

# Why Are People Downloading the Freeware AIDA Diabetes Computing Software Program: A Pilot Study

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## ABSTRACT

The purpose of this paper is to report a pilot survey about why people are downloading the AIDA interactive educational diabetes simulator. AIDA is a diabetes computer program that permits the interactive simulation of plasma insulin and blood glucose profiles for teaching, demonstration, and self-learning purposes. It has been made freely available, without charge, on the Internet as a noncommercial contribution to continuing diabetes education. Since its launch in 1996 well over 200,000 visits have been logged at the main AIDA Website—[www.2aida.org](http://www.2aida.org)—and over 40,000 copies of the AIDA program have been downloaded free-of-charge. This article documents a pilot survey of comments left by Website visitors while they were downloading the AIDA software, before they had a chance to actually use the program. The overall paradigm adopted for this study has endeavored to establish why people are resorting to the Internet to obtain diabetes information. Specific intended goals of the study were: (1) to demonstrate ongoing use of the World Wide Web for surveying diabetes software users by obtaining their free-text comments; (2) to identify what sort of things people were planning to do with the AIDA software simulator; and (3) to more generally gain some insight into why people are turning to the Web for healthcare-related information. The Internet-based survey methodology was found to be robust and reliable. Over an 8-month period (from February 2, 2001 to October 1, 2001) 642 responses were received. During the corresponding period 2,248 actual visits were made to the Website survey page—giving a response rate to this pilot study of 28.6%. Responses were received from participants in over 56 countries—although over half of these ( $n = 343$ ; 53.4%) originated from the United States and United Kingdom. Two hundred forty-four responses (38.0%) were received from patients with diabetes, and 73 (11.4%) from relatives of patients, with fewer responses from doctors, students, diabetes educators, nurses, pharmacists, and other end users. This pilot survey has confirmed the feasibility of using the Internet to obtain free-text comments, at no real cost, from a large number of medical software downloaders/users. The survey has also offered a valuable insight into why members of the public are turning to the Internet for medical information. Furthermore it has provided useful information about why people are actually downloading the AIDA interactive educational “virtual diabetes patient” simulator.

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The AIDA software referred to in this report 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

**A**IDA IS A FREeware COMPUTER PROGRAM that permits the interactive simulation of plasma insulin and blood glucose profiles for demonstration, teaching, and self-learning purposes. It has been made freely available, without charge, via the Internet as a noncommercial contribution to continuing diabetes education. In the 6+ years since its original World Wide Web launch in March/April 1996 well over 200,000 people have visited the main AIDA Web pages at [www.2aida.org](http://www.2aida.org), and over 40,000 copies of the program have been downloaded, *gratis*.

The AIDA software has been previously described in detail elsewhere in this journal.<sup>1</sup> Briefly, it incorporates a compartmental model that describes glucose–insulin interaction in patients completely lacking endogenous insulin secretion. It contains a single extracellular glucose compartment into which glucose enters via both intestinal absorption and hepatic glucose production. The AIDA model also contains separate compartments for plasma and “active” insulin<sup>2,3</sup>—the latter being responsible for glycemic control, while insulin is removed from the former by hepatic degradation. The actual mathematics underlying the model have been fully documented elsewhere.<sup>2</sup> Details of the AIDA model are also accessible from within the AIDA software package, and can be viewed and printed separately via the Internet (from [www.2aida.org/technical](http://www.2aida.org/technical)). Examples of the sort of simulations that AIDA can offer can be found elsewhere in this journal<sup>1,4–6</sup> and the literature,<sup>7–10</sup> as well as at [www.2aida.org/demo](http://www.2aida.org/demo) on the Internet.

While other interactive simulators of glucose–insulin interaction in diabetes have been described in the literature,<sup>3,8,11–16</sup> to date these do not seem to have been extensively distributed via the World Wide Web, or been made particularly widely available. Furthermore for a number of these<sup>11,13–15</sup> it would seem that readers are totally dependent on the authors’ own descriptions of their prototypes, since no versions appear generally available for usage by others. This is not the case with AIDA, where all the AIDA simulators are freely available on the Internet, without charge, at an independent dot org (.org) not-for-profit Website

([www.2aida.org](http://www.2aida.org)) as noncommercial contributions to continuing diabetes education. However, it is important to point out that AIDA, like other model-based simulators, is not sufficiently accurate to be used for individual patient simulation or glycemic prediction.<sup>17–19</sup> Therefore, as the program and Website make clear, AIDA is not intended for therapy planning and can only be used for teaching, self-learning, or demonstration purposes.<sup>9</sup>

In order to understand more about what AIDA users like and dislike about the diabetes simulation program, and in order to identify what people are finding useful with the software, various preliminary audits and surveys have been undertaken via the AIDA Website ([www.2aida.org](http://www.2aida.org)), and via the program application itself. These are yielding useful information about what sort of people are downloading and using the software.<sup>9,20</sup>

For the current study we had three main aims. These were: (1) to demonstrate the ongoing use of the World Wide Web for surveying diabetes software users by obtaining their free-text comments; (2) to identify what sort of things people were planning to do with the AIDA software simulator; and (3) to more generally gain some insight into why people are turning to the Internet for healthcare-related information.

## METHODOLOGY

For the current work we have sought to establish the feasibility of undertaking a free-text survey about downloading of AIDA v4.3 and v4.3a via the Internet. For this initial, pilot survey we were particularly keen to test out a new approach and find out why people are actually turning to the World Wide Web and downloading the AIDA software.

In this respect, an ongoing, long-term audit has been run via the AIDA download Web page ([www.2aida.org/download](http://www.2aida.org/download)) whereby people accessing the AIDA software have been invited to anonymously answer some simple questions about themselves. Initially five questions were asked;<sup>9</sup> however, since the release of a newer version of the AIDA program, six questions have been used.<sup>20</sup> The basic questions have

been documented previously elsewhere in this journal.<sup>20</sup> In addition to identifying the sort of end users that were downloading the software, a further purpose of the previous surveys<sup>9,20</sup> has been to identify what computer hardware and operating systems people are using—which has facilitated distribution via the Internet of new freeware releases of the AIDA program.

