

The Diabetes Information Jigsaw

Report investigating information access for people with diabetes



Seek knowledge for informed choice and better health

Developed by the Association of the British Pharmaceutical Industry
Diabetes UK and Ask About Medicines – July 2006



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Crynodeb

Mae yna wyth mlynedd ers cyhoeddi'r adroddiad arloesol *UK Prospective Diabetes Study*,¹ ble pwysleiswyd yr angen am reolaeth gaeth o lefel glwcos y gwaed, ond degnys y canlyniadau diweddaraf bod lefel cymhlethdodau yn sgil diabetes yn dal yn uchel. Ar hyn o bryd, mae bron i £1 o bob £10 sy'n cael ei wario gan y Gwasanaeth Iechyd yn mynd tuag at drin diabetes a chymhlethdodau cysylltiedig, megis clefyd y galon, dallineb, methiant arenol, a thorri i ffwrdd troed neu waelod y goes. Gellir osgoi llawer o'r cymhlethdodau hyn trwy gyfuniad o brofion glwcos rheolaidd, cynlluniau i reoli'r afiechyd, diet priodol, ymarfer corff a meddyginiaeth, ond dengys adroddiadau bod llai na 1 o bob 5 o bobl yn cydymffurfio gyda'u cynlluniau rheoli diabetes².

Mae angen mwy o ymateb gweithredol gan bobl sy'n dioddef diabetes nag unrhyw gyflwr cronig arall. Hunanofal yw hyd at 95% o ofal diabetes, a hynny wrth gwrs trwy gydol oes y claf, ac mae pobl angen nifer o sgiliau a gwybodaeth er mwyn eu galluogi i reoli eu cyflwr o ddydd i ddydd a newid eu hymateb pan mae eu sefyllfa yn newid. Mae'n destun pryder bod mwy o bobl iau yn dioddef diabetes Math 2, a bydd cydymffurfiaeth hirdymor gyda chynlluniau rheoli iechyd yn ffactor cynyddol pwysig.

Blaenoriaeth llywodraethau yw sicrhau bod rôl y claf yn greiddiol i ofal diabetes³.

Fodd bynnag, methwyd cwrdd targedau allweddol i ddarparu strwythur addysg a hyfforddiant hunanreolaeth i bawb sydd â diabetes erbyn diwedd 2004 yng Ngymru ac erbyn diwedd 2005 yn Lloegr. Dengys adroddiad diweddar gan brif elusen diabetes Prydain, Diabetes UK, y bu rhywfaint o gynnydd (yn enwedig o ran datblygu rhaglenni addysg strwythuredig), ond bod angen gwneud llawer mwy.

Mae'n destun pryder bod dros hanner y bobl sydd â diabetes yn dioddef iselder oherwydd eu cyflwr⁴. Mae ymchwil yn cadarnhau hefyd bod iselder yn rhwystro cryn dipyn ar allu pobl i reoli eu diabetes, a gall hyn arwain at ddirywiad o ran rheoli lefel glwcos y gwaed, a'i gwneud hi'n anoddach iddynt ddilyn rhaglenni triniaeth, diet ac ymarfer corff.

Mae gan y meddyginiaethau a ddefnyddir i drin diabetes rôl allweddol o ran cadw lefel glwcos y gwaed dan reolaeth a chynorthwyo pobl i gadw cymhlethdodau eraill cysylltiedig dan reolaeth. Ond yn aml, ymwybyddiaeth isel sydd gan bobl o ba driniaethau sydd ar gael a pha feddyginiaethau maent yn eu derbyn. Mae angen i weithiwr iechyd proffesiynol helpu pobl sydd â diabetes i ddeall difrifoldeb eu cyflwr a'u cynorthwyo i wneud penderfyniadau mwy deallus ynglyn â chymryd meddyginiaeth.

Canfu *Arolwg Jig-so Gwybodaeth Diabetes*⁵, a gomisiynwyd ar y cyd mewn partneriaeth gan yr ABPI, Diabetes UK ac Ask About Medicines, nad yw 58% o'r bobl sy'n gwybod bod ganddynt ddiabetes yn deall beth mae'r diagnosis yn ei olygu, ac nad yw traean ohonynt yn gwybod pa gwestiynnau i ofyn i'w gofalwyr. Yn ogystal â hyn, doedd 60% o'r cleifion a holwyd ddim yn deall pa wahanol feddyginiaethau sydd ar gael, a doedd nifer ohonynt ddim yn deall beth roedd eu gweithwyr iechyd proffesiynol yn ei ddweud wrthyt na'r iaith a ddefnyddir mewn llenyddiaeth. Mae hyn yn arwain at rwystredigaeth, iselder a theimlad o ddiymadferthedd. Canfu'r adroddiad hefyd mai dim ond 17% o'r bobl sydd â diabetes sy'n derbyn gwybodaeth ynglyn â'u diabetes bob tro maent yn derbyn presgripsiwn.

Y mae angen felly i weithwyr iechyd proffesiynol rymuso eu cleifion i geisio gwybodaeth am y meddyginiaethau maent yn eu defnyddio i drin eu diabetes. Bydd grymuso pobl sydd â diabetes i ddeall eu cyflwr yn eu galluogi i wneud penderfyniadau deallus ynglyn â pha feddyginiaeth briodol sydd ei angen arnynt i wella eu hiechyd yn y pen draw. Trwy gynyddu gwybodaeth ynglyn â diabetes ac annog pobl i ofyn cwestiynnau, byddant yn deall eu cyflwr a'u meddyginiaeth yn well, a bydd hyn yn arwain at well cydymffurfiaeth gyda rhaglenni triniaeth ac yn caniatáu i bobl sydd â diabetes i reoli eu cyflwr.

