Information Provision in Diabetes

'Good Practice Forum' Report

Developed by a partnership of the Association of the British Pharmaceutical Industry, Ask About Medicines and Diabetes UK

January 2007







Contents

Executive summary	
Introduction	pg 5
The information gaps and information needs	pg 7
The national strategy for information	pg 9
Requirements for information provision - National perspective - Local perspective - A parliamentary and a personal perspective - Personal perspective	pg 11 pg 11 pg 12 pg 12 pg 13
Information provision – meeting the individual needs of people with diabetes	pg 14
Perspectives from the forum and working group feedback	
Conclusions	
Contributors	
Further reading	
References	pg 23
Appendix - Agenda for 'Good Practice Forum'	

The origins of this report lie in a workshop, co-hosted by the ABPI, Ask About Medicines and Diabetes UK to discuss information provision for people with diabetes, held in London on 13 October 2006.

The organisers would like to thank all who participated and shared their experiences and views.

Executive summary



More than in any other chronic condition, people with diabetes play a key role in ensuring that their condition is effectively controlled. As much as 95%¹ of diabetes is self-care and it is essential that people with diabetes are empowered to understand their diabetes and its treatments in order to stay in control of their condition and minimise long term complications.

In June 2006, a partnership formed by the Association of the British Pharmaceutical Industry (ABPI), Diabetes UK and Ask About Medicines published the findings of the *Diabetes Information Jigsaw Report* which highlighted information gaps in information about the treatments that directly affect the success of self-management of diabetes.

Continuing to raise awareness of the need to improve information provision and dialogue about medicines for people with diabetes, the partnership hosted a 'Good Practice Forum' in October 2006. This enabled a range of stakeholders with different insights and experiences of diabetes to discuss information provision and facilitate the sharing of existing practice and ideas on delivering medicine information. The meeting also aimed to:

- Influence and input into the Department of Health's approach to developing the information prescription concept for piloting and national roll out
- Identify barriers to providing information prescriptions to people with diabetes and explore solutions for overcoming them
- Identify possible pilot sites for developing information prescriptions for people with diabetes

Diabetes is recognised as a condition where information needs not only differ by individual but change over time, for instance, varying according to whether a person is newly diagnosed or has had their diabetes for some time. Whilst the work of patient organisations and existing support services for people with diabetes is very valuable, they currently reach only a limited number of patients and a standardised system of information provision for everyone receiving healthcare and treatment for diabetes is needed. There is also a recognised tension between information gaps on the one hand, due to low levels of support and signposting to information currently offered, and on the other hand, the potential for overload, where patients are in danger of being overwhelmed by a plethora of information.

Executive summary

The answer to this conundrum is personalisation, with health professionals encouraging people to ask questions so they can accurately gauge the type, amount and depth of information that best suits the needs of each individual patient and their family. There is a need to signpost people with diabetes to information that supports disease management, encourages enquiry and empowers them to achieve successful control of their condition. Information provision needs to be tailored to suit individual needs, relating not only to a person's clinical needs and lifestyle, but also to their acceptance of and preference for different forms of information. One way of achieving this is through the use of the 'information prescription'. An information prescription could be provided by the healthcare professional at the time of consultation as an individualised way of signposting patients to the most appropriate sources of further information and support. Information prescriptions are a potentially important piece of the current information jigsaw which need to be piloted and then rolled out nationally.

As a result of discussions, the workshop broadly agreed that everybody with diabetes has a right to expect:

- A personalised information prescription expressed in an appropriate format as part of their care planning process
- That everyone involved in their care knows what information they have been prescribed if they (the patient) wish
- Access to clear and consistent information that is accurate, up-to-date and trustworthy, to enable them
 to understand their condition and treatment options regardless of their age, ethnicity, disability or postcode
- Encouragement to seek information on medicines and other treatments by discussing their condition with and asking questions of a range of healthcare professionals or other forms of support
- Information should be tailored for each person in their particular situation

Ultimately, the healthcare team, in both primary and secondary care, needs to work in partnership with patients and their carers. Empowering people with diabetes to understand their condition and its treatment will result in them making better informed choices and will lead to better long term health.