Depending on the speed of the Internet connection (modem, telephone line, Ethernet link, or Broadband, etc.)—it can take around 5 min to download the AIDA software. While this download is taking place it is possible for visitors to be asked questions, and answer them, without interfering with the actual download process. For our continuing audit we have taken advantage of this 5-min “window of opportunity” to ask the questions for which we were seeking answers. We also took advantage of the fact that Internet Common Gateway Interfaces (CGI-BINs) provide an easy way for people to offer responses via the Internet. The use of such CGI-BINs does not require the respondents to have an e-mail address, and, importantly, permits their answers to be submitted completely anonymously. It was felt to be important to allow the responses to be given confidentially—as some Internet users are not keen to identify themselves on the Web. Therefore by keeping the survey anonymous it was expected that the response rate could be increased, with the expectation being that this would reduce the likelihood of people being inhibited about actually answering the questions.<sup>20</sup>

For the current survey—to identify people’s expectations when they download the AIDA software (before they had a chance to try the program)—downloaders who had answered the initial six questions posed on the [www.2aida.org/download](http://www.2aida.org/download) Web page were subsequently asked a further question. This was to anonymously give some indication as to “How do you see yourself maybe making use of the AIDA software?” and in particular “What sort of things do you plan to do with the AIDA diabetes simulator?” (Fig. 1).

It was felt best, for the current study, to ask the main survey question of people who had already volunteered to answer the previous six questions<sup>20</sup> in order to select out site visitors

who would be less likely to provide meaningful responses. Connected with this, it was felt that people who were not willing or able to complete the initial survey—with simple pull-down menu questions/answers—would be unlikely to provide meaningful free-text responses. Therefore the comments documented below are necessarily from a self-selected group of AIDA downloaders. Nevertheless the responses are illuminating. Furthermore, while the question that was posed is quite simple, the power of such a Web-based survey comes from the large number of replies that can be received over a period of time.

AIDA Website visitors were surveyed for a period of 8 months between February 2, 2001 and October 1, 2001. Responses were submitted by end users using a “guestbook”-type of free-text CGI-BIN script operating on the AIDA Web server. All comments were each individually stored in a dedicated HyperText Markup Language (HTML) database at the AIDA Website. The raw, source data for this pilot study—from both the main AIDA Website ([www.2aida.org](http://www.2aida.org)) and from the former AIDA U.S. mirror site (<http://us.2aida.org>)—can be viewed directly on the Internet at [www.2aida.org/why](http://www.2aida.org/why) (Fig. 2). (Please note that since this study was undertaken the AIDA U.S. mirror site has moved from <http://us.2aida.org>—which was based in Baltimore, MD—to a new separate facility at <http://www.2aida.net>—based in California.)

## RESULTS

Six hundred forty-two pilot survey responses were received during the 8 months between February 2, 2001 and October 1, 2001. During this period there were 2,248 visits logged in total to the pilot survey Web pages at the main AIDA Website and the former AIDA U.S. mirror site—accessible by answering the preliminary questions at [www.2aida.org/aida/aidadown.htm](http://www.2aida.org/aida/aidadown.htm) and <http://us.2aida.org/aida/aidadown.htm>—giving a response rate to this pilot survey of 28.6%.

Two hundred forty-four responses (38.0%) were received from patients with diabetes, 73 (11.4%) from relatives of patients, 67 (10.4%) from doctors, 33 (5.1%) from students, 24 (3.7%)



Thank you for answering those six questions. If you wish to be automatically informed by email about updates and enhancements to the AIDA software range - please feel free to join the AIDA registration / announcement list by sending a blank email note to: [subscribe@2aida.org](mailto:subscribe@2aida.org)

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While you are downloading your copy of AIDA it would be much appreciated if you could also anonymously give some indication as to how you see yourself maybe making use of the software. Any comments you provide are once again completely confidential - but they will give the AIDA developers some idea as to how people are planning to make use of the program.

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What sort of things do you plan to do with the AIDA diabetes software simulator?  
(free text)

Plan to use the simulator to experiment with different insulin regimens, and see how best to combine insulin and diet. I won't make any changes to my regimen on the basis of the simulations (without discussing the suggestions first with my doctor), but I hope to learn some things that might help me in the long term improve my blood glucose control.

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If you are providing some comments, it would really help if you could quickly answer the next two questions (again)

Which of the following categories best describes you?

Where are you from?

- A patient with diabetes
- A relative of a patient
- A student
- A doctor
- A nurse
- A diabetes educator
- A pharmacist
- None of the above

FIG. 1. Shows the Web page at the AIDA Website (accessible by answering the six questions at [www.2aida.org/download](http://www.2aida.org/download)) where downloaders can provide their survey responses. In addition to the free-text comments about "What sort of things do you plan to do with the AIDA diabetes software simulator?" respondents were asked to confirm which country they were from and what sort of category best described them.

from diabetes educators, 13 (2.0%) from nurses, 13 (2.0%) from pharmacists, and 11 (1.7%) from people with an information technology interest. Twenty-one responses (3.3%) were received from people who regarded themselves as being in none of the aforementioned categories. Thirty-seven responses (5.8%) were received from people who seemed to "miss the point" as to what AIDA was about, with 100 responses (15.6%) being received from people who reported that they were downloading the program to find out what it was all about. Only four responses (0.6%) were from people who reported intending to try and adjust their carbohydrate intake/insulin regimen using the program (the software is not meant for this). Two responses (0.3%) were entered in non-English languages that could not be interpreted.