Mae'r adroddiad yma felly yn cefnogi mabwysiadu agwedd newydd tuag at ddarparu gwybodaeth i bobl sy'n cael eu heffeithio gan ddiabetes. Mae'n annog cynnwys gwybodaeth fwy penodol ar brescripsiynau ynglyn â sefyllfa bersonol y claf a'r gwasanaethau sydd ar gael yn lleol. Mae angen i bobl sydd â diabetes gymryd rhan fwy gweithredol wrth gwrdd â'u meddygon er mwyn gwella eu cyflwr a safon byw. Gellid cyflawni hyn trwy annog pobl i ofyn cwestiynnau a pharatoi ar gyfer eu hymgyngoriadau, a thrwy awgrymu cwestiynnau y gallant eu gofyn i'w gweithwyr iechyd proffesiynol ac wrth chwilio am wybodaeth o ffynonellau eraill. Byddai darparu set o gwestiynnau yn rhoi'r arfau a'r hyder i bobl ddeall eu cyflwr a'u triniaeth yn well. Y nod yw gwneud y wybodaeth a ddarperir i bobl sy'n cael eu heffeithio gan ddiabetes yn fwy perthnasol i'w anghenion a'u sefyllfa benodol. Gall pobl sy'n deall eu cyflwr wneud penderfyniadau gwell ynglyn â'u hiechyd, gan gynnwys cytuno a chydymffurfio gyda strategaeth rheoli diabetes sy'n effeithiol iddynt. Ac ar hyn o bryd mae'r ddarpariaeth wybodaeth i grwpiau ethnig lleiafrifol (mae diabetes bum gwaith yn fwy cyffredin ym mysg y grwpiau yma na gweddill y boblogaeth), plant, pobl ifanc, a mamau beichiog yn bytiog, a byddai'r ymdriniaeth fwy personol a ddisgrifir yn fwy o help o bosib – ac yn helpu i lenwi'r darnau coll yn y jig-so gwybodaeth diabetes.

Executive Summary

Eight years on from the first report of the groundbreaking UK Prospective Diabetes Study,¹ which emphasised the need for tight blood glucose and blood pressure control, latest findings show that complications from diabetes are still high. Currently, almost £1 in every £10 spent by the NHS goes towards treating diabetes and its complications, which include heart disease, blindness, kidney failure, and amputations of the foot and lower leg. Many of these complications can be prevented by a combination of regular blood glucose testing and a management plan comprising appropriate diet, physical activity and medication, yet reports show that less than 1 in 5 people comply with all aspects of their management plan².

More than any other chronic condition, diabetes requires a great deal of active input from people themselves. As much as 95% of diabetes care is self-care, and over the course of a lifetime, people will need a variety of skills and knowledge to enable them to control their condition on a day-to-day basis and to modify their approach when circumstances change. Worryingly, people with Type 2 diabetes are also getting younger, so that long-term compliance to health management plans will become increasingly important.

The government has made patient-centred care for diabetes a priority³. However, key deadlines have already been missed for structured education and self-management training for all people with diabetes by the end of 2004 in Wales and by the end of 2005 in England. A recent report by the UK's leading diabetes charity, Diabetes UK, shows that while some progress has been made (most notably in the area of structured education programmes), much more still needs to be done.

One of the most worrying impacts of this is that more than half of people with diabetes are depressed because of their condition⁴. Research also confirms that depression greatly reduces the ability of people with diabetes to manage their condition, which can result in poorer control of blood glucose, and difficulty in sticking to exercise, diet and treatment programmes.

The medicines used to treat diabetes are vital in keeping blood glucose levels under control and in helping to stabilise any other complications that result from the condition. People's understanding of the treatment options available and of the medicines they have been prescribed is often very low. Healthcare professionals need to help people with diabetes understand the seriousness of their condition and support them to make better informed decisions about medicine-taking.

A partnership between the ABPI, Diabetes UK and Ask About Medicines commissioned the *Diabetes Information Jigsaw Survey*⁵, which found that 58% of people diagnosed with diabetes do not know what the diagnosis means and over a third do not know what questions to ask those who provide their care. In addition, 60% of patients with diabetes do not understand what different medicines are available, and many do not understand what their healthcare professional is telling them or the language in which the literature is written. This leads to a feeling of frustration, depression and helplessness. The report found that only 17% of people with diabetes receive information about their diabetes treatment every time they are given a prescription.

Therefore, there is a need for healthcare professionals to empower people with diabetes to seek knowledge about the medicines that they use for the treatment of diabetes. Empowering people with diabetes to understand their condition will result in them making an informed choice of the appropriate medication that is needed to ultimately lead to better health. By increasing knowledge about diabetes and being encouraged to ask questions, people with diabetes will understand their condition and medications better, which would result in improved compliance with their treatment programmes and people with diabetes staying in control of their condition.

This report therefore supports a new approach to information provision for people affected by diabetes. This approach involves the use of personalised information prescriptions that focus on individual circumstances and locally available services. To manage their condition and improve their quality of life, people with diabetes need to take a more active part in their interactions with their doctors. This could be achieved through encouraging more people to ask questions and to prepare for their consultations, and through suggesting questions that they could ask their health professional and in their own information searches. Providing a set of questions to ask could give people the tools and the confidence to understand their condition and its treatment better. The aim is to make the information provided to people affected by diabetes more relevant to their own particular needs and circumstances. People who are well informed about their condition are equipped to make better decisions about their health, including agreeing and sticking to a diabetes management strategy that works for them.

This more personalised approach may also be helpful in supporting black and minority ethnic groups, in which diabetes is up to six times more prevalent than in the general population, and children, adolescents, and pregnant mothers, for whom information provision is patchy – thus filling in the missing pieces of the diabetes information jigsaw.

Diabetes in the UK today

The 2005 annual State of the Nations report classed diabetes as one of the greatest health challenges facing the UK today⁶. Since 1996, the number of people within the UK with a diagnosis of diabetes has increased from 1.4 million to over 2 million. Another three quarters of a million people are believed to have the condition without yet being aware of it. The number of people with diabetes is set to rise as our population ages and more of us become overweight. Deaths from diabetes are predicted to rise by 25% over the next 10 years.

Nation	Type 1	Type 2	Total number
England	211,000	1,555,000	1,766,000
Scotland	20,000	147,000	167,000
Wales	13,000	104,000	117,000
Northern Ireland	7,000	46,000	53,000
UK	251,000	1,852,000	2,103,000

Table: Diabetes in the UK today⁶

People with diabetes are also getting younger. According to Simon O'Neill, Director of Care and Policy for leading diabetes charity, Diabetes UK, as many as 1,500 children in the UK are now estimated to have Type 2 diabetes. These young people may face serious health problems within only a few years.

If not properly controlled, diabetes can lead to serious complications, including heart disease, stroke, blindness, kidney failure, and amputations of the foot and lower leg. Currently, almost 10% of the NHS budget is spent on treating diabetes⁸. People with diabetes spend 1.1 million days in hospital each year – mainly to deal with the long-term complications of the condition.

Many of these complications are considered to be preventable. Findings from the groundbreaking UK Prospective Diabetes Study (UKPDS)^{1,9} emphasise that tight control of blood glucose and blood pressure levels can markedly reduce the risk of developing complications, yet complication rates remain high. The latest data to be released from this long-running study show that around a third of patients develop kidney impairment within 15 years of diagnosis¹.