Introduction

People with diabetes are charged with assuming responsibility for a great deal of the care and management of their condition. As a long term condition, as much as 95% of diabetes care is self-care¹. Over the course of a lifetime, people with diabetes need a variety of skills and knowledge not just to help control their condition on a day-to-day basis but also to adapt to changing circumstances relating to the condition, its treatment and its effects on health and lifestyle.

People with diabetes have a right to expect personalised, accurate and up-to-date information to support understanding of their condition and to



inform decisions about treatment. The government has made patient-centred care for diabetes a priority² and there is a wealth of education, support and information available about diabetes, much of it designed with the specific needs and interests of people with diabetes in mind. However, recent research has highlighted that people with diabetes are not always able, or encouraged, to find the information they need about medicines in order to manage their condition effectively³. In general, the issue is not one of lack of information but the absence of a reliable mechanism to give everyone with diabetes access to information relevant to their condition and current, individual needs and circumstances. The situation has been likened to a jigsaw – sometimes a puzzle with some pieces missing, and other times where all the correct pieces are available but need to be re-assembled to reveal a clear picture.

To support a new approach to information provision for people with diabetes and to close current information gaps, a partnership was formed by the ABPI, Diabetes UK and Ask About Medicines. This partnership commissioned the *Diabetes Information Jigsaw Report* in July 2006. The report highlights that in the UK today, 58% of people diagnosed with diabetes do not know what the diagnosis means, 60% do not understand what different medicines are available to treat their condition, and over a third do not know what questions to ask those who are providing their care³. As a result, one in five people with diabetes are suffering from preventable complications through neglecting to take their medicines, and around half are depressed.^{3,4}

Based on these findings, the ABPI, Diabetes UK and Ask About Medicines partnership seeks to raise awareness of the need to improve information provision and dialogue about medicines for people affected by diabetes. It is also committed to supporting thought leadership in the broader goal to inform, encourage and empower people with diabetes and their carers.

Introduction

This report provides a summary of the proceedings of the 'Good Practice Forum' on Information Provision in Diabetes. Hosted by the ABPI, Diabetes UK and Ask About Medicines partnership, the workshop brought together a range of stakeholders with useful insight and experiences to explore ways of ensuring that people with diabetes are signposted to a variety of sources of information and are encouraged to ask about and be supported in their diabetes care.

The following sections of this report provide a summary of key presentations and discussion at the workshop. The report concludes with a consensus statement, prepared by the partnership and broadly endorsed by the forum, that conveys the essential elements necessary to enable people with diabetes and their healthcare professionals to work in partnership towards improved information access.



The information gaps and information needs



As the largest organisation in the UK working for people with diabetes, the charity Diabetes UK funds research, campaigns on behalf of and helps people living with the condition. Through its Careline, accessible by telephone and email, Diabetes UK receives over 40,000 direct enquiries every year. According to Simon O'Neill, Director of Care and Policy at Diabetes UK, most callers to the Careline are seeking information and support that they have not found from, or been afraid to ask of, their healthcare team. Many are unsure what the condition actually means since some have been told by a healthcare professional that they have only 'mild' or a 'touch of' diabetes.

Through the Diabetes UK Listening Project 2006, which gathered experiences from people diagnosed with diabetes over the past year, it was found that some 46% of people received no information on diet at diagnosis and around a quarter received no information at all. 50% of those surveyed said they wanted to leave the consultation where a diabetes diagnosis was made, armed with basic written information that they could take home, read and reflect upon⁵.

Diabetes UK has therefore been pleased to collaborate with the ABPI and Ask About Medicines on the recently published Diabetes Information Jigsaw Report³ which surveyed over 500 people with diabetes on the information they had received about the condition and their understanding of their diagnosis and outlook.

The Diabetes Information Jigsaw Report found that 58% of people did not know what the diagnosis meant, over a third did not realise that diabetes is a life-long condition, and half did not appreciate that diabetes can reduce life expectancy by anything between 10-20 years especially when poorly controlled³. An alarming 65% of those surveyed, including people on insulin, were not using their medicines as prescribed and one in five suffered complications because of not taking medications. As many as 57% of people said that they find it difficult to ask questions of their doctors and nurses³.

