

Working together for better diabetes care

*Clinical case for change: Report by Sue Roberts,
National Director for Diabetes*



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Working together for better diabetes care

Partnerships between patients and clinicians and between primary and secondary care are critical to supporting people with diabetes according to Dr Sue Roberts, National Clinical Director for Diabetes.

Introduction

Living with any long term condition is challenging. People with diabetes have to think about what they eat, their physical activity, and whether and when to take up to three or four different types of tablet or insulin injections every single day – as well as coping with the demands and pleasures of friends, family, work and leisure. This is especially hard if you feel and look healthy, as many people with diabetes do. But to stay healthy and avoid complications in the future, they know they must master this juggling act hour by hour. Self management is truly at the heart of living with diabetes.

The challenge for health, social and community services is to provide help and support to enable people with diabetes to do this well. Poorly controlled diabetes can have a profound effect on mood, work, income and lifestyle. It shortens life, and can lead to a range of complications including blindness, heart attacks, strokes, kidney disease, amputation and

depression. So the NHS must also be there, in the right place, at the right time and with the right amount of expertise if things should go wrong.

And there are not just a few thousand people involved in this. In England there are at least 2.35 million infants, children, young people and adults of all ages living with diabetes. This figure is growing daily – partly due to our ageing population and partly because of the effect of our lifestyles on young people. Within three years we expect that figure to rise by 150,000.

This places tremendous demands on the NHS. As my fellow National Clinical Directors have emphasised in their reports, the NHS was set up to deal with people with acute illnesses and has a great track record of getting people back

Diabetes in Numbers

There are an estimated 2.35 million people with diabetes in England. This is predicted to grow to more than 2.5 million by 2010 – 9% of which will be due to an increase in obesity.

It is estimated that around 90% of people with diabetes have Type 2 diabetes.

The incidence of Type 2 diabetes is growing at 15% a year in some areas of the country.

Prevalence of Type 2 diabetes is at least 5 times higher amongst those from a Black or Minority Ethnic background in the UK.

The average patient with diabetes will spend three hours a year with a professional and the remaining 8,757 hours caring for themselves.

There are an estimated 25,000 young people (under 25) with Type 1 diabetes in the UK.

to health. These services are not designed to help people with long term conditions, and this is a particular problem for those with diabetes who often have two or three related conditions like high blood pressure and heart disease to manage simultaneously.

Diabetes affects almost every organ of the body. The NHS has a specialist service for every part, but to get the best health outcomes they need to be fully joined up. People with diabetes don't want to traipse round different departments telling the same story time and again. They also want to be seen as a whole person, not a collection of organs and problems.

So my report is about working together. Firstly, at the individual level, healthcare professionals must work together with patients to support them in choosing the best approach to care for them from the many options available. Secondly, no one healthcare professional will have all the skills and knowledge needed, so professionals themselves must work more effectively in multidisciplinary teams. Thirdly, different organisations must work together as a coherent whole.

We know it can be done, and this report outlines some of the many examples of what can go well. But my challenge to local communities is to make sure it is done for everyone. Services need to be redesigned on a more radical scale.

A quality service

Over the last three decades, research has told us that to achieve the best outcomes you need three things:

1. Patients who are engaged in their own care and empowered to self-manage
2. Diabetes teams that are organised, that plan well and actively seek out people to ensure they get the best care
3. Partnerships between people with diabetes and healthcare professionals to solve problems and plan care

Diabetes: the cost

Personal impact

- In the UK, people with diabetes spend 1.1 million days in hospital each year
- 80% of people with diabetes will die of cardiovascular disease
- Life expectancy is reduced on average by 15 years in those with Type 1 diabetes, and up to 7 years in those with Type 2

Cost to the NHS

- 5% of the NHS budget is spent on treating diabetes and its complications
- This equates to £3.5bn per year, or £9.6m a day

Cost to the individual

- People with diabetes in the UK are spending around £500m per year on coping with their condition
- Social services costs for people with diabetes are around £230m per year

**Organised
proactive
services**



Partnership

**Engaged
empowered
patient**

=

**Better
outcomes**

This ‘better outcomes equation’ needs to be the foundation of services for all people with long term conditions and I believe that the NHS needs to rethink and reorganise itself to achieve this.

