ABSTRACT

AIDA is a diabetes-computing program freely available from www.2aida.org on the Web. The software is intended to serve as an educational support tool, and can be used by anyone who has an interest in diabetes, whether they be patients, relatives, health-care professionals, or students. In 1996, during the beta-testing phase of the AIDA v4 project, the British Diabetic Association (BDA)—now called Diabetes UK—was approached and offered the AIDA software by the author, without charge, as a noncommercial contribution to continuing diabetes education. The BDA undertook their own independent assessment of the program, which involved distributing AIDA to a panel of potential end-users (health-care professionals and patients). Comments were solicited regarding the utility, clarity, and perceived safety of the software from users outside the BDA, as well as from various internal assessors. As a result of the feedback, a decision was taken by the BDA to offer AIDA to health-care professionals through the BDA’s health-care professional brochure. One thousand copies of the software were produced on diskette, and 1,000 copies of the BDA’s version of the program’s user guide—printed as a small book—were made available for distribution by post. In this Diabetes Information Technology & WebWatch column an overview is given of the anonymous feedback provided to the BDA by some of the external evaluators. Looking back, nearly 8 years after the launch of AIDA, it is interesting to review some of the comments received and compare these with what has actually happened with the software. To date over 400,000 visits have been logged at the AIDA Web pages, and over 80,000 copies of the program have been downloaded free-of-charge. It is highlighted that this widespread downloading of, and interest in, the AIDA software seems to largely have been fuelled by the program’s free availability on the Internet. The use of the World Wide Web to enhance the distribution of other medical (diabetes) programs is highlighted.

1Academic Department of Radiology, Barts and The London NHS Trust, St. Bartholomew’s Hospital; and Department of Imaging (MRU), NHLI (Imperial College of Science, Technology and Medicine), Royal Brompton Hospital, London, United Kingdom.
2Dr. Lehmann is a co-developer of the AIDA diabetes simulator.
AIDA is an independent, noncommercial development which is being made available free-of-charge via the Internet—at a dot org (.org) not-for-profit Website—as a noncommercial contribution to continuing diabetes education.
INTRODUCTION

AIDA is a freeware computer program that permits the interactive simulation of plasma insulin and blood glucose profiles for demonstration, teaching, self-learning, and research purposes. It has been made freely available, without charge, on the World Wide Web as a noncommercial contribution to continuing diabetes education. In the nearly 8 years since its original Internet launch well over 400,000 visits have been logged to the AIDA Web pages at www.2aida.org, and over 80,000 copies of the program have been downloaded, gratis. Further copies have been made available, in the past, on diskette by the system developers. The AIDA software and its use have been described previously in this journal, as well as elsewhere in the literature. In previous articles, and Diabetes Information Technology & WebWatch columns, various indicators of usage of AIDA have also been reviewed, and various comments from users of the software have been documented.

METHODOLOGY

In 1996, during the beta-testing phase of the AIDA v4 project, the British Diabetic Association (BDA)—now called Diabetes UK—was approached and offered the AIDA software, without charge, by the author as a noncommercial contribution to continuing diabetes education. The BDA undertook its own independent assessment of the program, which involved distributing AIDA to a panel of potential end-users (health-care professionals and patients). Comments were solicited regarding the utility, clarity, and perceived safety of the software from users outside the BDA, as well as from various internal assessors. Some of the feedback was apparently made informally (by telephone). Comments from eight of the external evaluators were passed back in an anonymised fashion to the author. As we approach the 8th anniversary of the launch of AIDA, it is interesting to review these comments and compare them with what has actually happened with the software.

Table 1 illustrates some of the questions asked of the evaluators by the BDA. All the anonymised responses that the author received back from the BDA are reproduced below.

PATIENTS’ RESPONSES

Patient #1

Although I have had some involvement in the development of the AIDA program and the User Guide, I will try to answer your questions [as] objectively as possible.

