

Diabetes Information Technology & Webwatch

Diabetes and the World Wide Web

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ABSTRACT

The World Wide Web has become remarkably quickly an alternative source of information for patients and their relatives, as well as students and health-care professionals. A whole plethora of websites and Internet-based applications related to diabetes have appeared in recent years. In this column, selected issues surrounding the use of such websites are considered and the need for more evaluation of such diabetes sites, as well as the Internet medium itself, is highlighted.

DIABETES ON THE INTERNET

THE INTERNET HAS RAPIDLY BECOME an alternative source of information for patients and their relatives, as well as students and some health-care professionals (HCPs).^{3,4} A whole range of websites and Internet-based applications related to diabetes have appeared in recent years. Table 1 lists just a few of these. It is beyond the scope of this column to provide a review of all diabetes websites. A search on <http://www.google.com> for “diabetes” sites yields over 5.5 million Web addresses!

Such websites range from providing static, informational resources about diabetes to more dynamic, interactive sites. Without a doubt there is a considerable amount of duplication of information about diabetes on the Web (as there is for other subjects as well).

Intuitively the benefits of the Web as a

method of disseminating knowledge are clear. By placing information on the Internet, the resource becomes very widely available to a vast potential audience, certainly in countries with ready Internet access, and penetration of the medium is growing all the time.

Much of this information is available without charge, which helps it reach an even wider audience. The resource becomes available 24 hours a day, 7 days a week, 52 weeks a year. Therefore once the time, effort, and expense of placing information on the Web has been addressed, very little effort is required for maintenance—unless of course changes are required. However, at the same time information may become out of date, over time, if it is not updated and revised as medical knowledge advances. Furthermore, while placing information on the Web is technically relatively straightforward, editing a large number of Web

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TABLE 1. A SELECTION OF DIABETES CHARITY/ORGANISATION WEBSITE ADDRESSES

American Diabetes Association (ADA)	www.diabetes.org
Juvenile Diabetes Foundation	www.jdfcure.org
American Association of Diabetes Educators (AADE)	www.aadenet.org
American Association of Clinical Endocrinologists (AACE)	www.aace.com
World Health Organisation (WHO)	www.who.int
International Diabetes Federation (IDF)	www.idf.org
International Diabetic Athletes Association	www.diabetes-exercise.org
National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health (NIH), Diabetes Centers for Disease Control (CDC), Diabetes	www.niddk.nih.gov/health/diabetes/diabetes.htm
Diabetes UK	www.cdc.gov/health/diabetes.htm
Canadian Diabetes Association (CDA)	www.diabetes.org.uk
Diabetes New Zealand	www.diabetes.ca
	www.diabetes.org.nz

The World Wide Web is constantly changing, and being updated. Some sites cease to function, or change Web addresses. Therefore any printed list of Internet information will necessarily become out of date. A site with up-to-date information about the latest diabetes resources on the Web is David Mendosa's "On-line Diabetes Resources" at <http://www.mendosa.com/diabetes.htm>. Reproduced with permission from Lehmann.¹

pages and keeping them up-to-date actually can be quite a time-consuming exercise. If sub-contracted out, this can necessitate a considerable amount of resources or on-going funding. Furthermore, dealing with all the e-mail enquiries that can arise from a website can also take time.

The costs of Web hosting and publishing material on the Internet have fallen dramatically in recent years, and nowadays a site can be easily hosted for around \$100 (US) per year. This has led to a sharp rise in the number of personal and small organisation websites providing information about diabetes. The number of diabetes websites that were created in a "fit" of enthusiasm in the early days of the Internet, but which have not been updated since, is a testament to this. Also separating the "wheat from the chaff," and good websites from the not so good, is not so straightforward. Various vetting systems have been proposed (e.g., <http://www.hon.ch/HONcode>), but these have not yet been universally adopted, and, as with much of the Web, it is a case of *caveat lector* (reader beware).