People with diabetes can be supported to manage their condition and can lead long and healthy lives. The UKPDS recommends regular blood glucose monitoring and appropriate use of available medications, along with diet and physical activity, as a means of maintaining control of the condition. As with many other long-term conditions, most of the burden falls on the person with diabetes and their family.

As much as 95% of diabetes care is self-care¹⁰ and, over the course of a lifetime, people with diabetes will need a variety of skills and the knowledge to enable them not only to live with their condition on a day-to-day basis but to cope when crises occur. However, many people still find that the information and support that they require to maintain their health is not readily available.

A condition with a high need for information

The need for high-quality structured patient education was one of the key themes of the recent Diabetes Dialogue, an online consultation managed by the Hansard Society.

“We cannot stop the rising numbers of people with Type 2 diabetes but we can act to limit the complications. A key point to this, however, is motivation. There is a need to educate healthcare professionals and patients alike to look ahead, rather than just focusing on short-term achievements such as reducing blood sugar levels.”
David Levy, Consultant Diabetologist.

The aim of patient education is for people with diabetes to improve their knowledge, skills and confidence, enabling them to take increasing control of their own condition and to integrate effective self-management into their daily lives. High-quality structured information on medicines can have a profound effect on biomedical outcomes, and can significantly improve quality of life and satisfaction. Everyone with diabetes needs to be provided with information on medicines, as they need to effectively manage their condition, because 95% of diabetes management is self-care.

However, recent research has highlighted that people with diabetes are not always able or encouraged to find the information that they need about medicines in order to manage their condition effectively. In order to understand this issue better, a partnership between the ABPI, Diabetes UK and Ask About Medicines commissioned the *Diabetes Information Jigsaw Survey*⁵. This survey found that nearly 60% of people with diabetes do not fully understand the meaning of their

diagnosis or as much as they would like about the medicines that are available to treat their condition. Furthermore, more than a third don't even know what questions to ask in order to find out more about their treatment options.

This research also revealed that only 35% of people with diabetes take their medicines as prescribed and 1 in 3 people don't understand what their insulin or tablets are for or how to take them because they feel stupid asking questions.

A diverse condition

One of the major barriers to the understanding of diabetes is the diversity of the condition. Diabetes exists in two main forms: Type 1 and Type 2. Although both relate to the inability of the body to control glucose levels effectively, they affect people in different ways, have different causes and require different management strategies (see box). In addition, some women also suffer from gestational diabetes in which blood glucose levels increase to dangerous levels during pregnancy. By 2010, it is predicted that 3 million people in the UK will have diabetes, which is more than 5% of the population⁷.

	Type 1	Type 2
Occurs because:	Body is unable to produce insulin	Amount of insulin produced by the body is not sufficient for need, or insulin produced does not work properly
Cause:	An autoimmune condition – can be genetic	Often a consequence of being overweight as body struggles to cope, or of getting older. Numbers are rising rapidly. Strong genetic tendency
Who is usually affected:	Younger people (under 40 yrs)	Traditionally middle-aged and above but population getting younger
Treatment:	Require insulin from onset	Managed initially through improved diet and increased physical activity. Tablets, and later on insulin, are often required as the condition progresses

Box: Diabetes is a diverse condition

Some people with diabetes have commented on the confusion that surrounds these two types of diabetes and how the information available is not always suitable for both types¹¹.

A changing condition

People diagnosed with diabetes will have to live with the condition for the rest of their lives. As Type 2 diabetes is now increasingly being identified at a younger

age, new problems are emerging. Not only will people's treatment need to change as their condition progresses and if complications develop, but people with diabetes and the healthcare professionals who manage them will need to keep themselves up-to-date about new medications and approaches to care.

Widespread complications

With diabetes, high levels of glucose in the blood can affect the body in many different ways and lead to a wide variety of seemingly unconnected complications, as follows:

- Slow healing of wounds
- Impotence / erectile dysfunction
- Heart attacks
- Kidney damage / failure
- Stillbirth / congenital malformations
- Strokes
- Blindness
- Amputations
- Death

Although some people may be fortunate enough to escape these complications, about 1 in 5 of those living with diabetes will experience two or more complications, further complicating their treatment plan¹².

However, studies commissioned by Diabetes UK show that more than a third of people with diabetes are unaware that they will have the condition for life¹⁰ and that only just over half of people understand that diabetes can reduce life expectancy¹³. The *Diabetes Information Jigsaw Survey*⁵ investigated this issue further and established that 1 in 5 people with diabetes think it is not very important to take their prescription, as most are not aware of the complications of not managing their condition:

- 81% do not realise that stillbirth / congenital malformations could be a result of not adequately managing their condition during pregnancy
- Half do not realise that erectile dysfunction could be a complication of not adequately managing diabetes in men
- 40% do not realise that stroke could be a complication of not managing their condition
- 30% do not realise that kidney failure can be a complication of not managing their condition
- Almost a third (32%) do not realise that heart disease is a common complication of diabetes
- Almost a fifth (18%) do not realise that amputations could be a result of not managing their condition
- Nearly 1 in 10 (9%) do not know that blindness could be a complication of not managing their condition

Polypharmacy

Many people with diabetes are prescribed many different medications, especially if they develop kidney or heart problems. Polypharmacy is therefore a common problem for people living with diabetes for long periods. According to Simon O’Neill from Diabetes UK, “people with Type 2 diabetes often need to control their blood glucose, blood pressure and other cardiovascular risk factors to prevent complications and death. To do this many need to take several glucose lowering tablets, up to three blood pressure tablets as well as lipid lowering agents every day,” he explained.

Many callers to the Diabetes UK Careline are concerned about diabetes medications, especially about when to take their tablets and whether they will clash with other medications that they are already taking. People also seek clarification on side-effects and the contra-indications that are listed in package inserts. The prescribing of statins is a leading concern, with many people with diabetes unclear as to why they were given them and whether they should continue to take them.

Some people with diabetes have commented about how prescriptions tend to be written at the end of a consultation, with no time left to discuss how the medication should be taken or to ask questions¹⁴. Findings from the *Diabetes*

*Information Jigsaw Survey*⁵ confirm that only 17% of people with diabetes receive information about their diabetes treatment every time they are given a prescription and 8% receive no information at all from their healthcare professionals.