Table 1. Questions Posed of (a) Health-Care Professionals and (b) Patients with Diabetes in the BDA’s Assessment of AIDA

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<th>(a) Health-care professional questions:</th>
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<td>1. Do you consider there is a demand for this type of product?</td>
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<td>2. Is the product medically accurate?</td>
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<td>3. In your opinion, does the product have educational (or other) value?</td>
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<td>4. Is the product suitable for unsupervised use by people with diabetes?</td>
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<td>5. Is the product useful in a clinical education situation?</td>
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<td>6. Is the product useful for training of health care professionals?</td>
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<td>7. What is your opinion of the content and design?</td>
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<td>8. How, if at all, in your opinion, could the product be improved?</td>
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<td>9. How computer literate do people need to be in order to make full use of the product?</td>
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<th>(b) Patient questions:</th>
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<tr>
<td>1. Do you consider there is a demand for this type of product?</td>
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<td>2. Did you find the package easy to use?</td>
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<td>3. What is your opinion of the content and the design?</td>
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<td>6. What value does the product have from the point of view of someone with diabetes?</td>
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<td>7. How much do you need to know about diabetes in order to benefit from the package?</td>
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<td>8. How, if at all, did your knowledge of blood glucose control increase after using the product?</td>
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Derived from Lehmann.
Do you consider there is a demand for this type of product? Yes I do consider there to be a demand for this program; since this version of the program has become available over 1300 copies have been downloaded from the Diabetes UK-AIDA web site. The program is also available from two other web sites and I understand that over 250 copies have been downloaded from those sites.

Did you find the package easy to use? The program is reasonably easy to use once you have used it several times. I did have some difficulty in finding my way around the program initially, although that was with the pre-release version of the current program. The availability of a hard copy of the User Guide would make it easier to get started with the program.

What is your opinion of the content and design? Overall I think the content and the design is very good.

How, if at all, in your opinion, could the product be improved? As a DOS based program I don’t think the program could be improved. The next logical step would be to develop a Windows based version of [the] program.

How computer literate do people need to be in order to make full use of the product? People need to have a basic understanding of how to use computer programs, most of the program is reasonably self explanatory.

What value does the product have from the point of view of someone with diabetes? I think the product can have a great value to someone with IDDM [insulin-dependent diabetes mellitus]. It would be extremely useful as a teaching aid to newly diagnosed diabetics to explain the interaction between insulin and carbohydrates. Understanding this interaction took me a long while to [get to] grips with when I was diagnosed. This program would be able to show people what happens when you make adjustments [to] your regime.

I also find the program useful if I have to make significant changes to my regime; although the program cannot accurately predict what will happen with individuals, it does give a reasonable indication of what might happen and in particular in identifying times when hypo might occur.

How much do you need to know about diabetes in order to benefit from the package? I feel you need to have a basic understanding of diabetes in order to benefit from it. As I said before it would be useful as a training aid for newly diagnosed diabetics.

How, if at all, did your knowledge of blood glucose control increase after using the product? I have been a diabetic for nearly 10 years and I already have a good understanding of BG [blood glucose] control; therefore my knowledge did not significantly increase after using the program.

Patient #2

I have found AIDA to be useful although having been a diabetic for 37 years, you can’t teach an old dog new tricks. I certainly don’t use it on a daily basis although, when traveling abroad and having to deal with time changes, I have experimented with it. The best diabetic patient care comes from the patient themselves and subsequently, the more they know, the better they care.

The authors have done a fine job with AIDA. My constructive criticisms would be that:—

1. As a program that would appeal to doctors, nurse practitioners and patients alike, it is difficult to phrase such software in a language all would understand. At present, it appears to be written by a doctor for doctors (e.g.: page one in Graphics). This is a superb package for teaching all concerned but for the patient of whatever age, it reads like a paper for the Lancet! You would not insult the intelligence of those who are doctors by explaining, in plain English, to those who aren’t.