However, while there are a plethora of websites devoted to diabetes care and diabetes education, there seems to have been relatively little evaluation of the true benefits of such sites. Intuitively it would seem self-evident that providing patients with accurate information about their condition can only be a "good

thing." However, as with medical Internet sites generally there do not appear to have been many robust attempts to test out this hypothesis with randomised controlled trials (RCTs) comparing usage of diabetes websites with other media. Furthermore, while assessment of the perceived educational benefits of a standard informational diabetes resource such as, say, the American Diabetes Association website at <http://www.diabetes.org> might be one thing—the need for evaluation becomes all the more relevant with less standard uses of the Web.

For instance, there are websites that offer people with diabetes facilities to upload their blood glucose data onto the Internet and graph their results online. While such sites may offer patients and their HCPs greater flexibility, which of course is a good thing, the objective benefits of such tools—as with much of the use of Internet-based applications in clinical diabetes care—remains to be objectively proven and demonstrated in formal evaluation studies.

In addition to textual and graphical information on the Web, a fair amount of software that has been written for use by people with diabetes and/or their carers can also be found on the Internet. Some of this is even available without charge, for free, as so called "freeware" software. A good list of such programs, both freeware and commercial, can be found at

TABLE 2. CATEGORIES OF DIABETES COMPUTER SOFTWARE AVAILABLE ON THE WEB

Web-based software	20 programs
Commercial Windows software	26 programs
Shareware and freeware Windows software	24 programs
MS-DOS software	10 programs
Software for Macintosh and other computers	23 programs
Platform-independent software	3 programs
Diet and food programs	5 programs
Discontinued software	19 programs

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<http://www.mendosa.com/software.htm>. Table 2 summarises the categories and number of computer programs that can be found here. Further information about a wide range of other diabetes Websites can also be found at <http://www.mendosa.com/diabetes.htm> or in Lehmann.⁵

Additional uses of the Internet for sharing information about diabetes include e-mail and Web-based diabetes discussion forums and chat rooms. Table 3 lists a few of the larger of these. The views expressed in these are unedited, are often unmoderated, and can sometimes be plainly wrong. Nevertheless, much of the information seems to be of interest to people with diabetes and their carers. Judging by the thousands of subscribers regis-

tered with some of these facilities and the countless e-mails that are exchanged, clearly people do find these services very useful. Indeed there can be few primary care physicians/general practitioners and hospital-based HCPs in industrialised countries who have not had patients bring them printouts from such diabetes discussion lists or the wider Internet.

DEVELOPING A BUSINESS MODEL

As illustrated by the dot com (.com) boom and crash, a number of Website owners have found that making money out of the Internet—despite the wide, potentially global, market—can be fraught with difficulties. In particular, a

TABLE 3. DETAILS OF A SELECTION OF DIABETES E-MAIL LISTS AND DISCUSSION FORUMS

Usenet newsgroups. Many of these are now also accessible via the Web, for instance via <http://groups.google.com>:
 misc.health.diabetes: <http://groups.google.com/groups?&group=misc.health.diabetes>
 alt.support.diabetes: <http://groups.google.com/groups?&group=alt.support.diabetes>
 alt.support.diabetes.kids: accessible via the same Web address
 alt.support.diabetes.uk: accessible via the same Web address
 Yahoo! groups (<http://dir.groups.yahoo.com>) has a wide range of discussion groups freely available. A directory of all its diabetes-related groups can be found at:
[http://dir.groups.yahoo.com/dir/Health_ _Wellness/Support/Illnesses/Diabetes](http://dir.groups.yahoo.com/dir/Health_-_Wellness/Support/Illnesses/Diabetes)
 Microsoft Network (MSN) Web Communities (<http://communities.msn.com/home>) all have message boards. The most active MSN message boards related to diabetes are:
 MSN Diabetes: <http://communities.msn.com/Diabetes>
 MSN Diabetics Support Room: <http://communities.msn.com/DiabeticsSupportRoom>
 The Lehigh “Diabetic” e-mail list is the oldest, and one of the largest and most active of all the on-line groups concerned with diabetes. To join the “Diabetic” list you need to send an e-mail to listproc@lehigh.edu containing the message: subscribe diabetic firstname lastname. Once subscribed you will receive instructions by e-mail about how to post messages.
 The Lehigh Diabetic Archive contains a repository of messages sent via the “Diabetic” mailing list. This archive can be viewed at <http://listserv.lehigh.edu/lists/diabetic>
 A website with details of many more diabetes discussion forums and e-mail lists can be found at: www.mendosa.com/diabetes.htm