Responses were received from end users in

over 56 countries, including (in alphabetical order): Argentina, Australia, Austria, Belgium, Brazil, Bulgaria, Canada, China, Colombia, Czech Republic, Denmark, Egypt, Finland, France, Germany, Greece, Hungary, India, Indonesia, Israel, Italy, Japan, Korea, Latvia, Lebanon, Libya, Malaysia, Maldives, Mexico, Nepal, the Netherlands, New Zealand, Norway, Philippines, Poland, Portugal, Romania, Russia, Saudia Arabia, Singapore, South Africa, Spain, Sweden, Switzerland, Syria, Taiwan, Thailand, Togo, Trinidad and Tobago, Turkey, United Kingdom, United Arab Emirates, Uruguay, U.S. Minor Outlying Islands, United States, Uzbekistan, Venezuela, and Yugoslavia. However, over half the responses (53.4%) came from the United States and the United Kingdom: 233 (36.3%) and 110 (17.1%), respectively. Table 1 summarizes the number of responses

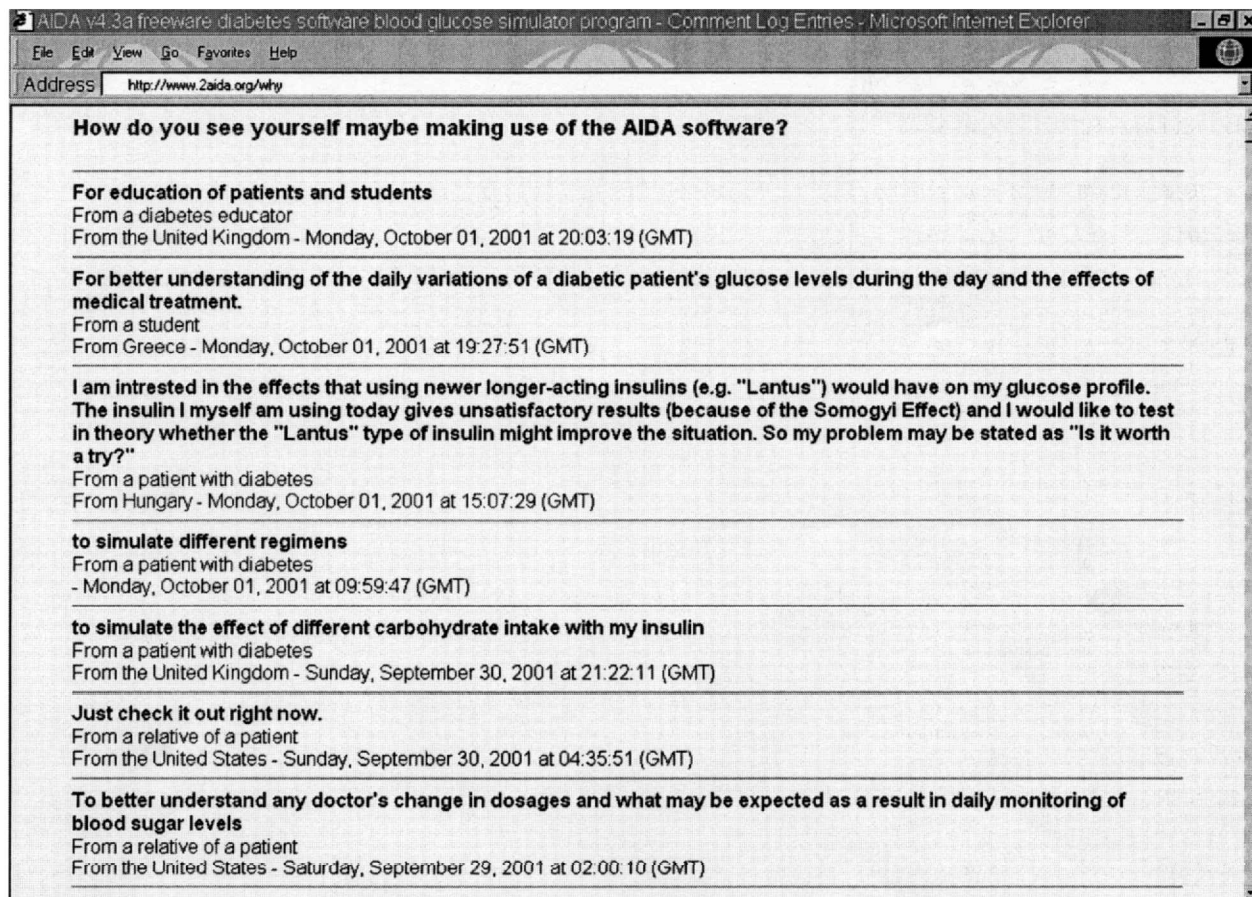


FIG. 2. Shows some of the respondents' comments as stored in the HTML database at the AIDA Website. These can be viewed directly at [www.2aida.org/why](http://www.2aida.org/why) on the Internet.

per country with five or more responses. For 118 responses (18.4%) no country was specified.

These summary statistics, although interesting, do not, however, tell the personal story as to why people have actually been turning to the Internet and downloading the AIDA software. Limited space precludes publication here of all the free-text comments—although these can be read directly on the Web at [www.2aida.org/why](http://www.2aida.org/why). Nevertheless, selected responses are documented in the Appendix under separate headings for each of the groups of respondents.

## DISCUSSION

While a large number of downloads of the AIDA software have been logged on the Internet, up to now, apart from user testimonials about the program<sup>7,21,22</sup>—and *ad hoc* com-

ments received by the system developers via e-mail<sup>23–25</sup>—there has been little formal assessment as to who has actually been downloading or making use of the simulator, or more importantly, *why*.

In the Appendix selected comments left by visitors at the AIDA Website have been documented. These illustrate the wide variety of ways in which people from a large number of different backgrounds expected to make use of the software. While some of the respondents in this pilot survey clearly missed the point about AIDA, and what it is meant for—the majority seemed to expect to derive some benefit from use of the simulator—and for the correct, intended purpose of the program. Their comments also mirror those of independent health-care professionals, as well as people with diabetes and their relatives, and others who have actually used the simulator. A range of these comments can be found at [www.2aida.org](http://www.2aida.org).



TABLE 1. SUMMARY OF THE NUMBER OF RESPONSES PER COUNTRY WITH FIVE OR MORE RESPONSES

Country	Number of responses <sup>a</sup>	Percentage (of 642 total)
United States	233	36.3
United Kingdom	110	17.1
Canada	30	4.7
India	16	2.5
Australia	13	2.0
Germany	13	2.0
Brazil	9	1.4
Mexico	7	1.1
South Africa	6	0.9
The Netherlands	5	0.8

<sup>a</sup>442 responses (68.8%) from 10 countries. The remaining 200 responses (31.2%) from over 46 other countries (with four or fewer responses per country) are not shown. No country was specified for 118 responses (18.4%).

org/reviews on the Web. However, while intuitively the benefits of such an interactive educational diabetes simulation approach may seem self-evident, it is acknowledged that formal evaluation studies are still required, as for any other medical intervention, to demonstrate a definite clinical/educational utility for the use of such software.