Carol Williams, Head of Care Support at Diabetes UK, agrees that medicines advice for people with diabetes can be poor. “Few people with diabetes are given a detailed explanation about the medicines they are given and how they work. There is much confusion, particularly around the need to take medicines regularly and consistently,” she said. “Few people are told how to use their medications appropriately to help them stay well.”

Multidisciplinary care

One consequence of the range of complications associated with diabetes is the number of specialists involved in the care of someone with diabetes. A patient with uncontrolled diabetes may need to keep in regular contact with an eye specialist, a podiatrist, cardiac and kidney specialists, as well as their consultant diabetologist, a dietitian, their GP and local diabetes care nurse. Maintaining a consistent approach to management and making sure that people with diabetes get the information that they need can be difficult. Given the number of different individual healthcare professionals who will be involved over a period of 20-plus years, it is clear that the person with diabetes needs to be the true custodian of their care.



Lack of awareness

Few people are aware of how their lifestyle is putting them at risk of diabetes and of how serious the condition can be. A recent MORI poll commissioned by Diabetes UK shows that only just over half of people understand that diabetes can shorten life, and that less than half had grasped the fact that it could kill¹³. Interviewees who fell into the ‘at risk’ category for diabetes thought themselves far more likely to develop heart disease (30%) over their lifetime than diabetes (18%).

Many people who have been diagnosed with diabetes also fail to realise the seriousness of their condition. This is in part because diabetes in its early stages

is a 'silent condition', in which cells are being damaged long before clinical symptoms are seen or recognised. The complications of diabetes can often take many years to develop and it is not always easy to convince people of the hidden damage that is happening to their bodies. For example, the *Diabetes Information Jigsaw Survey*⁵ established that only half of people with diabetes are aware that impotence or erectile dysfunction is a possible complication of diabetes in men when in fact, up to 50% of men with diabetes experience erectile dysfunction¹⁵.

Furthermore, Type 2 diabetes is now second only to cigarette smoking as the major causative factor in cardiovascular disease and people with diabetes have as high a risk of having a heart attack as people without diabetes who have already suffered a heart attack. However, a third of people with diabetes do not realise that heart disease can be a complication of their condition.

Simon O'Neill, from Diabetes UK, feels that many doctors are still playing down the seriousness of the diagnosis. "Diabetes UK's Careline regularly receives calls from people who have been told by their healthcare professionals that they have 'mild' diabetes or 'a touch of diabetes'," he says. "Diabetes should always be taken seriously – it is the biggest cause of kidney failure, the leading cause of blindness in adults of working age, and one of the biggest causes of lower limb amputation in the developed world." Carol Williams, also from Diabetes UK, agrees. "Many people do not understand their condition and think that because they are diet-controlled, their diabetes is mild and they do not have to think about it."

Short-termism is a great enemy of good diabetes care. Many people struggle to realise the importance of complying with their medications, especially if the consequences of their treatment are not immediately apparent. Young people in particular, are prone to not thinking about the future, and there have been reports of complications developing in individuals in their early 20s due to teenage non-compliance with insulin treatment.

Need for self-management / complicated treatment pathways

As with many life-long conditions, the most important person in diabetes care is the person with diabetes themselves.

Diabetes can be a complicated condition to manage. Individuals are required to monitor the level of glucose in their blood or urine regularly and to modify their behaviour if levels are too high or low. Factors such as a cold or flu, an unusual amount of exercise, stress or a variation in their normal carbohydrate intake can all require usual treatments or food regimes to be adjusted. It is often

difficult for people with diabetes to understand the relationships between the different aspects of diabetes management.

Blood glucose monitoring is the cornerstone of diabetes self-management. Blood glucose testing strips prescribed in general practice cost the NHS £130 million per year, but worryingly, the Department of Health's latest report on diabetes care states that there is evidence of potential over-use of these testing strips due to insufficient understanding about their use in good management of blood glucose levels⁸.

There is a wide range of medicines available for the treatment of Type 2 diabetes and these too may need to be adjusted or treatment may need to be changed to bring blood glucose levels within acceptable limits. People with diabetes need to be helped through the complicated 'step-up' approach to the management of Type 2 diabetes, which progresses from lifestyle modification alone, through the use of oral medications and finally onto insulin.

Compliance with diabetes medication is known to be poor, with one study showing that only 1 in 3 people with Type 2 diabetes on oral medication or treatment took their tablets regularly, as instructed¹⁶. Compliance dropped to around 1 in 8 among people taking two or more medications daily. Findings from the *Diabetes Information Jigsaw Survey*⁵ have shown that nearly 1 in 5 people with diabetes think it is not very important to take their insulin or tablets everyday according to their doctor's or nurse's instructions.

Poor compliance with complex medication regimens is a major obstacle to improving the long-term health of people with diabetes. Reports show that fewer than 1 in 5 of people with diabetes (19.4% of those with Type 1 and 16.2% of those with Type 2) comply with all aspects of their management plan². The reasons for this vary, but 1 in 6 people taking tablets to control their diabetes feel that their treatment is too complicated, whereas 1 in 3 say that they are tired of complying with their medication regimen. Teenagers and young adults are particularly poor at complying with diabetes management plans for a number of reasons, including a desire to fit in with their peers, a wish for independence and the physical, emotional and social changes that they are going through¹⁴.

- Confusion regarding Type 1 and Type 2 diabetes
- A high degree of self-management required
- Information needs change as the condition and complications develop
- Complicated treatment pathways – polypharmacy, poor compliance
- Lack of awareness of seriousness of diabetes
- A tendency towards ‘short-termism’
- A wide range of possible complications
- Often associated with other diseases
- Multiple healthcare professionals involved

Box: Diabetes – a condition with a high need for information

What do people with diabetes want?