People with diabetes turn to Diabetes UK with a battery of questions, ranging from what diabetes is and how it is going to affect them, to specific enquiries about diet and modifying what they eat, through to queries about medical complications and treatments for diabetes. Concerns include how medicines might interact, what side effects to expect and how to take medicines. Underlying all enquiries is a strong desire to live a healthy normal life with diabetes.

With over 2.1 million people in the UK today with diabetes and a current NHS spend of £400,000 an hour (5% of current NHS expenditure) diabetes incidence is predicted to double by 2010^{7,8}. Diabetes remains a leading cause of blindness, kidney failure, heart disease and death. Organisations like Diabetes UK offer a range of services, publications and programmes to support people with diabetes.

The information gaps and information needs

The Diabetes UK website receives over a million hits a month and its programme of support is available to all who can access it, and seeks to be inclusive and relevant for the many and diverse groups of people affected by diabetes in the UK today. Yet the work of the charity currently reaches just 20% of people in the UK with diabetes, highlighting again that many people are not accessing information that could help improve their health and outlook.

Much is being done to improve communication between healthcare professionals and patients through the Department of Health model for care planning which aims to make the person with diabetes an equal partner in care and treatment. Diabetes UK supports access to structured information and education, including the NICE approved DAFNE course, and the organisation welcomes new Department of Health initiatives, such as the information prescription, which may help complete some missing sections of the diabetes information jigsaw.



The national strategy for information

The government has made putting information at the centre of health a key component of its health agenda for the 21st century¹⁰. According to Mary Simpson, from the Information for Choice Strategy team at the Department of Health, the vision for the future recognises that information is essential for people making choices about their care and the department is creating new ways to make information relevant, trustworthy and timely for everybody, so that the right to choose is available to all.

Currently, people want information to support decision-making and believe that clear accessible information about their health and about local services would make a real difference. Yet surveys show that there is no consistency in information provided and people are not sure what information to trust. For people with chronic conditions like diabetes, information needs to be timely and may need to be adapted according to changing needs and individual circumstances.



Information Prescription

The information prescription has been devised so that services can give all people with long-term health and social care needs, and their carers, a 'prescription' of relevant information. Since the meeting, the Department of Health has announced the piloting of information prescriptions in the therapy areas of cancer, mental health and vulnerable older people. It is planned that information prescriptions will be given out to people using services, and their carers, by health and social care workers (e.g. GPs, social workers, district nurses). Such a prescription signposts people to further information and advice to help them manage their condition. A prescription could be provided at consultations and could be tailored to suit an individual's needs and to reflect available local services and support facilities. It therefore seeks to 'join up' the available sources of information and would be given following discussions about a person's concerns, fears and specific information needs surrounding their diagnosis and treatment.

The Department of Health recognises that the information prescription has to work for all people and not just for those who know their way around the services, systems and information network. Information provided in a prescription has to be in a format that works for a given patient and must be relevant to, and supportive of, self-care and management.

As a systemised means of providing information, the information prescription will offer a less ad hoc approach to health information. According to Mary Simpson, information prescription pilots will be evaluated to establish their impact on the patient, on care, consultations, and on voluntary organisations and associations providing services, support and information. The evaluations will be conducted by an independent, academic organisation that will help assess the evidence for the impact of information prescriptions on clinical outcomes and resource usage. This will advise on refinements and development of the process should the pilot scheme move forward.

The national strategy for information

Information Accreditation Scheme

There are also parallel plans to develop an information accreditation scheme, for roll out in 2008, that will "kite mark" information providers. This scheme will allow information users to judge whether information is trustworthy according to national, approved standards.

Community Information

To be most effective and pertinent to users, information prescriptions will be populated with information collected on local services, information sources, support groups and facilities. Importantly, local information sources recognise that for people with long-term medical conditions, access to forums where they can meet with other people locally and in similar circumstances, can be valuable support.

Power Questions

Within the information system, the Department of Health recognises the need for people to be able to ask questions of healthcare professionals. There are plans to look at generic power questions to help people ask for the information that is important to them for living with and managing their condition.