Connected with this, it is a responsibility of programmers to fully evaluate their software and learn as much as they can from their users. Only in this way can programs be refined and improved, and enhancements made to the functions offered by such software applications. This need to assess and evaluate a program's usage is particularly important with healthcare applications, where many programs seem to fail both due to human factor issues—such as the ease of use of the user interface—as well as due to concerns about what it is claimed the program can actually do.

For the current survey it was felt to be informative to discover *why* people are in the first place actually turning to the AIDA site and downloading the program. To address this point a pilot study has been run whereby visitors to the Website who answered selected questions on the AIDA software download Web page were then asked how they maybe saw themselves making use of the AIDA program.

In this respect, the current pilot study has confirmed the feasibility of using the Internet to solicit free-text comments from large numbers of users/downloaders of diabetes software. It has also provided useful and interest-

ing information—highlighting that nearly half the respondents [317 (49.4%)] are people with diabetes or their relatives. We do not wish to overinterpret these findings—but it is a recurring observation being made in separately conducted audits/surveys<sup>9,20</sup> that so many patients and their relatives are turning to the Internet for diabetes-related information and guidance. Perhaps, however, we should not be surprised by this.

Various studies have been reported as showing that 65% of consumers in the United States get medical/health information from the Internet, and apparently up to 45% of all Web searches are healthcare-related.<sup>26</sup> Connected with this a substantial proportion of patients with chronic conditions seem to look for information about their disease on the Web, with the implication being that they may not be getting all they need from their healthcare professionals locally. In diabetes care, perhaps this is understandable—because of the lack of time and resources available to healthcare professionals and the increasing number of patients with diabetes who require treatment and long-term care. In this respect a gap clearly exists between the intellectual knowledge of clinicians and the needs of patients. However, a question that remains to be formally assessed is whether information technology can help to bridge some of this gap.<sup>10</sup>

#### *Indicators of usage*

Clearly this pilot survey has some limitations. Most obvious is the fact that, like many

surveys, it is based upon self-reported data, although the substantial number of responses received do go some way to offset this. However, a relatively major limitation of the current study is that while it offers an indication as to *why* people have been downloading the software—we do not know how much these people have actually used AIDA. For instance, whether people download the install file and then do nothing with the program—or use it a great deal—cannot be formally established from a survey conducted, as this one has been, at the point of download. However, “word of mouth” referrals, as are overviewed below, do imply that people are using the program, and that is why they are telling others.

Furthermore we do have various other methods of assessing use of the simulator—and all these different indicators need to be considered together to compile an overall perspective of usage. For instance, numbers of AIDA program downloads and numbers of AIDA online Web-based diabetes simulations at [www.2aida.org/online](http://www.2aida.org/online)<sup>16,27</sup>—as documented elsewhere<sup>20</sup>—provide an indication of ongoing interest and usage.

Similarly, since AIDA moved to its own standalone Website at [www.2aida.org](http://www.2aida.org) in October 2000 it has been possible to properly monitor the dedicated statistics (logstats) for the site. A full analysis of these will be reported separately. However, it is interesting to note that during the 273-day period from February 2, 2001 to November 1, 2001—which encompasses the current pilot survey—there were in total over 1.3 million requests for information (“hits”) received at the AIDA Websites. Over the 273-day period this equates to approximately 4,795 requests for information each day, with in total 34,925 distinct external hosts being served; 8.47 gigabytes of data were transferred from the AIDA Websites during this time—which equates with an average transfer rate of 31.85 megabytes of data per day.

As well as the downloadable AIDA PC install file, there is a considerable amount of extra useful information available at the AIDA Websites. For instance, in addition to the Web-based version of the simulator (AIDA online)—accessible directly at [www.2aida.org/online](http://www.2aida.org/online)—there is also a diabetes-insulin tutorial that can be accessed directly at [www.2aida.org/tutorial](http://www.2aida.org/tutorial). This on-line tutorial aims to teach a little bit

about balancing insulin and diet in diabetes, as well as offering some information about different insulin-dosage adjustment regimens.

While there are many sites on the Web that offer information about the different types of insulin that are available, and their action profiles, etc.—for the most part such sites provide static repositories of information, which can be read/viewed—but with little or no interaction being possible. The AIDA online diabetes-insulin tutorial aims to be different by combining such purely static/informational Web pages with a more dynamic Web-based diabetes simulator to allow interactive educational simulations to be performed of clinically relevant diabetes situations. Therefore, while reading about, say, “conventional insulin therapy” it is possible to click on an HTML link and see some examples of such therapeutic regimens being simulated. The intention is that this approach should provide a more integrated (and fun) way for people to learn some more about diabetes. It is also expected that combining static/informational Web-based resources with AIDA online will offer a more sophisticated/“intelligent” way of making use of what the online diabetes simulator can offer.

In total there are more than 200 Web pages at each AIDA site, and numerous portable document format (PDF) diabetes articles, all of which can be accessed completely free of charge. No single indicator can offer a definitive view of continued use of the diabetes simulator/Website. However, it does seem particularly informative when a whole series of variables [e.g., number of program downloads and on-line simulations,<sup>20</sup> user comments, diabetes article downloads, Website statistics (logstats), and survey results] from different sources, and collected in different ways, all point in the same direction, as they do for AIDA.

## CONCLUSION

While this current research is clearly qualitative—there is a very real need for such studies to understand more about why people are turning to the Web for medical information. In this respect, there is a massive expansion in use of the Internet, and for healthcare purposes it would appear that information retrieval via the

Web is on the increase. Therefore it becomes important to learn as much as possible about why patients, and relatives, as well as others are turning to the World Wide Web for this type of information.