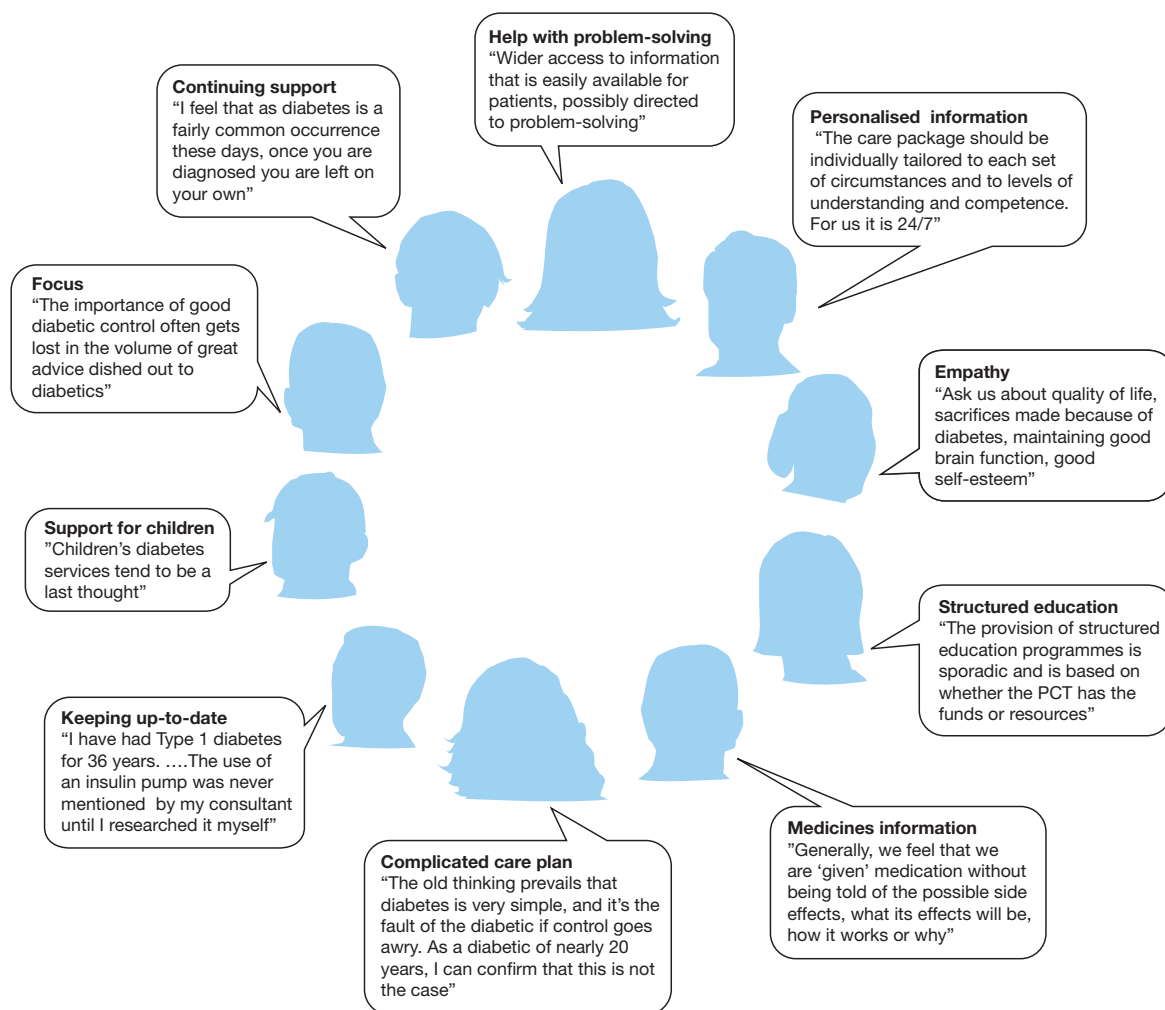
The demand for information from people affected by diabetes is high. Diabetes UK receives over 45,000 diabetes-related enquiries to its telephone Careline and over one million people visit its website each year. A look at the information requests to its Careline over the first five months of 2006 shows that the most frequent requests were from people who were newly diagnosed, or seeking advice about travel, diet and medications. There were over 62,000 visits to its website treatment pages over this period alone.

People living with diabetes largely accept the fact that the overwhelming majority of their care is their own responsibility. However, many are unhappy with the amount of support and information available to enable them to live with and take control of their own diabetes. This has also been recognised by the State of the Nations report⁶, whose authors call for a more long-term view and a less patronising approach to diabetes.

People with diabetes make decisions everyday of their lives that will affect their health. Yet the State of the Nations report⁶ found significant gaps in the ability of the NHS to empower people with diabetes to manage their condition effectively. In particular, the need for organised and planned education is not matched with the support and ability to deliver at a local level.

A recent consultation exercise for people affected by diabetes found many to be angry and frustrated about their ability to self-care effectively¹¹.

Many felt that their healthcare professionals were woefully inadequate in providing help in the form of truthful and accurate advice. They called for education that could empower individuals to take control of their diabetes and provide them with the means to monitor their progress, and for self-monitoring to be combined with other aspects, such as education, to enable the person with diabetes to act on the results.



Box: Listen to what people with diabetes want. Comments from Hansard 2005

The *Diabetes Information Jigsaw Survey*⁵ found that over half of people with diabetes don't find it easy to ask questions about their treatments because there is not enough time during their consultation to answer all their queries, or that their doctor or nurse seems too busy. Perhaps most worryingly, 16% don't ask any questions because they 'don't want to bother anyone'. Joanne Shaw, Chair of Ask About Medicines, noted that, "there is a real need for greater understanding

of the importance of medicines in treating diabetes. People with diabetes should be encouraged to ask questions about their treatment because better compliance with diabetes treatment programmes is a proven result of improved knowledge and understanding of the condition.”

One initiative to ensure people with diabetes have access to information that has worked well for the people who have tried it is a more structured approach to patient education. e.g. DAFNE, DESMOND and XPERT.

DAFNE (Dose Adjustment For Normal Eating) – Type 1 skills-based programme where people learn to adjust their insulin to match their choice of food rather than having to work their lives around their insulin doses.

DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) – Type 2 group education programme that supports people with diabetes in identifying their own health risks and setting their own specific behavioural goals – is based in primary care and is delivered locally.

XPERT is an example of a local programme that has been produced. The XPERT Patient Programme aims to increase the knowledge, skills and confidence of people with Type 2 diabetes so that they can make more informed decisions about treating their condition and improving their lifestyle. The programme lasts a number of weeks and involves the expertise of a range of health and social care staff, including podiatrists, diabetes specialist nurses, dietitians, psychologists and hospital consultants. Sessions include exercise, weight management, carbohydrates, causes of diabetes, complications and a supermarket tour with a dietitian.