2. The graphics and presentation could be better. Appreciating that huge funds and time were not available, one can see why it looks as it does. The software does the job but graphics and presentation count for a lot. Some of the colours used are gaudy and some coloured backgrounds used for text...
make the text difficult to read, even on a high resolution monitor like mine!

3. Although this software is likely to be used on many different computers, I would suggest that in most cases it is likely to be used under Microsoft Windows or Windows 95. You don’t need to be a rocket scientist to use this software but a better user interface would be advantageous. Many novice computer users don’t know the DOS environment or how to change directories, although adequate guidance is given in the manual. It would be of great help if you could use a computer mouse within the program as well.

I found this software an education to read and of practical use on many occasions. The better informed a diabetic becomes, the better they are at taking care of themselves. Doctors and nurse practitioners will be helped by this software in its current format but I think the greatest benefit will be derived by the patients themselves.

I have always been of the opinion that when I visit a doctor, it is but for a fleeting moment to get advice (and, of course, for emergency help when I get it wrong!!). It is I that bears the responsibility of day to day treatment. Anything that helps me do that more effectively can only be a good thing. This software helps me do that.

For the non computer users, seeing and using this software on a GP [general practitioner] or hospital visit would be a fine education. A more patient orientated package would be an advantage in this situation.

As for the future, I think of when I became a diabetic aged seven. I was told I would have to stick a needle in me for the rest of my life! Things have changed, I know, but a children’s version of something similar would be a great success. Think how many children are more computer literate than ourselves!

Patient #3

General observations. Overall I thought the package would have been most helpful when I was first diagnosed, perhaps being shown it in conjunction with guidance from a practice or diabetes specialist nurse.

However, having come to expect so many applications to be Windows aware it was strange to see something where the interface is so ‘unsophisticated.’

Installation. Instructions on disk label rather unclear: should say something like ‘place disk in disk drive and from Windows File menu choose RUN and type in SET UP.’

Some of the colours for screens are unpleasant (yellow background and green text for example—makes reading difficult?).

Set-up/Quick start instructions. Annoyingly refers to ‘his’ or ‘him’—a ‘her’ from time to time would be nice?! Once set-up has finished, there are no instructions on the last screen (starting with the text “Selecting option n for No. . . . “) as to which key to press next.

Win95 installation instructions “Environment not found” didn’t cure problem. I tried changing the initial environment setting to 512 and it now works.

Case scenario browser. Would be better to see more of a list rather than a form view of the data. Navigation instructions take up far too much space on this screen.

I would expect the up arrow to take me backwards and the down arrow to take me forwards, not the other way around as programmed.

Patient #4

Before I give you my comments on the above product, may I just let you know a little about myself and therefore, under what authority I can comment on this subject.

I was diagnosed type 1 diabetic on the 10th October 1995.

Some days there is very little stress, other days you can be hit with a whole lot within half an hour. . . . Therefore, the use of four injections a day using Actrapid and Insulatard is really the only way of attacking the day. I use a blood [glucose] meter which records the readings and will download the maximum number of 250 readings into an Excel spreadsheet, which then gives me the ability to plot a graph week by week to show the amplitude and in-
deed, work out the RMS [root mean square] to see what the maximum and minimum swings are in my readings. As we all know, the amplitude is the dangerous point and leads to long term problems with the glycated albumin and other by-products.

The process of loading AIDA on to a PC was certainly not difficult, although my first observation is that if this was written as a Windows package, it would certainly be much more compatible. The programme did not give the same results as the graphs that I get from my real time values. This is because stress and exercise are not incorporated as part of the programme. I fully understand that the objective of the programme is to show the effects of insulin and carbohydrate on the subject’s blood glucose levels.

The most important point to note would be the prevention of any hypo-glycemic attack, which is the most frightening thing at [an] early stage of diagnosis. Therefore, my question would be is there any way we could allow for the system to calculate, even in a rough scheme of things, the effects of exercise, stress and alcohol. For example, after a year of being diabetic, I can safely say that the effects of alcohol are easier to monitor and control than huge fluctuations that are caused by exercise. For example alcohol can result in a 2 or 4 point movement in blood glucose levels and exercise could be as 5 to 7 points. The consequence of regular exercise can have a greater effect in the delayed reaction than people realise. I completely understand that the reaction will be different for every individual but maybe an indication would be more useful than showing nothing?