In diabetes there is a marked increase in the number of cases that are being diagnosed, with important personal, societal, and economic ramifications. Given this, it becomes important with this growing "burden" of disease to try and establish if properly applied use of the Internet, as well as information technology in general, might be able to assist in the more widespread provision of quality diabetes care.

Connected with this, the current pilot survey is obviously only one very small step on a long, long road. However, the free-text comments documented in the Appendix do go some way to help us appreciate why people are resorting to the Internet to obtain general diabetes healthcare information, and more particularly throw some light on why members of the public are actually downloading the AIDA diabetes software.

#### APPENDIX: "HOW DO YOU SEE YOURSELF MAYBE MAKING USE OF THE AIDA SOFTWARE?"

##### *Downloader comments from patients with diabetes*

From the UK: To help understand the effects of insulin over time versus carbohydrate intake and potentially compare the simulation results with my own blood glucose levels.

From the USA: See how I can get ideas to improve my health. But nothing is ever done without a doctor's involvement.

From the USA: Find out more about how well insulin will react with the carbohydrates that a person consumes, as well as how long it will take for the reaction to take place and how long it will last.

From Hungary: I am interested in the effects that using newer longer-acting insulins (e.g., "Lantus") would have on my glucose profile. The insulin I myself am using today gives unsatisfactory results (because of the Somogyi Effect) and I would like to test in theory whether the "Lantus" type of insulin might improve the

situation. So my problem may be stated as "Is it worth a try?"

From the USA: I have only been on insulin for about 6 weeks. Prior to that time, I was on oral antidiabetics for over 10 years. On orals, my blood glucose (BG) readings were fairly stable, but high [around 180 mg/dL (10 mmol/L)]. During the time I have been on insulin, my BG levels have swung wildly each day from over 300 mg/dL (16.7 mmol/L) to under 40 mg/dL (2.2 mmol/L). I have tried all sorts of sources around town, including the local diabetes education center and my own physician, to get more information on how insulin works, how to select the proper type of insulin, and how to manage the dosage of insulin. In addition, I have done extensive searches on the Internet for this type of information. The results of my local search was that the diabetes education center refused to discuss the subject of insulin with me and would only allow me to take their course, which dealt with insulin for a total of less than 30 seconds out of 10 hours, and my physician doesn't seem to be knowledgeable about the newer forms of insulin available. The Internet was by far the best source. My physician does seem to listen well to my suggestions and allows me to try them, within the bounds of safety (i.e., he modifies my suggestions to make them safer). I expect to use AIDA to do comparative simulations of dosage, schedules, and combinations of different types of insulin to achieve the response curve that I am looking for. I will then show the results to my physician to see whether we can come up with something else to try. I should point out that I am a former military physicians' assistant, so I have a clinical background. In addition, I have a Master's degree in computer science and make my living writing advanced distributed simulation software, so I am aware of the uses and limitations of simulations.

From the UK: A friend has told me great things about this program. I would like to try it and see for myself.

From the Philippines: Good program. I tried the online version—now I want to use the PC download.

From the USA: Get a better understanding about how insulin and food intake affect each



other. To help me understand and control my diabetes better.

No country specified: I am a medical student and want this to increase my knowledge in the subject.

From the UK: Have been using AIDA v4.0 and v4.3 to simulate different regimens before taking the suggestions to discuss with my doctor. Have found this all very useful. Now am downloading AIDA v4.3a.

From the UK: I hope to increase my understanding of the relationships between some of the factors that affect my blood glucose characteristics. I am a newly diagnosed diabetic and nuclear engineer and, consequently, fully realise the value of simulations in education and training.

From South Africa: I am a newly diagnosed diabetic, and I really want to understand this condition, and how my body reacts to what I eat, so hopefully I will glean some knowledge from this.

From the USA: Intend to use this to teach myself a bit more about insulin dose adjustment and how to juggle insulin and meals in diabetes.

From New Zealand: Learn more about my diabetic condition in order to make informed decisions regarding my medical care.

From the UK: Plan to use the simulator to experiment with different insulin regimens, and see how best to combine insulin and diet. I won't make any changes to my regimen on the basis of the simulations (without discussing the suggestions first with my doctor), but I hope to learn some things that might help me in the long term improve my blood glucose control.

From Canada: I would like to try it out and see if it can help me better understand the actions of the types of insulin that I am taking.

From the USA: Use AIDA to help in trying to work out changes in insulin dosages when I have drastic changes in my schedule.

From the UK: A friend who has diabetes has found this really useful, so I thought I would give it a try. I intend to use this to learn a bit about what affects blood sugar levels, and how to balance insulin and diet in diabetes mellitus.

From the UK: Get a better understanding of

the performance of isophane insulins over a 24 hour time frame.

From the USA: Want to learn more about diabetes, especially balancing insulin and diet in diabetes management. Need to improve my blood sugar control. I hope this program may be able to help me.

From the UK: Try and learn how different insulins work with set regimens in order to try and control my diabetes better. I will feel more confident in approaching the consultant for what I want if armed with some hypothetical data to prove what I am saying.

From the USA: I have to try it before I can tell what I plan to do. I was using a glucose monitor on-line that helped me to keep track of my daily readings at work and at home. I was able to print and submit these readings to my physician. I was on oral medications and I am now on insulin and have only been on it for about a month and as yet they have not been able to adjust the correct dosage but as I'm sure you are aware that takes time. I am obese and also have asthma and small cell non-Hodgkins lymphoma. I went to a nutritionist who set up a diet that I follow but I'm not really losing weight on it but one thing I don't do and that is exercise enough. My job requires me to do computer work pretty much of my 7 hours a day. I get involved and forget to get up and walk around. I hope this program will help me to learn about balancing insulin and diet in diabetes.

From the USA: Aid in managing my care. Also I am part of a task force for early detection and treatment of diabetes and I thought I would share this with the members of my group.

From South Africa: To find out action of insulin dose at particular time points, comparing it with carbohydrate intake and blood glucose levels.

From the USA: I just started on tube feeding as a result of colon cancer. I am going to see how these eating changes will affect my glucose and then discuss it with my doctor. Thanks.