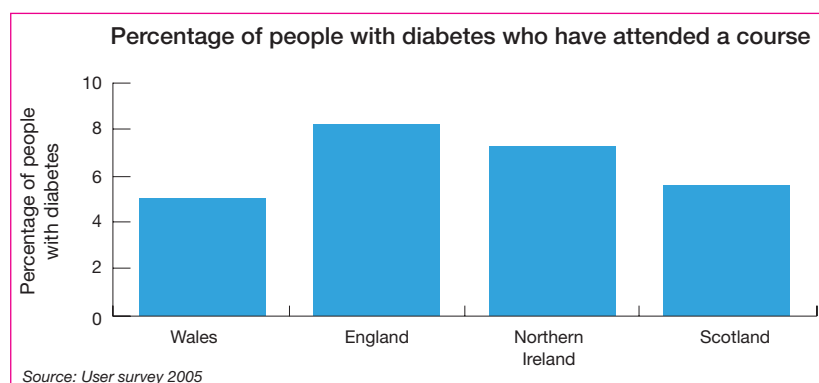


Figure: People with diabetes who have attended a structured education course⁶

Although access to these programmes is currently limited, many attendees have commented favourably (see below).

- “Following the DAFNE experience, I realised how little I actually did know...”
- “I have been able to start exercise without stuffing myself with a [chocolate] bar and hence have slowly started losing weight instead of putting it on for the first time in years”
- “I have had misconceptions blown away and feel more positive about my diabetes”
- “I learnt more about my diabetes in 1 week with DAFNE than in the prior 20 years”

Box: Comments from participants on DAFNE (structured education) courses¹¹

Many people with diabetes and their healthcare professionals believe that structured education has the potential to become a central part of diabetes care. But participants emphasised that such programmes must become more widely available with easier access to local schemes and must be arranged at times that people can attend alongside their other commitments to work or childcare. They also called for a greater emphasis on self-management skills, which should more closely match patient needs, and should include regular interactive updates and support.

The widespread provision of structured education to enable patients to better handle self-care is one of the five priority areas earmarked by Diabetes UK and its members as key to improving diabetes care through its ‘Action Today, Health Tomorrow’ campaign launched at the beginning of 2005.

Is patient-centred care working?

Patient-centred care lies at the heart of the government’s proposed changes for services for people living with diabetes, yet many people still feel marginalised by the healthcare professionals that they come into contact with.

A recent report by the Picker Institute Europe¹⁷ showed that, despite this proclaimed strong commitment to patient-centred care, people living with long-term conditions in the UK were

The Diabetes Information Jigsaw Survey – Participants’ Comments

If you don’t understand as much as you would like to about your insulin or tablets, why is this?

“*Maybe I’m not asking the right questions*”
– Type 2 diabetes, female, 50 years.

“*It is so confusing*”
– Type 2 diabetes, female, 22 years.

“*Not fully aware of the questions to ask*” – Type 2 diabetes, male, 54 years.

“*I just don’t ask and they don’t tell me*”
– Type 2 diabetes, female, 55 years.

“*Don’t like to ask*” – Type 2 diabetes, male, 57 years.

“*I want to know what options are available [and] try different types of insulin*”
– Type 1 diabetes, female, 49 years.

less positive about their care than in other countries (USA, Canada, New Zealand, Australia and Germany).

In particular, British people with long-term conditions:

- Were the least likely to say that they had received opportunistic advice from their doctor on disease prevention and lifestyle modification. e.g. weight, diet and exercise
- Were least likely to be involved in treatment decisions
- Were least likely to have participated in a treatment review
- Were least likely to have been given information about the side-effects of their medication. Somewhat surprisingly, people with multiple conditions were the least likely to have been informed about side-effects.

“Because I don’t have a say about what I use”
– Type 1 diabetes, male, 59 years.

“They say things too fast and don’t give it time to sink in”
– Type 2 diabetes, female, 38 years.

“Because I don’t feel enough time is available to properly consult my doctor/nurse” – Type 2 diabetes, female, 43 years.

“Just don’t understand how the new tablets work”
– Type 1 diabetes, female, 55 years.

The survey also showed that within the UK:

- Fewer than half of people were involved in shared decision-making – compared with around two-thirds of people in New Zealand
- Only 54% of people with chronic conditions were given dietary advice
- Fewer than 1 in 5 people with chronic conditions had been given a plan for managing their self-care at home. This fell to 1 in 10 for people diagnosed with diabetes (see figure).

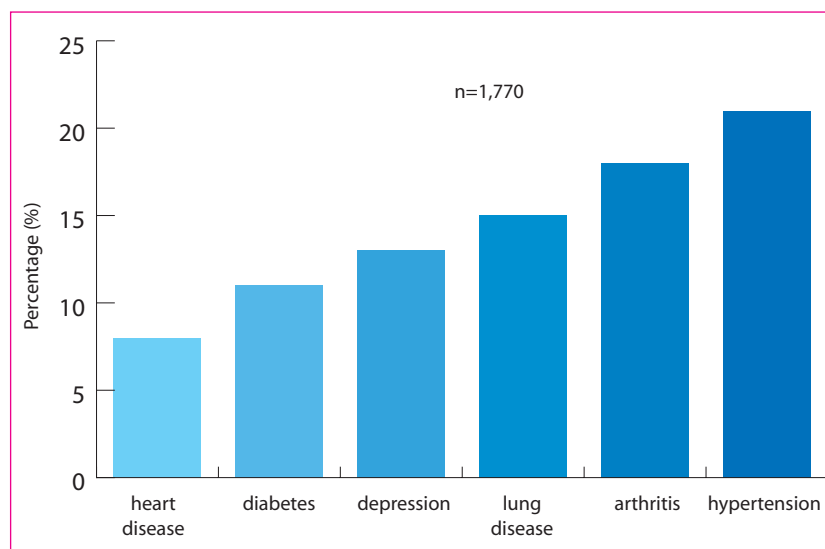


Figure: Fewer people with diabetes receive self-management plans than for most other chronic conditions¹⁷

Defining information needs

The effective provision of information is vital for partnership between healthcare professionals and patients – with effects ranging from the psychological benefits of accepting and understanding what is happening to them, to empowering people to actively share in their care.

Empowerment involves having rights, capabilities, resources and opportunities so that strategic choices and decisions can be made. Empowerment enables people to obtain information on the nature of their condition and its treatment and make joint decisions about their care. For people with diabetes, this means having the knowledge and means to monitor and control their condition on a day-to-day basis through a combination of testing, diet, physical activity and medication, and having the confidence to adapt their approach if circumstances require it.

Information accessibility

The level of functional literacy and numeracy – defined as “the ability to read, write and speak in English and to use mathematics at a level necessary to function at work and in society in general”¹⁸ – is often forgotten in the UK when information provision is planned. Over seven million adults in England (around 1 in 5 of the population) are estimated to have difficulties with literacy and numeracy¹⁸. Around one million of these have a first language other than English. A more recent report showed that a total of 5.2 million adults in England lack basic literacy, whereas 17.8 million adults (56%) of the overall population between the ages of 16 and 65 years of age have literacy skills at Level 1 or below¹⁹. In Wales, people’s preference to access material in their first language of Welsh may provide an added challenge.