Information System



Requirements for information provision

Successful information provision must fit with the needs of users and the capability of providers and has to work consistently at both national and local levels. During the workshop, a panel discussion was held to discuss information requirements at different levels, preceded

by brief presentations by each panel member on their perspectives on information provision.

The national perspective

In seeking to improve and facilitate information provision within health service delivery, a national vision is required to ensure that new policies and initiatives fit within the wide range of services currently available to people with chronic conditions such as diabetes.

As National Clinical Director for Diabetes at the Department of Health, Sue Roberts stressed that information prescriptions will need to sit comfortably with National Service Frameworks for diabetes to provide people with chronic illnesses with care planning. These initiatives have to be seen as complementary by a person with diabetes, who should not view information provision as something extra, but as something integral to their plans for long-term disease management. Dr Roberts believes that a fundamental revolution is needed in the way we help people self-manage diabetes.

While at national level there is a need for consistency of information offered through initiatives such as the information prescription, Dr Roberts stressed that the key to good information lies in its personal relevance. This means that time will be needed to tailor information for the person with diabetes. Information also has to be conveyed and delivered in an emotionally balanced way that offers hope and that leads to changes in behaviour that enable successful self-care.



Sue Roberts, National Clinical Director for Diabetes, Department of Health

Requirements for information provision

A local perspective

At local level, information and support for people with chronic medical conditions can take many forms. Sharing experiences from Merthyr Tydfil primary care and community services, Stephen Davies, Assistant Director of Primary Care, Merthyr Tydfil Local Health Board, highlighted the information sources available in local health regions. Within Merthyr Tydfil these include:

- Educational programmes
- Peer-support groups
- School networks
- Reference groups
- Local champions
- Access to books and literature



Merthyr Tydfil Local Health Board

He described an existing project called 'Prescribe A Book' which has proved successful in the arena of mental health nationally and has been adapted locally to accommodate people with diabetes, heart disease and stroke. This scheme allows people controlled access, via a local host library, to books, CD's and video on these specific long term conditions, offering a mix of education, autobiography and self-help advice.

In consultation with people with diabetes, the local health board has found that high on the wish list for information are requests for access to recipe books and healthy eating suggestions.

At a local level, patient information is often accessed via the practice nurse. In seeking to improve and develop information provision, it is important to consider who is the best gate-keeper and dispenser of information and to ensure that when information is provided, or can be accessed directly by users, that it comes in a medium and format relevant to the people of a local community. This may mean information in different languages, and formats (visual, written, verbal, illustrative) that work best for the recipient.

A parliamentary and a personal perspective

MP Adrian Sanders is Chair of the All-Party Parliamentary Group on Diabetes and also has diabetes. He highlighted that there are at least three stages at which a person with diabetes needs to receive information support:

- Pre-diabetes diagnosis
- At diagnosis
- After diagnosis when living with the condition

Before a definitive diagnosis, many people may come to connect emerging symptoms of the condition with some understanding of diabetes, but often public knowledge about this condition is low.

Requirements for information provision

At diagnosis, there is a need to convey that diabetes is a chronic condition and for healthcare providers to appreciate that there is a significant psychological aspect to receiving a life-changing diagnosis. If information is not made clear or not received in a positive way, this can have a lasting impact on attitudes and approach to the condition.

After diagnosis, without steering and support, there is a risk that the person with diabetes is exposed to an information overload. Diabetes requires a person to change their diet, reconsider lifestyle and nutrition, undergo numerous health checks, self-monitor glycaemic control and self-manage treatment that often involves multiple medications. Seeking information on all these aspects of diabetes can be overwhelming.

Ultimately a person with diabetes understands what its like to have diabetes better than any medical expert, and for this reason, Adrian Sanders believes that often the most influential source of information for a person with diabetes comes from peer-groups and support from others with diabetes.

Adrian Sanders, MP and Chair of the All-Party Parliamentary Group on Diabetes

A personal perspective

Clare Mehmet, who has diabetes, shared her personal experiences of information provision with the workshop. Her response to a diagnosis of diabetes was to want to find out everything she could about her condition, leading her friends to call her 'the leaflet queen'. With no family history of diabetes she started from scratch to find out about diabetes – using the many services provided by Diabetes UK and joining a local support group.