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number of the .com software firms that developed and distributed diabetes-related programs in the early days of the Internet appear to no longer be trading now. Whether this is a result of the .com bubble bursting is not clear—but a number of commercially developed programs that were quite fun and/or medically/clinically useful are no longer around or easily available now because of commercial or other pressures. For instance, a medical computer game producer, Raya Systems Inc., is no longer trading, and so fun diabetes-computing games for kids with diabetes and their friends—such as *BGPilot*, *Captain Novolin*, *Captain Novocare*, and *Packy & Marlon*—overviewed elsewhere,^{1,6} are all no longer being sold. At <http://www.mendosa.com/software.htm> a list of over 18 other discontinued diabetes computer programs can also be found.

Furthermore, a number of software developers have reported commercial difficulties with actually selling their diabetes program(s) despite having novel, useful software—which in some cases have been encouragingly evaluated in RCTs. For instance, the *Packy & Marlon* video game was unsustainable commercially, even though ported to a PC platform, and tens of thousands of copies were sold. This is despite being successful clinically, certainly in one RCT.⁷

The interaction between software development and diabetes commerce is a complex area, beyond the scope of this column. Nevertheless, issues of business cases/financial overheads do become of importance in assessing the financial viability of the on-going sale and distribution of diabetes software. Clearly costs must be kept to a minimum if the commercial sale of some program is to succeed.

Without a doubt there were lots of wild claims made during the .com “boom” so that now people are (understandably) somewhat sceptical about such claims. However, a healthy dose of realism does seem to have entered the marketplace. In addition to there being examples of diabetes software developers no longer trading, there are also cases of software no longer being supported, or not working with the latest operating systems, so over time such programs may become out of date or

unusable. Therefore on-going simple maintenance of software, as well as updating programs, becomes an important issue.

There must be a lesson in here somewhere for such commercial developments and other software developers. Basically it is not just enough to produce a useful program and validate it. As well as clinically evaluating the program, unless it is going to be distributed for free, there also needs to be a well-thought-out business case. This is required to facilitate the long-term commercial distribution of the software. Without such a commercial case, fun products may be developed, but they may not stay around long enough to really make an impact and benefit a large number of people with diabetes. Quite what that business model should be is unclear—but many commercial entrepreneurs seem to be moving towards subscription-based services where subscribers pay for on-going use of a service, as opposed to paying just once to purchase the program. Such a subscription-based business model may possibly be one way to sustain on-going research, development, and distribution of information technology-based applications in diabetes care.

However, if the motivation is not to make money, there are alternatives. A business model is by no means the sole approach to software development and distribution. Many useful diabetes-computing programs are distributed for free, and an open-access approach to software coding has been shown to have major benefits⁸; programs like Linux challenging even the domination of Microsoft™ Windows™ in the operating system market. There are also many computer software developments now that make use of a .GNU public licence (<http://www.gnu.org>)—making the software source code open access to all who wish to further develop such applications. Time will tell whether this approach catches on in the diabetes-computing field.

FURTHER TOPICS

If you would like to suggest further topics or Websites for future “Diabetes Information Technology and WebWatch” columns, please e-mail information—with a brief description of

the site/suggestion—to Dr. E.D. Lehmann: info-www@2aida.org (please write Diabetes WebWatch in the subject line). You can also fax information to: (503) 218-0828, quoting Diabetes Information Technology and WebWatch.

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