The quality challenge

My first experience of what was wrong with the traditional way of organising things was on my very first day as a consultant back in February 1978. The clinic was typical of hospital-based care at that time. There was no diabetes team, and I was expected to see about 45 patients in three hours. There was no time to check important things like blood pressure or to talk about anything in depth. Patients were clearly self managing – because they had no other option – but didn’t have the knowledge and skills to do this safely.

Towards the end of the morning, a middle-aged man who had taken the day off work to come for his five minutes with me, asked me if the sudden loss of vision in his left eye could be anything to do with diabetes. I was shocked. He neither knew that that diabetes can lead to sight loss, nor that this can be prevented by control of blood sugar at safe levels and by regular eye checks to address the earliest sign of trouble. Fortunately an expert eye surgeon was able to operate to partially save the sight in his eye. But the operation was complex and expensive, and he was never able to work again.

I was only one of many people in the diabetes community in the 1980s who recognised that prevention was not just better for the patients but long term much less expensive for the NHS. Services began to change fundamentally.

Diabetes Definitions

Type 1 diabetes develops if the body is unable to produce any insulin. This type of diabetes usually appears before the age of 40. Type 1 diabetes is the least common of the two main types and accounts for around 10% of all people with diabetes.

Type 2 diabetes develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly (known as insulin resistance). In most cases this is linked with being overweight. This type of diabetes usually appears in people over the age of 40, though in South Asian and African-Caribbean people it often appears after the age of 25.

However, recently, more children are being diagnosed with the condition, some as young as seven. Type 2 diabetes is the most common of the two main types and accounts for 90% of all people with diabetes.

Organising services

Innovative specialists, working with equally enterprising primary care teams, led the way by setting up diabetes clinics within GP surgeries. People with diabetes were recorded on registers and called for regular appointments where everything was checked. The majority of diabetes care in England is now delivered in this way. New incentives in the GPs' contract have led to an extra 100,000 people being identified in the last year so they can have the right checks, and in April this year the Healthcare Commission reported that over 85 per cent of registered patients in England are getting the checks they need. This now includes an annual offer of a digital photograph of the back of the eye to detect and then treat the first signs of eye disease. Nearly 80 per cent of people were offered this service in 2006 and we expect this to rise to 100 per cent by the end of 2007.

This kind of service should be available in general practice for the large majority of people with diabetes, but as many as 30 to 40 per cent of people – especially in inner cities – are still having to attend hospital. Southport and Formby started to make changes last September.

Dr Jeff Simmonds, consultant diabetologist at Southport and Ormskirk Hospital NHS Trust, explains: “We want the annual review process to be as easy and convenient for patients as possible. Providing the service on their doorstep at their local surgery is major step forward in achieving this.

“The programme is also freeing-up appointments at the hospital, giving the specialist services the time to focus on more complex cases. Now if a GP needs to refer a patient to hospital following the outcome of their review, the patient will be seen much more quickly rather than waiting months for an appointment.”

David Waugh, Patient Representative and Expert Patient Programme Tutor, is delighted with the changes: “It should make life a lot easier for a great number of people. It can sometimes be difficult for people to travel the distance to hospital for their review. Because the examination will be at the local surgery, there should be a bit more flexibility with appointment times as well.”

Engaging patients

The other part of the better outcomes equation was still lagging behind. The professional thinking on patient engagement changed when we realised we were checking everything but weren't achieving the expected results. In some places 90 per cent of people with diabetes were being tested regularly but only 60-70 per cent were achieving healthy results.

That's a significant mismatch. People with diabetes had more information, and we were developing a structure and process that proactively sought people out, but it wasn't necessarily giving them the skills to self manage.

Healthcare professionals needed new skills too to help them to engage patients in better self management and alert them to risks. Most newly diagnosed middle-aged diabetic patients have a 40 per cent chance of having a heart attack or stroke, and a ten per cent chance of being dead in 10 years – that’s worse than many cancers. Not many people know that because it sounds too alarmist, but not knowing means you have no chance to prevent it happening. Striking this balance between awareness and anxiety is a skill that some clinicians find difficult. This is now changing – the Royal College of Physicians, for example, has produced advice for doctors on how to communicate risk to patients effectively.