From Trinidad and Tobago: I am the Chairman of the local branch of the Diabetes Association of Trinidad and Tobago. This program

will help to educate me and members of the association.

From the USA: As a student the use of this software will help in the understanding of diabetes in the pre-hospital care work that I am currently studying at university. Thank you.

From the USA: I have difficulty maintaining an eating schedule. I hope by seeing a graph of my blood sugar levels, I will be encouraged to attempt a more even level rather than peaks and valleys.

From the USA: Try to adjust basal doses of insulin for my son. Can do the meal dosing, but the basal is driving me nuts.

From the USA: I have IDDM [insulin-dependent diabetes mellitus]. I was diagnosed 23 years ago. I presently calculate my insulin requirements using insulin algorithms. I take insulin 4/5 times per day. I also calculate what I expect my dawn phenomena to be and take NPH insulin at 1:00 a.m. to cover it. I also have a diabetes program that approximates HbA1c [glycosylated hemoglobin] levels. It provides 90 day averages on a daily basis so I can tell if one of my test times are moving in the wrong direction. I have recently added 3 postprandial BG [blood glucose] levels to the program. I take 8 regular tests per day. I am interested in anything that can help me to improve my BG control.

From the USA: Well, without much thought, just now found out about this. I seem to be very "brittle," my blood sugar (BS) is high when I get up and within 2 hours I am hypoglycemic. I will "play" with this program till I can simulate my actual BS. I will then attempt changes to the program to reach a better control, then discuss making changes with my doctor. Just a thought.

From the USA: I have had diabetes for 11 years and was recently put on a different more regimented program by my doctor. I would like something that I could use to follow and see what is going on with my diabetes. I like to have as many sources of information as I can.

From the USA: I am new to the diabetic's problems. Will use this program to get an idea of what could happen with different scenarios. Not to be used for treatment or replacement for any type of treatment.

From Canada: Being an active type 1, I am always looking for the easiest ways to keep my

glucose stable, with as little interruption as possible in my daily life. Because it is not routine, I have a hard time keeping it where I want it. That said, I do maintain good control. I am just looking for ways to have more control over my life itself. I have come up with many new ideas and formulas for calculating insulin injections/timing, but I am hoping I can come up with them more easily using your software. It has been given much approval by other people. I did download it before the latest version came out, and with my limited computer skills, hope to use it more this time. Thank-you.

From the UK: Plan to see what it does. Have heard fun things about this program, and would like to see for myself.

From the UK: Explore the results from different combinations of carbohydrate intake, insulin injections, types of insulin, and timings.

From Turkey: Try to understand how my glucose level changes during the day and maybe adjust my insulin dose after discussions with my doctor.

From the UK: Not sure until I try it! But some friends with diabetes have told me it has been very useful to them, so I thought I would give it a try.

#### *Downloader comments from relatives of patients*

While these comments are clearly from interested and motivated patients, it is also informative to hear why relatives of patients with diabetes have been turning to the Internet to download AIDA.

From the USA: My 14 year old son was diagnosed with type 1 about 18 months ago. I will use the program to further educate both of us, and to prepare questions and ideas for his regular visits to the clinic.

From Singapore: I am writing software for diabetics on Pocket PC systems and want to understand more about insulin reactions so as to develop better software and care programs for my 4 year old son who is suffering from juvenile IDDM [insulin-dependent diabetes mellitus].

From the USA: My daughter is a type 1 and I am a service technician trying to do what I can to better understand the nature of diabetes and reaction to doses and activity.

From Brazil: I want to analyse if I could improve the control of the glucose levels of my son (6 years old), using insulin mixtures, without increasing the number of daily shots (2 by now).

From the USA: Use to see if I can learn a bit about diabetes and help my daughter who has DM [diabetes mellitus]. She is 14 and not too well controlled, despite lots of efforts.

From the USA: Figure out how to map similarities in glucose readings to insulin profiles, perhaps an exercise in futility, but hopefully to see if there is some sort of pattern in utilization.

From Germany: General understanding/interest and potentially help my diabetic son to better/easier control his glucose/insulin balance.

From the USA: Heard about AIDA from a friend. Would like to use this to help my daughter who is 11 and has had diabetes for 4 years.

From the UK: Attempt to model (to some degree) insulin dosages for my son and compare to manual computations.

From the USA: To be decided. Give to my father on behalf of my mother.

From the UK: Parent/child 4.5 years old; give him greater understanding as well as his sibling and two cousins aged between 5 and 8 years old.

From Mexico: To help my father who has diabetes.

From the UK: Explore in a general way the effects of different timings and dose of insulin on sugar levels experienced by my wife (we will do together!!).

From the UK: Learn to better control my son's diabetes. He is 14 and has had diabetes for 7 years. Am always keen to learn and improve things with this complicated disease.

From the USA: My wife has diabetes. She understands about the disease—but I don't really. I would like to use your program to help me understand more, so perhaps I can help her more.

From Greece: Work along with the doctor to find the best solution to my wife's diabetes control.

From the USA: It will help us visualize how our son's insulin regimen is functioning. It may

also suggest improvements we may want to discuss with his diabetes medical team.

From the UK: Given the context of strict medical supervision, I believe the hypothetical scenarios may be useful in stimulating future targets. While individual circumstances cannot be covered by the AIDA program, the same would be true of any specialist opinion (simply by virtue of lack of information). Given that careful iteration under controlled circumstances is the foundation of individual treatment, the AIDA simulation can usefully spawn possibilities. My wife aged 60 (IDDM [insulin-dependent diabetes mellitus] since 18) has already benefited by nutritional changes which have reduced daily insulin from 120 units per day to 12 to 15 units per day without loss of energy (quite the contrary), eliminated the savage hyperglycaemic attacks of "standard assessment" (which would have left her right where she was), and put a profound and measurable brake on retinopathy. This was not so much due to any application of AIDA but a process of gradually nudging things along iteratively. The change from hundreds to tens of units per day was pointed out to clinical supervisors hoping it might be checked for any useful implications for other patients. The total response was "Oooh yes. That's strange!" Long live any tool which stimulates thoughts of possible scenarios as distinct from brain-dead procedural thinking!