Low adult literacy has an impact on the provision of effective healthcare. A report by the National Consumer Council in 2004²⁰ called upon the NHS to take action to address the persistent gaps in ‘health literacy’, especially among people who are socially disadvantaged. ‘Health literacy’ means more than just being able to take in information. It includes developing the skills to acquire and read relevant health information and successfully applying it to one’s own situation. The government report *Tackling Health Equalities*²¹ found that poor educational attainment was a key factor in the cycle of health equalities.

Supporting people with low literacy skills remains a considerable challenge for healthcare professionals¹⁸. As summed up by Ed Mayo, NCC chief executive: “Building health literacy isn't only about changing the mindset of a population trapped by their respect for and deference to health professionals. It also means a more user-focused approach from the NHS – making information available in plain language, when and how patients want it.”

How information helps people living with long-term conditions

Information is important to help people with major long-term conditions, such as diabetes, to regain control over their life. It is also invaluable in promoting treatment compliance and self-management, as people are able to understand the reasons behind their treatment and the consequences of their actions.

A particular need for people with diabetes is how to interpret changes in the results of self-monitoring, and how to balance lifestyle changes and medication accordingly. People may also need help in fitting their management around their chosen work and leisure choices.

Information can help in the long term to conserve healthcare resources, as individuals take up the responsibility for their care, taking appropriate action at an earlier stage if things start to go wrong. The Wanless Report²² identifies health information as being essential for a fully engaged society in which people understand and take full responsibility for living healthier lives and for decisions about their healthcare. This ‘fully engaged scenario’ would provide a far more efficient use of NHS resources than is possible today, while improving life expectancy and the chance of a healthy life for longer across the population. The report estimates that for every £100 spent on encouraging self-care, around £150 worth of health benefits could be delivered in return.

Depression – a downward spiral

Information can also help promote individual health, as research has shown that people with diabetes who are dissatisfied with the information they receive are more likely to be depressed than those who are satisfied. Furthermore, half of the people with diabetes in the UK are depressed because of their condition⁴. The effects of diabetes coupled with depression can be seen in poorer blood glucose control and the prevalence of more diabetes symptoms, as people with diabetes and depression find it more difficult to stick to an appropriate diet, exercise and treatment regimes²³.

Education that improves self-care can have wide-ranging benefits. People with Type 2 diabetes who are suffering from depression are more likely to improve their health-related quality of life by preventing complications and treating their depression²⁴. Healthcare professionals need to understand and accommodate the depression, stress and anxiety that are brought about by diabetes when setting blood glucose targets and treatment programmes for their patients²⁵.

The information gaps in diabetes

There is no doubt that voluntary sources of health information work. A great deal of information on diabetes and its management is available, especially through the efforts of charitable organisations such as Diabetes UK. Surveys have shown that people with diabetes who have been in contact with Diabetes UK are more likely to have received specific education about diabetes and to be more aware of their condition. Despite this, many individuals have difficulty finding the information that they need or finding information that is directly relevant to their circumstances.

According to Diabetes UK, healthcare professionals could do more to point people in the direction of the information that is available. In particular, there are certain groups of people who find it hard to access quality information for whom more could be done.

Type 1 diabetes

Most information that is available for people with diabetes appears to be about Type 2 diabetes. Although much information can be related to either condition, relatively little information is produced specifically for the 15% of people living with Type 1 diabetes, and some people can find this confusing.

Black and minority ethnic groups

One of the most worrying gaps is information for black and minority ethnic (BME) groups in the UK. People from BME backgrounds often experience particular problems with understanding information about their care, particularly when English is not their first language. These problems are exacerbated by the fact that Type 2 diabetes is up to six times higher amongst people of African Caribbean or South Asian origin. Cultural differences in diet and attitude towards exercise and close attachment to family traditions means that much of the available information is not relevant to the very people that need it.

A MORI poll commissioned by Diabetes UK shows how far awareness and knowledge about diabetes and its complications among the BME community lags behind the white population within the UK, despite the higher risk status of the BME community¹³. BME respondents were also far less likely to have heard of Diabetes UK or to have used its services. A survey of the callers to the Diabetes UK Careline during 2005 showed that very few callers were of BME origin.

Ethnicity in the context of health education and care is a complex issue, with language being only one factor. It is important that any self-management programme specifically addresses the issue of health beliefs. For example, it has been shown that people from BME backgrounds are less likely to agree that their diabetes is a chronic condition, to see it as a threat to their health or to feel that it had a great impact on their lives.

In a recent survey, less than 60% of PCOs across England and Wales reported that strategies are in place to deal with BME groups in their areas. The State of the Nation report⁶ recognises this, and has called for investment to be made available to develop health education courses to meet the specific needs of BME groups.

Pregnant women

Diabetes is the most common pre-existing medical disorder that complicates pregnancy in the UK, with approximately one pregnant woman in 250 having pre-existing Type 1 or Type 2 diabetes. A recent survey demonstrated that congenital malformation rates in these babies were 4 to 10 times higher than in the general population.

Pregnancy outcomes in women with pre-existing diabetes are closely linked with the level of blood glucose control that is present immediately before and during pregnancy. There is increasing evidence to demonstrate that pre-conception counselling and care (which has been shown to be cost-effective) can reduce both maternal and foetal deaths (including congenital malformations) to levels similar to those of the general population²⁶.

There is a shortage of quality information for both pregnant women who develop diabetes during pregnancy and those with a pre-existing condition on how to protect themselves and their babies and how to prepare for their time in hospital. There is also little advice available to women with diabetes who are thinking of trying for a baby.

A recent report looking at how women with diabetes prepare for and cope with pregnancy shows the risks that they take if they are unprepared²⁶. Good control of blood glucose, especially around the time of conception and during the early stages of pregnancy, can help prevent these problems, yet many women with diabetes remain unaware that they are putting themselves and their baby at risk and are poorly prepared for pregnancy. Sadly, babies born by women with diabetes are five times more likely to be stillborn²⁶. Despite this, the *Diabetes Information Jigsaw Survey*⁵ found that more than one third of mothers with diabetes did not get any advice about the possible complications of having diabetes during their pregnancy. Furthermore, over 60% did not realise that stillbirths of newborns is a possible complication of having diabetes during pregnancy.

