helps the body to control blood glucose levels and to control energy production.

**Islets:** Islet cells are the cells inside the Islets of Langerhans, part of the pancreas. There are three types of islet cells: alpha cells, which produce gut enzymes; delta cells, which act as a support structure for the islet cells; and beta cells, which produce insulin. All of the different types of islet cells are used in islet transplantation.

**Islets of Langerhans:** The Islets of Langerhans are the ribbon-shaped structures within the pancreas which house the insulin-producing beta cells.

**Isolation:** The process by which islets are separated from the other cell types within the pancreas. In the Edmonton protocol, special enzymes were used to

digest the unusable pancreas tissue. A further stage of purification is also required.

**Liver:** The liver is a large organ located in the abdomen, which processes nutrients for use in the rest of the body.

**Lymphocyte:** Small white blood cells that form a critical part of our immune system. There are several different types of lymphocyte including B cells (see B cells) and T cells (see T cells).

**Metabolism:** The process by which we convert the food we eat into the energy that cells in the body need to live.

**Mitochondria:** The powerhouses of the cell that convert glucose (sugar) into energy.

**Monogenic:** Single gene. 'Monogenic' conditions are caused by a defect in a single gene, e.g. cystic fibrosis.

**Nephropathy:** A complication of diabetes that results from damage to the blood vessels in the kidney.

**Neuropathy:** A complication of diabetes that results from damage to the nerves.

**NIDDM:** Non insulin dependent diabetes mellitus. Now more commonly known as Type 2 diabetes. It usually results from reduced insulin secretion together with insulin resistance. It is usually managed by diet alone, diet and tablets, or diet and insulin injections.

**Pancreas:** The elongated organ situated just below the liver, which contains the islets of Langerhans. These in turn house the various islet cells, which include the insulin-producing beta cells.

**Peristalsis:** A series of normal coordinated muscle contractions that occurs automatically, for example to move food through the digestive tract.

**Polygenic:** Several genes. 'Polygenic' conditions are caused by a number of genes.

**Portal vein:** A large vein that carries blood rich in digested nutrients from the stomach, spleen and oesophagus, and into the liver.

**Purification:** The process for preparing islets ready for transplantation. If islets are not carefully purified other potentially harmful material stored within the pancreas might be transplanted with them.

**Rapumane:** Another name for sirolimus, one of the drugs used to prevent the body from rejecting the islet transplants.

**Receptor:** A specialised molecule on the surface or within a cell that recognises and binds other specific molecules or proteins, triggering a response in the cell.

**Retinopathy:** A complication of diabetes that results from damage to the blood vessels in the back of the eye. It can lead to blindness.

**Sirolimus:** Another name for Rapumane, one of the drugs used to prevent the body from rejecting the islet transplants.

**T cells:** These are cells that play a key role in the body's mechanisms for defending itself against foreign bodies (such as bacteria or viruses). Type 1 diabetes is caused by squads of T cells attacking the beta cells in the pancreas, for reasons we do not fully understand.

**Transplantee:** The person who receives a transplant.

**Transplantation:** The process by which damaged cells are replaced with healthy cells from another person.

**Type 1 diabetes:** Type 1 diabetes (also known as insulin dependent diabetes) develops when there is a severe lack of insulin in the body because most or all of the cells in the pancreas that produce it have been destroyed. It usually appears in people under the age of 40, often in childhood, and is treated by insulin injections and a healthy balanced diet.

**Type 2 diabetes:** Type 2 diabetes develops when the body can still produce some insulin, though not enough for its needs, or when the insulin that the body does produce does not work properly. This type of diabetes usually appears in people over the age of 40 and is treated by diet alone, by a combination of diet and tablets or by a combination of diet and insulin injection.

*This Glossary has been reproduced from Diabetes UK's website with the kind permission of Diabetes UK, the charity for people with diabetes.*

*For more information on diabetes call 020 7424 1000 or visit [www.diabetes.org.uk](http://www.diabetes.org.uk)*