From Greece: Help my brother in law who has diabetes.

From the USA: I plan to use the knowledge presented to educate my father, the patient, as to how a high carbohydrate diet and minimal exercise may worsen his condition. Hopefully, the simulators also include suggestions as to how patients can improve their health and promote a "normal" lifestyle in spite of diabetes.

From Canada: My 9 month old son was diagnosed last week and we are still experimenting with his insulin dosages to stop his high/low swings. I am interested in trying to reproduce the readings that we are taking and try to find ways to identify the correct dosages. These dosages are being revised under the care and advice of our endocrinology pediatrician.

From Canada: My wife keeps excellent records of her carbohydrate intake, insulin used, and glu-



cose levels. I would like to try this program to use as a tool to help attain a higher level of control and help us to hone in on possibilities for glucose roller coasters.

#### *Downloader comments from doctors*

However, it is not just patients' relatives who have been leaving interesting comments at the Website. Healthcare professionals' reasons for downloading the software have also been informative.

From the UK: First of all to familiarise myself with software and then to see about possible usage clinically.

From the USA: A number of my patients have told me about this program, and even brought me printouts from the software to discuss in clinic, so I thought I had better find out about this for myself!

No country specified: Make information [available] to my patients with diabetes.

From Austria: Perhaps for educating patients.

From Lebanon: To produce a simulated tutorial for medical staff.

From Canada: As a first year internal medicine resident, I would like to have an introduction about the management of serum glycemia with different types of insulin.

From Libya: Learning about this interesting program.

No country specified: Its very good presentation and it will be useful for our medical students.

From the USA: Use as a teaching tool for resident/students.

From the UK: Plan to try and use the program to teach some of my diabetic patients. Can't say for sure until I have tried the program, but I have a colleague who has been using the program to teach medical students, and it seems fun! Will let you know how I get on.

From the Czech Republic: Teach my patients about diabetes.

From the Maldives: I want to use it to teach junior doctors.

From Brazil: Use AIDA to help diabetics to learn to improve their control.

From Mexico: To inform and teach medical students.

From Finland: To teach medical candidates in clinical endocrinology courses.

From Nepal: For educating patients and Post Graduate Diploma in Lifestyle Medicine students.

From the Netherlands: For simulation of clinical situations.

From Russia: Translate it into Russian and put on my Website for Russian diabetic patients.

From Italy: To enhance and update my knowledge of diabetes management.

From Switzerland: Let's try to see if it helps manage my patients with decompensated diabetes.

From the USA: I'd like to introduce this software to students and colleagues.

From Japan: I would like to know more about AIDA, because I am a specialist for diabetes mellitus in Japan.

From the UK: Use it to teach student nurses and medical students. Once I have gained some experience with the program I shall see if it might be appropriate for use in teaching people with diabetes.

From Canada: Enhance my ability to assist people with diabetes to improve glycemic control through more effective management of diet, activity and insulin therapy.

From Venezuela: Learning day by day using the software to plan strategies with my diabetes patients in my service of endocrinology.

From Spain: Evaluate it with some of my type-1 diabetic patients, especially in cases of "brittle" glucose control due to asymptomatic hypoglycemia.

From the USA: Become well versed in the interrelation between diet and blood sugar levels. I plan to run simulations using the foods listed by patients in class so that we can delve into diet, blood sugar level, exercise, and medications.

From the UK: Some colleagues have shown me the program, and I wanted to give it a try myself. I think it could be useful for teaching medical students, as well as for teaching some patients.

From the USA: Heard about it from a colleague, who praised it a lot. Would like to see what all the "fuss" is about! :-)

From China: For patient education.

From the USA: Try and simulate some exam-

ple regimens to use to help with teaching my patients (and maybe also learn something myself!).

#### *Downloader comments from students*

Students' reasons for downloading the AIDA software have also been interesting.

From Greece: For better understanding of the daily variations of a diabetic patient's glucose levels during the day and the effects of medical treatment.

From Mexico: I plan to use this software, to understand the way insulin works on people and how can I improve the treatment on my patients.

From Australia: Interested in looking at the design of the program. Never seen anything like it before.

From Egypt: Find out about diabetic diet in relation to insulin.

From the USA: For scientific research modelling.

From the UK: Want to use the program to learn for a student assignment/project that I have been set about diabetes.

From Malaysia: Use it as a study aid.

From the UK: For a diabetes project assignment that I have been set at college. I would like to learn more about diabetes, particularly how patients juggle insulin and diet to control their blood sugars.

From the USA: To brush up on insulin regimen protocols.

From Uzbekistan: Educate people.

From Belgium: To learn a little bit more about diabetes.

#### *Downloader comments from diabetes educators*

Comments from other healthcare professionals—diabetes educators, nurses, and pharmacists—have also been informative.

From the UK: For education of patients and students.

From the USA: I am a certified diabetes educator as well as a person with diabetes. I plan to review the educational software and use it as appropriate.

From the USA: Looking for diabetes software to use for teaching.

From Switzerland: I'm looking for good soft-

ware to use in Swiss schools. Somebody told me, that AIDA is supposed to be good to use in biology lessons.

From the USA: I am pharmacology faculty in a medical school and teach therapeutics of diabetes to the medical students. I'd like to see whether I can use some of the information in my lectures.

From the USA: Look at the modules and see if they would be useful to some of the clients we have in our clinic.

From the UK: Creating insulin learning pack for diabetes specialist nurses (DSNs). I hope this program will help.

From the USA: Show to patients for learning insulin and food relationships.

From India: To teach diabetics in a different way.

From Canada: Useful tool for GP [general practitioner] clinics too?

#### *Downloader comments from nurses*

From the USA: I am planning on viewing the software simulator and evaluating its effectiveness for a course I am taking in graduate school (university).

No country specified: To further my knowledge of diabetes since I am a nurse as well as someone with diabetes.

From the USA: A colleague told me about the program. I hope to use this to help some of my patients who have diabetes.

From Canada: I am involved in a research project following diabetic patients. Its focus is promoting health in chronic illness. This program can be used as a teaching tool for me.