Keeping a diary; having access to hand-held records; learning from clinic visits and from other people with diabetes; these are all ways in which people with diabetes can build their knowledge of their condition.

With the help and support of healthcare workers, local diabetes groups, the Diabetes UK Careline and the many other services and forums open to people with diabetes, Clare has found that it is possible to learn self-care and is passionate in her desire to raise awareness about diabetes. She runs support groups, speaks at local and national forums and often helps raise awareness in the media about diabetes.

Information provision – meeting the individual needs of people with diabetes



People with diabetes are among the least compliant with their medications compared with other chronic diseases. According to Joanne Shaw, Director of Ask About Medicines, as many as 55% of people with diabetes fail to take their medicines as directed, while the figures for arthritis are 35%, hypertension 40% and epilepsy 40%¹¹.

Not taking medicines as prescribed or directed leads to longer term problems with health and has an individual, familial, healthcare and societal cost.

In diabetes, multiple medications are the norm and are needed to provide optimal disease control. But people with diabetes often have worries about issues such as dependence, safety of treatments and interactions that they have to balance against their need to take a medicine to control their condition¹².

Surveys have shown that the general public today want a say and share in decisions regarding their medical treatment and want to work in partnership with their healthcare professionals in deciding the best course of action. Yet the reality is that many people are reluctant to ask about their medicines or don't know what to ask.

Engineering information provision into healthcare

Information needs to be embedded into the care-giving process and cannot rely only on the work of local champions and enthusiasts and the work of overstretched charities.

The formulary model – information supply

The supply and delivery of information will need to be considered as plans move forward for information prescriptions. Healthcare groups will need support in dispensing information. A system similar to formulary dispensing could be employed, with individual information prescriptions drawn from an approved and authorised formulary, dispensed to patients via different care givers, and the impact of information prescriptions then monitored and supported through existing reporting and care services.

Information provision -

meeting the individual needs of people with diabetes

The supply and delivery of information prescriptions



There are considerable organisational and technological challenges to overcome in establishing the information prescription.

Many questions remain unanswered about how to make the information prescription concept work in diabetes, how to fill the information gaps and manage the potential for information overload, and how to encourage people with diabetes to ask about their condition and its treatment.

Perspectives from the forum and working group feedback



Workshop participants discussed the tension that exists between needing to bridge information gaps revealed by surveys such as The Listening Project and the *Diabetes Information Jigsaw Report*, and the dangers of information overload. The result may be that a person with diabetes is left, without signposting, to seek answers to the many questions arising from a diagnosis of life-long diabetes.

It was felt that a basic minimum amount of information should be provided to people with Type 1 and Type 2 diabetes as standard at diagnosis. Information needs will

change according to the stage of the condition, with different information needed for people facing the risk or reality of diabetic complications in the longer-term management of their condition.

At diagnosis, care plans should also be used to help people understand 'what comes next' in terms of a management plan. People with diabetes should be made aware of health services available in addition to advice and help on where to seek further information. Importantly, the first interaction that a newly diagnosed patient has will, to some extent, set the long term course for that person so it is vital to get it right.

People with diabetes should also be signposted to the expertise and support that can be provided locally by the Expert Patient Programme and to Diabetes UK.

Workshop participants discussed the particular needs of elderly, institutionalised people with diabetes. It is estimated that as many as one in four people in care homes have diabetes and their information needs and goals for care may differ greatly from other people in the community with diabetes. Information for these groups may have to be relayed via care staff and many people in care homes may have disabilities that affect their skills of communication and understanding. In addition, many elderly or dependent people with diabetes are cared for in the community by unpaid carers and again this group needs information tailored to suit their particular needs and circumstances.



Perspectives from the forum and working group feedback

The needs of people with diabetes from different ethnic and cultural groups in the community were also discussed. Information prescriptions should take account of cultural needs and help people access appropriate information and support services sensitive to the issues, concerns and needs of diverse sectors of the community. Therefore it is vital that information is tailored for each person in their particular situation.

Pharmacists are an underused facility but they have skills and knowledge which could be used in schemes to improve information provision for people with diabetes. In particular, pharmacists are well placed to answer questions and offer advice on medicines as they are a regular point of contact for patients collecting their medicines.