I think in terms of “Is the product useful for training of healthcare professionals?” my answer would be that there are so many factors which are different in every diabetic that the programme does not cover these aspects. In my own experience, the most important thing is to encourage regular testing on diagnosis and to stress the point that fluctuations in the readings is what you are trying to avoid. When I was diagnosed, the doctor concerned had no way of showing me a simulation of the effects of my life style. I was told that I could get away with testing once a day and should remain on a two injection a day regime. This is not something that would work and indeed, could cause problems in later life if I had stayed to it. If there had been an educational product that could have all the events of my day put into it, we might have been able to reach the conclusion of what treatment was more suitable a lot quicker. I now see someone in London who is fairly high up in the world of diabetes and agrees with many of the ideas to do with control and prevention earlier on in life, rather than suffering the consequences or trying to solve the problems in later life.

In summary, I feel that the product does not give a wide enough education to the individual and since it is not written in Windows, you would find it difficult for many people to pick up and use. The concept is fantastic and if funds could be found to take this further, I am sure it would be exactly what the market needs. If I could be of any help please do not hesitate to ask. I do a lot of work with software development within my work and therefore I am up to speed with the way in which the “end user” should be treated.

Patient #5

I refer to your letter asking for comments on the above interactive computer programme.

I am very familiar with the product and have been through all its versions. I have also had opportunities to feedback my comments to the authors. Many of my comments have been incorporated. Some have not and remain as negative comments from myself.

I will attempt to answer your questions first.

I am insulin dependent dating back to diagnosis some thirty years ago. I am 62 years old and suffer many diabetic complications. I have always been well controlled—helped by a scientific background and a family full of doctors! I would say I am exceptionally computer literate. I answer your questions in order.

Do you consider there is a demand for this type of product? Yes there is a demand for the product. This has been demonstrated by the interest shown by fellow sufferers and newsgroups on the Internet etc.
Did you find the package easy to use? Yes—easy enough but there are features that could be improved. A programme running under Windows would be better and easier to use by the majority of computer users. The programme is littered with warnings about how not to use it. There are too many of these screens which make it less user friendly than it might otherwise be.

What is your opinion of the content and the design? It is well designed and the content complete enough but it could be made more intuitive.

How, if at all, in your opinion, could the product be improved? See above, i.e. Windows based, fewer warnings, more user control over the presentation, etc. The main content is not questioned.

How computer literate do people need to be in order to make full use of the product? Enough to turn the computer on—and very little more. I have tried the product with two computer illiterate doctors, a semi literate practice nurse and a computer literate (!) eight year old. There were no problems that couldn’t be dealt with quickly and easily. The written help file is very good.

What value does the product have from the point of view of someone with diabetes? I have found it both interesting and useful. It is an excellent training tool to develop an understanding of insulin and insulin regimes on diabetic control. I have also found it a useful tool to educate my wife on what is happening.

How much do you need to know about diabetes in order to benefit from the package? A difficult one for me as I consider myself to be well educated on diabetes. I believe a very basic understanding is required such as the role of insulin, the effect of carbohydrates and the significance of timing.

How, if at all, did your knowledge of blood glucose control increase after using the product? In my case I gained an increased understanding at the detail level with one exception. The exception was to do with the timing of a daily Monotard injection—a change I made to excellent effect (despite the warnings about not making changes without your consultant’s advice!)

My own summary:—An excellent aid to the computer literate in developing an understanding of their conditions. It is also an excellent training tool for those caring for diabetics both lay and professional. I know of no similar product and would strongly support a move by the BDA to back and distribute the product.

HEALTH-CARE PROFESSIONALS’ RESPONSES

Health-care professional #1

In reply to your letter asking for general comments on this product.