From Germany: To learn about diabetes, insulin, and glucose-insulin interaction in the human body.

From the USA: Teaching a patient about disease and administration of insulin in layman's terms. Want to see if it is something I can use to aid the teaching/learning process.

From the UK: I work in the endocrine dept in a large teaching hospital. . . . I feel this Website will be a valuable resource to me and my patients.

#### *Downloader comments from pharmacists*

From the USA: I want to better understand the relationship between pharmacotherapy

and diet, particularly the different types and dosage regimens of insulin.

From Germany: Training of students of pharmacy while having lectures in diabetes.

From the USA: I am a pharmacist with a diabetes speciality and I could use it to gain understanding and as a teaching tool for insulin and its effects.

From India: For knowledge about diabetes, to help in drug design.

From Colombia: I just want to use AIDA as an educational tool for my job as resident pharmacist in a paediatric clinical center. Thanks.

From the United Arab Emirates: To study the effects of insulin.

#### *Information technology downloader comments*

Some people also seem to have been downloading AIDA for research/information technology-based usage.

From Russia: I'm investigating technical aspects of using diabetes software simulator on a Russian diabetes Website.

From a student from Hungary: I have to write my M.Sc. thesis in biomedical engineering. I'm trying to find a topic, and narrowed my search to diabetes. Now I need to collect information on glucose meters and software products.

From a student from Norway: Testing for Bluetooth [wireless data transfer] application.

From a patient with diabetes from the UK: Evaluate mechanisms of diabetes control interaction.

From Denmark: Learn more about glucose-insulin feedback dynamics.

From a patient with diabetes from the UK: I write engineering software and I was interested in the description in the AIDA technical guide. I plan to "experiment" with my own BG [blood glucose]/insulin behaviour to try and get a feel for the equations.

From a relative of a patient from the USA: I will be using the case studies as sample data in the training of a neural network/generic algorithm artificial intelligence program to try to predict the necessary insulin for a given patient with diabetes who has a given blood sugar. It's all theoretical right now, and I may not even be able to use the case study information, but

I'm looking for data with times, blood sugars, and insulin given to use as training data for my program. The program that I will create will be freeware, and if you like, when complete, I will forward a copy to you.

#### *Downloader comments from none of the prespecified categories*

Not all the downloaders fitted into the above prespecified categories. Here follows a selection of comments from downloaders who did not regard themselves as patients, relatives, or healthcarers.

From Taiwan: Learn more about diabetes

No country specified: I work in a homeless shelter setting. Need information about testing and trying to assist our poor people who have need for information. Many have no insurance.

No country specified: Compare it to a simulator of my own.

No country specified: See if the program can help me.

From the USA: I am a software developer with type 2 diabetes. The simulator will help me to better understand how the disease works.

From Australia: Wish to send it to a relative who is a Diabetes Specialist Doctor.

From the USA: Simulate blood glucose levels. See if the same approach can be used for proteins.

From the USA: Try it out and see if it is useful. I have developed an assessment software program for diabetes educators working with patients on behavior change.

From Bulgaria: Just see and estimate; if I like it, I'll give it to some who need it.

#### *Downloader comments from people who "missed the point" about AIDA*

Unfortunately, despite all the information given at the Website, a number of downloaders seemed to miss the point as to what AIDA is all about, as the software cannot provide a database for storing blood glucose readings or offer charting functions.

From a patient with diabetes from the USA: If I understood what I have read (and I didn't



read much) I would like to see a charted history of my blood sugar levels.

From a patient with diabetes (no country specified): I'm looking for a software program for diabetic persons to follow the curve of sugar levels and warnings.

From a diabetes educator from the USA: Track a class of 15 diabetics.

From a patient with diabetes from Canada: Use it to help me keep track of my sugar levels and insulin dosage, in addition to monitoring them with my physician and diabetes educator (nurse).

From a patient with diabetes from Australia: I am looking for a program that will give me past trends and averages.

#### *Usage for pets*

Also, AIDA has not been designed for usage with diabetic pets!

From a relative of a patient from Germany: Use on my cat's diabetes . . . and understanding more of the mechanisms myself.

From a relative of a patient from the USA: Figure out my dog's insulin adjustments needed, since the vet who I am paying my money to is not really able to help.

From a student from Italy: I would like to use Aida to help my diabetic cat. He is on humulin L, but shows blood glucose high after lunch. I would try to regulate him, with humulin R before lunch. Your site is very beautiful, thanks for making this available for free.

#### *Downloader comments from people who wanted to try and adjust their own regimen*

Fortunately there were only very few downloaders in this survey who contemplated trying to adjust their own carbohydrate and insulin dose on the basis of the program's simulations (contrary to the caveats at the Website and the instructions that come with the software).

From a patient with diabetes from the USA: To try to adapt it and maybe forecast my own body's reactions to different diets and insulins. Then to discuss this with my physician.

From a patient with diabetes from the USA:

Try and see if I can improve my blood glucose control, by balancing insulin and diet better in diabetes.

#### *Downloader comments from people who wanted to "try it and see"*

Understandably, as this survey was being run at the point of download, there were a number of respondents who could not comment properly until they had tried the program and found out what the software could do.

From a patient with diabetes from Poland: For testing. Thanks for making the program available for free.

From a relative of a patient from Finland: Don't know, have to look at the software first.

From a patient with diabetes from Italy: I don't know yet. I hope to learn what to do when I'm sick.

From a patient with diabetes from Argentina: I am a doctor and a diabetic patient. I want to know more about this program.

From a patient with diabetes from the USA: I study my diabetes as well as research the disease for patients and medical professionals. I am interested in seeing what the software has to offer both groups.

From a patient with diabetes from Brazil: I'd like to know more about the software first so that I can help people who are new to diabetes and are afraid of the disease. Later, when I know the software, I should be able to talk more about my experience with it. Thanks.

From a patient with diabetes from India: Understand how the program actually works and if it works then I shall recommend to others.

From Canada: Experiment with the software to get a better understanding of its possibilities and its limitations.

From a doctor from the UK: Try it and see. I won't know until I give it a go. However I have heard from others how useful the program can be, so I would like to try it for myself.

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