The value of peer-support in learning to live with and manage diabetes was a recurring theme.



Conclusions

People with diabetes often have a poor understanding of their condition and its management and need to be encouraged to work with their healthcare professionals to seek information that could help them manage their condition and achieve better long term quality of life.

The 'Good Practice Forum' highlighted the need for improved information provision in diabetes and identified a need to help people with diabetes piece together available information, from a number of sources, possibly through the development of diabetes-specific information prescriptions. Where possible, existing and evolving pathways, such as care planning and medicines reviews, should be used to help move this forward rather than the creation of new and unnecessary systems that may duplicate existing pathways.

Everyone with diabetes should be encouraged to contact a patient organisation at national or local level, to learn from peers, seek up-to-date trustworthy information and to take a major role as a partner in decisions relating to medical care.

An information prescription is in many ways a statement of needs. Information delivery should be in tune with a patient's sensitivities and in line with individual needs.

The 'Good Practice Forum' was held to drive the information agenda forward. The views and experiences shared at the workshop reflected the enthusiasm of dedicated healthcare professionals who want to add measurable value to patient-centred care. Great steps have been taken in improving the provision of information to people with diabetes. This momentum needs to be advanced even further by thought-leaders in information provision and ultimately put into practice to realise the benefits of empowered patients to our healthcare systems and society as a whole.

Consensus on the information provision needs of people with diabetes

The following consensus statement was broadly endorsed by the 'Good Practice Forum' and the partnership of the ABPI, Diabetes UK and Ask About Medicines as a foundation for information provision to people with diabetes:

Everybody with diabetes has a right to expect:

- A personalised information prescription expressed in an appropriate format as part of their care planning process
- That everyone involved in their care knows what information they have been prescribed if they (the patient) wish

- Access to clear and consistent information that is accurate, up-to-date and trustworthy to enable people
 with diabetes to understand their condition and treatment options regardless of their age, ethnicity, disability
 or postcode
- Encouragement to seek information on medicines and other treatments by discussing their condition with and asking questions of a range of healthcare professionals or other forms of support
- Information should be tailored for each person in their particular situation







Contributors

Thank you to everyone who participated and shared their experiences at the 'Good Practice Forum', Information Provision in Diabetes workshop.

Chairman

Richard Tiner, Medical Director, ABPI

Presenters

Simon O'Neill, Director of Care and Policy, Diabetes UK. Simon is responsible for promoting high quality diabetes care and education centred on the person with diabetes and for developing services to ensure this happens. He has had Type 1 diabetes for 15 years.

Mary Simpson, Information for Choice Strategy at the Department of Health. The Information for Choice team is implementing a range of projects about making information more accessible to members of the public and healthcare professionals.

Sue Roberts, National Clinical Director for Diabetes, Department of Health. She is responsible for providing support to the local NSF to deliver the Diabetes NSF and for providing links between the diabetes community, ministers and the Department of Health.

Stephen Davies, Assistant Director of Primary Care, Merthyr Tydfil Local Health Board. Throughout his career, Stephen has sought to support and develop new innovative ways of working in the field of mental health and other long term conditions. His current role is that of a service commissioner.

Clare Mehmet, Clare has diabetes and is involved in both local and national voluntary work, supporting people with diabetes, lecturing and helping to improve awareness of diabetes.

Adrian Sanders, Member of Parliament for Torbay. Adrian is also the Chair of the All-Party Parliamentary Group on Diabetes and has diabetes himself. Amongst other things, he has always campaigned strongly for issues surrounding diabetes and animal welfare.

Joanne Shaw, Chairman, Ask About Medicines. Joanne holds a number of non-executive positions with healthcare organisations in different sectors. She is currently Vice-Chairman of NHS Direct and Chairman of Datapharm Communications. She has a particular interest in medicine-taking issues and in shared decision making between patients and health professionals.

Contributors

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 interest of people with diabetes by lobbying the government for better standards of care and the best quality of life. Diabetes UK spends over £5 million on research every year to improve the treatment of diabetes and hopes 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.