1. Do you consider there is a demand for this type of product? I feel the demand is limited due to the very complicated material presented.
2. Is the product medically accurate? Yes.
3. In your opinion, does the product have educational (or other) value? Yes, but for a limited audience.
4. Is the product suitable for unsupervised use by people with diabetes? No.
5. Is the product useful in a clinical education situation? Yes, but for people with sufficient intelligence and interest.
7. What is your opinion of the content and design? There is a tremendous amount of work gone into this product and there is a great deal of information. It is well designed.
8. How, if at all, in your opinion, could the product be improved? It would be useful to a wider audience if it was simplified.
9. How computer literate do people need to be in order to make full use of the product? Basic computer skills are sufficient.

I have asked a number of patients whether they would use it and overall the comments are that they feel that they do not want or need to know all the information given on AIDA. It is a good teaching medium for health care pro-
professionals particularly newly appointed Diabetes Specialist Nurses.

Health-care professional #2

Thank you for your letter concerning the above software teaching programme. We have had a brief look at it. It certainly must have taken the authors a considerable time to put together and they are to be congratulated for the effort they have made. There is a great need for simple and exciting ways to educate diabetics. Good education is the cornerstone of proper therapy and the prevention of complications. A good therapeutic aid is worth three doctors!

Unfortunately we found the programme rather “erudite.” It was only moderately user friendly and was fairly intellectual. It would be extremely useful for, say, a computer literate lawyer who developed diabetes. Thus I don’t think, in its present form, it is suitable for general release. It might however be suitable for a targeted audience. It could be useful for beginner health care professionals who are going to deal with diabetes but its level is probably not sufficient for anyone with real life experience.

I am afraid our assessment of it was quite brief (due to pressure of work etc!!) and I certainly wouldn’t regard my comments as the final word. I doubt that we will be able to give it any more time, however.

Health-care professional #3

Below are my responses to your particular questions:

1. I know that trying to match changing blood sugar to insulin dosage can be very difficult both for patients and doctors. This product would act as a useful tool to the doctor in his choice of insulin dosage and management of diabetes overall.
2. Further to the above I believe this product is relatively accurate.
3. Its great educational value lies in showing patient and health care professional how changes in dietary intake and insulin dosage affect blood sugar.
4. I feel that until proven to be effective in a randomised controlled trial it would be fool

ish to remove the safety aspect of this information coming via a doctor.
5. See 3.
6. Whilst being clear in its approach a colour choice more ‘pleasing to the eye,’ may be advantageous.
7. I am a great believer in being able to use a program without an instruction manual. This product fulfills this without problem except for a lack of instruction on how to alter the initial data.
8. Beginners such as myself should have no difficulty!

RESULT

As a result of the independent feedback—both internal and external—received by the BDA a decision was taken by the organisation to offer AIDA to health-care professionals through the BDA’s health-care professional brochure. One thousand copies of the software were produced on diskette (L. Hallett, personal communication), and 1,000 copies of a BDA version of the program’s user guide were printed—as a small book (Fig. 1)—for distribution by post.

DISCUSSION

To date over 400,000 visits have been logged at the AIDA Web pages, and over 80,000 copies of the program have been downloaded free-of-charge. Looking back, nearly 8 years after the launch of AIDA, it is interesting to review some of the anonymised comments that were received by the BDA and compare these with what has actually happened with the software.

Clearly a wide variety of opinions are expressed, ranging from highly positive to quite negative. If nothing else, such surveys illustrate the need for large numbers of respondents in order to build up an overall picture of interest (or lack of interest) in a medical software program like AIDA. Obviously what works for one person may not be of so much use for someone else. In this respect, education programs often need to be tailored for the particular individual who is meant to learn from the software.
As Patient #4 highlighted above, exercise and alcohol would be two variables of interest for simulation, although these two factors are very difficult to simulate reliably or accurately. Not only is relevant physiological information about these factors not so readily available, but assessing the amount of—for instance—exercise undertaken can be fraught with difficulties. The duration and intensity of activity would need to be recorded, but there is no well-established global measure for this that patients can use. This is quite separate from the fact that the relationship between exercise and blood glucose can be complex. Further research is clearly needed in this area.