One way to present this information in a positive way and give people the skills and confidence to make the changes they need is by attending structured education programmes recommended by NICE. These need to be of high quality to equip the participant with the skills they need for daily life.

For instance the DAFNE programme, or Dose Adjustment for Normal Eating, has revolutionised daily life for people with Type 1 diabetes. Instead of changing eating patterns to fit with the amount of insulin taken, DAFNE gives people the skills to match insulin with the amount of food eaten. One participant wrote

“My bottom line in life is to function and DAFNE gives me that ability. For me, it is not a diabetic treatment initiative, it is my life. It informs my hourly, daily, weekly, monthly, yearly decisions; continually improving my health and my contribution to life. I have lost weight and vastly improved my blood glucose control. Together, DAFNE and I are delivering the best results in diabetic care I’ve experienced in 25 years.”

Programmes like this are also altering the way people with diabetes and the service work together:

“The frameworks that I need to independently self regulate my actions are in place. My attitude to the previously passive experience of going to clinic 12 for a review has radically changed. I now want to know what my test results are and explain to the professionals what I am up to – at last meaningful dialogue?”

In the last five years, we’ve learnt that people with long term conditions often learn best from each other, particularly when healthcare professionals are there to provide specific knowledge and support.

Tim Taylor was diagnosed with Type 2 diabetes two years ago. A visit to his local GP to sort out a knee injury led to the diagnosis.

“I didn’t realise how bad the condition was until I was diagnosed and read up on it. I was convinced I would go blind, have my leg amputated or even be dead with months. I was on the verge of depression,” Tim explained.

Instead the 47-year-old from Leicestershire got involved in DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed), a programme which uses group education to help people newly diagnosed with Type 2 diabetes to acquire the skills required to manage their condition.

Tim's wife went with him because she didn't think he would go otherwise, and he was immediately surprised at how "down to earth" and easy to understand the course was.

"It was very personal, in my home town and it has made a real difference to my life. It gave me the confidence to manage my diabetes – I don't fear it anymore."

Tim now exercises more, and eats more healthily. The result is he has good control over his blood glucose and can sometimes forget his condition and push the boat out a bit.

However, the Healthcare Commission recently found that only 11% of people with diabetes in England had been on an education course. We need to start providing education on an industrial scale if we are going to move from the traditional didactic approach and start working in partnership with patients to give people with diabetes the practical skills to become experts at managing themselves.

Self care has been helped enormously by advances in technology. The patients I met in my first clinic had to do a minor chemistry experiment to assess sugar levels. Urine was heated up and the colour compared against a table of sugar levels. It was a nightmare for people.

Since then a range of testing strips and meters has been produced that take less than a minute to use. But there's no point just throwing technology at the issue – people with diabetes still need information and support.

Providing we remember this, the world of technology holds great promise for people with long term conditions. We are just at the start of learning how to use the telephone, the internet and mobile phones to share information in new ways, increase the options of support for individuals and provide better quality, better value care.

Partnerships with patients

This new emphasis on skills training is designed to give people a personal understanding of diabetes and the confidence to control it efficiently and effectively. That inevitably leads to a very different relationship with healthcare professionals.

The process of care planning is one way to respond to this. We're working towards challenging targets. The National Service Framework said that everyone with diabetes must have a personal care plan by 2013. The White Paper *Our health, our care, our say* brought this deadline forward to 2010.

In the past, a care plan was when a doctor told a person what to do.

Each of us has our own ideas about our health and how we would like to be looked after. These ideas may not be the same as the doctor or nurse's agenda. We all need a chance to share these thoughts with the health care team looking after us. Being told what to do feels uncomfortable for most people! Care should be agreed not imposed (Respondent to 'Diabetes Dialogue')

The NSF agrees, describing a care plan as *'at the heart of a partnership approach to care and a central part of effective care management. The process of agreeing a care plan offers people active involvement in deciding, agreeing and owning how their diabetes is to be managed'*

Now we want to see patients armed with their own test results, talking to clinicians on equal terms, about their priorities and concerns, causes, consequences and treatment. As one of my colleagues never ceases to remind me, 'what patients need is a good listening to!'

This approach is already being piloted in Northumbria – as this case study shows.