- Type 1 not as well served as Type 2
- Children and adolescents (relevant issues and appropriate level)
- BME groups (language and cultural barriers)
- Pregnant women
- People without access to the internet (elderly, visually disabled, poorer households)
- People with learning disabilities
- People with low levels of literacy and numeracy

Box: The diabetes information jigsaw – gaps in information provision

Children and adolescents

In recent years, there has been a growing awareness of the needs of children and adolescents with diabetes and of their families and teachers. Advice on dealing with diabetes in schools, on psychological support, on dietary education and on what to tell friends is in short supply, especially at a level and in a language and context that children and adolescents can relate to. There is also a need for more information to support adolescents as they take over responsibility for their own care (for example, when they leave home).

According to the Patient Education Working Group, there is currently no evaluated paediatric or adolescent structured education being delivered systematically in the UK. Although many centres have educational programmes, few if any are structured, use formal curricula or provide training for educators

in paediatric diabetes. Some probably do provide useful information for both parents and children, but the extent to which they enable families and children to manage their own diabetes successfully is unclear. Other work suggests that, in some cases, overall glycaemic control in children and young people with Type 1 diabetes is worse in the UK than in some countries in Europe²⁷.

At least 85% of children with diabetes in the UK are not reaching recommended blood glucose levels, leaving them at risk of serious problems, such as heart disease, strokes, kidney failure and blindness in later life²⁸.

The way forward

Standard 3 of the National Service Framework for Diabetes in England and in Wales requires that all people with diabetes receive a service that encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. Unlike acute illnesses in which the physician will take the lead in identifying care, people with long-term conditions such as diabetes have a greater need to share responsibility.

Understanding the seriousness of the condition, its effects on lifestyle and the importance of medicines used to treat diabetes encourages a person with diabetes to take their medication as prescribed and helps prevent complications. Appropriate information is a prerequisite for a successful move towards increased involvement by the person with diabetes in decision-making about all aspects of their care.

Despite recommendations for regular reviews for people with diabetes and for a proportion of the consultation period to be set aside to specifically discuss and assess the individual's information needs, time to talk is generally short. One practical way that has been suggested to overcome time constraints while supporting the aim of information provision is the concept of the 'information prescription'. The information prescription, provided by the healthcare professional at the time of consultation, could be an individualised way to 'signpost' patients to the most appropriate sources of further information and support. The prescription could be given following discussions about the person's concerns, fears and information needs surrounding their diagnosis and treatment. Information prescriptions have the potential to become a useful focal point for a number of NHS activities²⁹.

Information prescriptions should have the power to improve the efficiency of consultations by reducing the need to write or draw during the consultation,

by matching the information to the particular patient pathway and by enabling more informed consent. The information prescription could help to resolve the dilemmas of how to embed information-giving into the process of care, and how to decide whose responsibility it is to offer information at a particular time. This is of particular concern in the multi-disciplinary environment of the person with diabetes.

Specialist diabetes nurses often play a central role in facilitating communication and the flow of information across the healthcare team (of which the person with diabetes is the key member). They provide expert advice, support and advocacy for people with diabetes throughout their journey and so may be ideally placed to coordinate their information needs as they change. It is essential that people with diabetes can access effective help and advice when problems or concerns arise between scheduled appointments, and contact with nurse specialists is one important way that information can be provided.

According to health psychologist, Dr Chas Skinner, from Southampton University, a particular problem in long-term conditions such as diabetes is that the purpose of the consultation is not always clear, either to the person with diabetes or their doctor. If follow-up meetings are considered 'routine', with no defined purpose and little advance preparation on either side, their quality is generally poor. A recent study has suggested that asking patients to use their pre-clinic waiting time to prepare a written personal agenda for their consultations can enable people to feel more satisfied and results in a more meaningful interaction³⁰.

A further concern is that issues with self-management may only become apparent during the course of the consultation, giving the person with diabetes little time to react. Dr Skinner recommends providing patients with the results of any clinic tests before they enter the consulting room so that they are given sufficient time to prepare questions or identify where help is needed.

Some patients also lack the confidence to question their doctor, according to Simon O'Neill of Diabetes UK. Many of the calls to the Diabetes UK Careline are from people checking whether it is appropriate to question aspects of their care, or to raise points that are worrying them, or who are afraid of using up too much consultation time with their queries. Healthcare providers need to support patients in improving their levels of understanding by providing them with easily accessible information, which is appropriate to individual patient needs and wishes. A set of questions that build people's confidence to ask about their care, personalised information prescriptions, and greater involvement of specialist

nurses as information providers and guides to services may all help to achieve patient empowerment and hence better long-term outcomes.

Improved information standards in other therapeutic areas, such as breast cancer, have already shown that patient organisations and the pharmaceutical industry can support empowered patients by helping people gain a greater knowledge and feeling of involvement. The 'Target Diabetes' booklet has shown that patient organisations and the pharmaceutical industry can empower people with diabetes by helping them to gain greater knowledge and involvement in treating their condition. However, there is no substitute for a good and open relationship between individuals and their healthcare professionals. It is important that healthcare professionals empower people with diabetes to seek more knowledge about the medicines used for the treatment of their condition so that there is informed choice of appropriate medication that will lead to better health. The information prescription and support for questions should help bring this a step closer.

The Association of the British Pharmaceutical Industry (www.abpi.org.uk) is the trade association for about a hundred companies in the UK that produce and research prescription medicines. As part of its role, it has worked with Datapharm to provide an online resource www.medicines.org.uk to help patients access information on medicines.

Diabetes UK (www.diabetes.org.uk) is the largest organisation in the UK working for people with diabetes, funding research, campaigning and helping people live with the condition. It has over 170,000 members and is working for people with diabetes, their carers, family and friends. The organisation represents the interests of people with diabetes by lobbying the government for better standards of care and the best quality of life. Diabetes UK spends over £6 million on research every year to improve the treatment of diabetes and hope that their research will ultimately lead to finding a cure for diabetes. Diabetes UK's mission is to improve the lives of people with diabetes and to work towards a future without diabetes.

Ask About Medicines (www.askaboutmedicines.org) is an independent campaign to increase people's involvement in decisions about their medicines use. The aim of the campaign is to contribute to people's ability to control their own health and healthcare through better understanding of what medicines do and how to make the most appropriate use of them.



Further reading

For more about diabetes treatments available or that are being tested for use within the UK, read the ABPI publication 'Target Diabetes', published in December 2005.

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