Many of the technical issues raised by Patient #3 have been addressed in subsequent updates to the AIDA software. In January 1997 a slightly revised version of AIDA v4.0 was released that had a simpler (improved) colour scheme, compared with the original version. In July 2000 AIDA v4.3 was launched. This incorporated a number of technical improvements—including allowing the option of a Windows install procedure to simplify setup of AIDA on Windows PCs. Along the way the DOS “Environment not found” operating system memory error has been addressed. Also issues about the diskette label instructions have been largely superseded by Internet distribution of the software, which

FIG. 1. Front cover of the BDA version of the AIDA hard copy manual,\textsuperscript{11} which was previously made available, in 1997, to health-care professional members of the BDA in the United Kingdom, together with the AIDA v4 software on 3\(\frac{1}{2}\)“ diskette. The BDA has since been renamed “Diabetes UK.” Reproduced from Tatti and Lehmann.\textsuperscript{12}
has been the primary (sole) method of making the program more widely available, for some time now. In August 2001 the most recent version of AIDA (v4.3a) was released, which contains the most up-to-date version of the software.

The point raised by Patient #2 about the language used to teach patients needing to be different (less technical) compared with that used for doctors/health-care professionals is well taken. However, it remains difficult to have a single “language for all” in one program—unless separate views of the same central data are provided, with different explanations/glossaries of terms. Also the issue of warnings is a complex area. It seems clear that people who make a reasonable amount of use of AIDA understand its limitations and what it is meant for. However, the warnings are really there to prevent any misunderstanding or misuse of the software. The caveats are particularly important for people who may just download the program to “dip” into it—without fully understanding what it can, and cannot, do. To err on the side of caution, the warnings are strong for such casual/occasional users of the software. This is especially the case as with freeware Internet distribution of the program we can have absolutely no control over what people do with the software once it has been downloaded.

An interesting observation to come out of this survey, which has been made before, is that health-care professionals’ views regarding what they think patients may want or need may not actually match what patients themselves are asking for. This certainly seems to be the case with AIDA, with health-carers in some cases perceiving that patients do not need/want so much information, but patients themselves continuing to download and make use of the program (and by implication seeming to want the type of information that AIDA provides).

Related to this, it seems self-evident that the widespread downloading and use of the AIDA software appears to largely have been fuelled by the program’s free availability on the Internet. Clearly, without the Internet, dissemination of information about AIDA would have been much slower and more difficult. Furthermore, without formal funding, international distribution of AIDA for free on diskette/compact disk would not have been feasible. Therefore much of the success of AIDA may in part simply be attributable to its widespread availability via the Web—although hopefully the useful functionality provided also contributes to the program’s ongoing appeal.

To address some of the issues raised above a separate, formal, detailed paper/e-mail-based survey of 200 AIDA users has been completed and is in the process of undergoing data entry and analysis. We hope that this larger study of AIDA users will yield further useful insight into what people think of the software, and how they have actually been using it.

Other medical (diabetes) software developers may find it very helpful, and satisfying, to distribute their own programs for free, via the Internet, in a similar way to AIDA.

ACKNOWLEDGMENT

The author acknowledges the kind help and support of Lesley Hallett, Publishing Director of the British Diabetic Association, in commissioning the feedback comments documented in this column.

FURTHER TOPICS

If you would like to suggest further topics or Websites for future “Diabetes Information Technology & 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 & WebWatch.

REFERENCES


Address reprint requests to:
Dr. Eldon D. Lehmann
c/o www.2aida.org Diabetes Simulator Development Team
P.O. Box 46104
London, EC2Y 8WN, UK

E-mail: info-www@2aida.org
Web: http://www.2aida.org/lehmann