Working together

During the 1990s, while primary care was showing it could provide systematic routine care for large numbers of patients, multidisciplinary specialist teams began to expand and appoint specialist nurses dieticians, podiatrists and sometimes – but not often enough – psychologists. The expertise they developed and began to share sometimes dramatically altered the life of those patients they met. Diabetes facilitators working alongside them began to transfer this expertise to others in the diabetes community. As more and more routine care was provided by others, this allowed the specialists more time to do what they are trained for: advising on complex care and problems that arise outside the usual experience.

People with diabetes point out that getting rapid specialist advice when they need it is just as important as good routine care. And as David Colin-Thomé noted in his report, nowadays we have the opportunity to bring the specialist to the patient, rather than the other way round.

Northumbria care planning pilots

In place of a traditional annual review patients had all the relevant tests completed with a healthcare assistant and the results were posted to them prior to their care planning appointment. The practitioners were trained to elicit the patients' agenda and agree priorities and goals in collaboration with the patient. This was assisted by a prompt sheet accompanying the results that encourages involvement in the consultation and listing of concerns or questions.

An evaluation of a total of 70 patients indicated very high levels of satisfaction with the process (91% response rate; 98% reported finding it helpful to have the results of the consultation; 98% felt more involved in the decision making.)

One patient said it *'gave me a chance to think about my diabetes and what I could do to improve things'*

Linda Helmore, the practice nurse involved in the pilot wrote *'it may take a little bit longer, but it is time well spent'*

This process has now been adopted as the standard model of diabetes care in Burn Brae surgery and a number of other practices in the area are taking it on.

Professionals who have tried this approach have improved their working lives too. Dr. John Dean, a consultant diabetologist in Bolton, has been working on breaking down the barriers between primary and secondary care since 1994. He and other health professionals across the Bolton Diabetes Centre redesigned the way the area cares for people with diabetes based on two simple principles: i) the condition needs daily management and ii) healthcare professionals have to work together to achieve that objective.

The roles of hospital-based specialists such as consultants, diabetes specialist nurses and dietitians have been changed along with the roles of practice nurses, community dietitians and podiatrists. Consultant physicians and other specialist groups now work from a centre in Bolton town centre where they co-ordinate care, education and training across primary and secondary care. That involves collaborative working, joint clinics and networking with host organisations, agencies, voluntary groups and individuals involved in the care of people with diabetes.

Most care now takes place in primary care and GPs opt to provide one of five levels of service depending on the appropriate level of competency they have in their practice. Referral at the point of diagnosis is now comparatively rare, leaving specialists at Bolton Diabetes Centre free to deal with the most complex cases.

Dr. Dean said: “This is the sort of thing specialist staff want to do. But often service commissioners don’t think they will be willing to do it or acute trusts can’t see the benefit of their staff working outside the hospital.

“Physically taking specialists out of the hospital has made a major difference. Patients find us more approachable and because they are not going to hospital they see coping with diabetes as an exercise in staying well, not being ill. Being based in the town centre means it is easier for them to pop in for advice. And the primary care staff are much happier to be trained by us and use our experience. Simply by coming outside the hospital we’ve removed a major barrier to team working.”

Dr. Dean added: “Now both the PCT and the Royal Bolton Hospital employ consultant diabetologists and we all move seamlessly from hospital ward rounds to consultation in GP practices and dealing with complex cases from the centre.”

I would like to see all diabetes communities think much more radically about new approaches to care, some of which might involve new partnerships. There are already many successful examples of diabetes communities that include independent providers. The involvement of high street pharmacies in an integrated model of care in Hillingdon is one example.

The benefits of partnerships with community groups has been demonstrated in Leamington where, working with the Sikh community, South Warwickshire Primary Care Trust supported the *Apnee Sehat* (Our Health) project. This has seen the ‘Temple to Table’ initiative lead to whole sale change in cooking practice throughout the community,

including in local restaurants. Temple leaders are involved in encouraging and leading local walking programmes. My view is that this is just as much a part of healthcare as a hospital outpatient appointment, and has the potential to benefit many more people all at once.

Planning together

But working together can only deliver quality care to everyone if the right services are already in place. Resources need to move around the health economy to respond to ever

Commissioning with networks – using the Diabetes Commissioning Toolkit in Hereford

When a new specialist team was appointed in Hereford a couple of years ago, they wanted to do things differently. Working in a reenergised network, they were able to plan supported discharge of around 30% of patients attending hospital clinics to primary care. 86% of patients now receive all their routine care in the community.