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 to help patients access information on medicines including the treatment of diabetes.

Ask About Medicines (www.askaboutmedicines.org) is the independent campaign to increase people's involvement in decisions about their use of medicines.

Further reading

Diabetes Information Jigsaw Report

Copies of the Diabetes Information Jigsaw Report can be found at: www.abpi.org.uk/%2Fpublications%2Fpdfs%2Fdiabetes_jigsaw.pdf

Piloting information prescriptions:

Invitation to bid (information only, bids have now closed)

(Gateway reference number: 7584)

The Department of Health (DH) is requesting proposals to pilot information prescriptions. Information prescriptions, given by health and social care professionals, will provide a list of valuable sources of information about managing and living with a long term condition. Funding support is available - closing date for bids is 31st January 2007.

For further details see the information prescriptions link at:

www.dh.gov.uk/PolicyAndGuidance/PatientChoice/Choice/BetterInformationChoicesHealth/BetterChoicesArticle/fs/en?CONTENT_ID=4123091&chk=i20vh1 OR telephone Clare MacDonald on 020 7210 5575 or email information.prescriptions@dh.gsi.gov.uk

References

- 1. Foster / Diabetes UK. Wales England and Northern Ireland. 2005.
- 2. Department of Health. Improving Diabetes Services the NSF two years on. March 2005.
- 3. ABPI/Diabetes UK/Ask About Medicines. The Diabetes Information Jigsaw Report. June 2006.
- 4. Accu-Chek survey among 962 people with diabetes, Jan-March 2004.
- 5. Diabetes UK. The Listening Project. 2006.
- 6. Krentz, AJ (Editor). Economic costs of diabetes, 2:84, Churchill's Pocketbook of Diabetes, 2000.
- 7. Dobson, R. Number of UK diabetic patients set to double by 2010. BMJ 320(7421):1029, 2000.
- 8. McCarty, D. and Zimmet, P. Diabetes 1994 to 2010: Global estimates and projections. International Diabetes Institute, Melbourne. 1994.
- 9. Drury, P and Gatling, W (Editors). Complications, 2:2.14, Diabetes. 2005.
- 10. Department of Health. Better information, better choices, better health: putting information at the centre of health. December 2004.
- 11. Whitney HAK, Jr et al (Editors). Medication compliance: a healthcare problem. Annals of Pharmacotherapy 1993;27 (9. Suppl)
- 12. Horne, R and Weinman J, Psychology and Health 2002; 17:17-32.

Appendix 1 — 'Good Practice Forum' Agenda

'Good Practice Forum' Agenda, Information Provision in Diabetes 13th October ABPI, Trafalgar Room

10.00-10.05	Welcome and introductions	Richard Tiner Medical Director, ABPI	
10.05-10.20	The information gaps and information needs	Simon O'Neill	
	 Feedback on Jigsaw report findings Helpline analysis; feedback from DUK helpline on key questions that people with diabetes have about their medicines and the information they request 	Director of Care and Policy, Diabetes UK	
10.20-10.35	The national strategy for information	Mary Simpson Department of Health lead	
	Overview of DH National Strategy for InformationProgress to dateNext steps and timelines	for information for choice strategy	
10.35-11.30	Presentation from each panel member on their requirements from information provision.	Tom Hain Deputy Chair, Patient Information Forum	
	Panel discussion on: What does 'good information' look like? Panellists will represent:	Dr Sue Roberts National Clinical Director for Diabetes, Department of Health	
	The national perspectiveThe local perspectiveThe personal perspective	Stephen Davies, Merthyr LHB Adrian Sanders, MP Clare Mehmet, Patient	
11.30-11.45	Information Provision – Meeting the Individual Needs of People with Diabetes	Joanne Shaw Director, Ask About Medicines	
	 Power of Information; impact of good information Information provision - need for an individualised tailored approach Resource implications and importance of evaluation 		
11.45-12.30	Breakout Group Discussion	All	
	Achieving consensus on the information provision needs of people with diabetes		
	Coffee provided		
12.30-13.15	Breakout groups reporting back	All	
13.15-13.30	Summary and Close	Richard Tiner Medical Director, ABPI	
13.30	Lunch	All	