To change things even further, the Hereford network – which includes the commissioners – applied to pilot the Diabetes Commissioning Toolkit earlier this year. Recognising that sound commissioning is based on comprehensive local needs assessment, they pulled together all the local data on diabetes they could find. They ran a visioning workshop bringing many people who had never talked together, worked together and certainly hadn't planned together. Over one third of the 50 attendees were people with diabetes.

Using this national resource they identified gaps in support for self management and education, in children's services, and in local awareness of diabetes. They realised savings could be made and quality improved by bringing distant specialist services closer to home and improving staff training.

This inclusive process has enabled the commissioners to understand the direction the local community wants to take. Within a month, they were supporting a variety of work streams to define a new model of diabetes care in its entirety. Everyone feels involved and is looking forward to working differently.

changing but clearly defined local needs. As new approaches begin to improve health, the needs of the population will change and services will have to adapt. John Dean points out that after three years of close working with primary care, many more practices were able to start patients on insulin themselves and look after people with Type 1 diabetes. Their skills had advanced, so the focus of the specialist team needed to change too.

The new national guidance on commissioning emphasises that commissioning itself must ensure that there is an inclusive design process that involves those that use the service and clinicians with both specialist and generalist interest. The Diabetes NSF established the principle that diabetes networks were the ideal place to be the hub of this activity. The NSF emphasised that a robust needs assessment based on hard data is the first step in quality commissioning.

The National Diabetes Support Team worked closely with the Primary Care Diabetes Society and other partners to produce a Diabetes Commissioning Toolkit, which gives commissioners detailed information about how to do this. It is already proving to be a useful and practical way for everyone to get involved. As the Hereford example describes, it includes all the information sources, linked to web tools, on how to do a local needs assessment. It also outlines all the components essential to a diabetes service, with national

quality indicators and outcome measures that commissioners might put in their specifications, following local consultation. It's all in there, from guidance on structured education and care planning to how to commission a specialist foot or maternity service.

Too much of network activity has been about tweaking around the edges of real service change. Often local plans have been quite small in scale: a new education programme here, a new foot service there. Meeting the challenge that this paper poses will need a whole scale rethink in many places.

Diabetes communities can work with local people to deliver this radical change, and new providers can be part of that. One of the priorities needs to be targeting tailored services to key communities of people at risk of poorer outcomes, such as those from black and minority ethnic or economically deprived groups. This approach – which was pioneered so successfully for people with diabetes in Slough – could be used with increased imagination in many long term conditions elsewhere.

Networks bring together a range of people from different disciplines with a mix of expertise. They can bring large numbers of people with diabetes into the process and achieve direction and action that can support commissioning of major change.

Roles of networks

- Planning together – to support commissioning
- Working together – to coordinate provision
- Using information to support both

Primary Care Trusts and GPs need to use local networks to reshape diabetes services and support them in commissioning quality services. I believe that if we are going to achieve the full potential of the National Service Framework, and all the services underpinning the better outcomes equation, local commissioners must look to diabetes networks not just to coordinate services but to support their health needs assessment and actually redesign services with the patient at the centre.

Conclusion

A few weeks ago the Journal of the American Medical Association reported that stem cell researchers had successfully suppressed the immune systems of 15 people with Type 1 diabetes with bone marrow stem cells. This meant some of the group didn't need insulin for up to 35 months and led to predictable headlines: "Stem cells could spell end of diabetes".

I'm sure many people with diabetes would welcome such a discovery. We all dream of a drug or treatment that might have a miracle effect for people with diabetes. But until that day comes we have to continue to focus on reconfiguring services around the best possible clinical evidence. At present, that means increasing support to people with diabetes in the community to help them manage their condition effectively and efficiently. The key is

proactive care, structured skills training and joint decisions backed by diabetes networks with no boundaries between primary and secondary care.

Redesigning health systems is about achieving better quality care. This approach puts into practice everything we have learned and opens the door to innovation. It is not about reducing access to professionals because the NHS is strapped for cash. It is driven by the desire to give the rapidly increasing numbers of people with diabetes in England the best, most joined-up care possible.



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