

Diabetes Information Technology & WebWatch

Why People Download the Freeware AIDA v4.3a Diabetes Software Program: A Proof-of-Concept Semi-Automated Analysis

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ABSTRACT

AIDA is a diabetes-computing program freely available at 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 previous "Diabetes Information Technology & WebWatch" columns various indicators of usage of the AIDA program have been reviewed, and various comments from users of the software have been documented. The purpose of this column is to overview a proof-of-concept semi-automated analysis about why people are downloading the latest version of the AIDA educational diabetes program. AIDA permits the interactive simulation of plasma insulin and blood glucose profiles for teaching, demonstration, self-learning, and research 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 over 300,000 visits have been logged at the main AIDA Website—www.2aida.org—and over 60,000 copies of the AIDA program have been downloaded free-of-charge. This column documents the results of a semi-automated analysis of comments left by Website visitors while they were downloading the AIDA software, before they had a chance to use the program. The Internet-based survey methodology and semi-automated analysis were both found to be robust and reliable. Over a 5-month period (from October 3, 2001 to February 28, 2002) 400 responses were received. During the corresponding period 1,770 actual visits were made to the Website survey page—giving a response rate to this proof-of-concept study of 22.6%. Responses were received from participants in over 54 countries—with nearly half of these ($n = 194$; 48.5%) originating from the United States, United Kingdom, and Canada; 208 responses (52.0%) were received from patients with diabetes, 50 (12.5%) from doctors, 49 (12.3%) from relatives of patients, with fewer responses from students, diabetes educators, nurses, pharmacists, and other end users. The semi-automated analysis adopted for this study has re-affirmed the feasibility

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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.

ity of using the Internet to obtain free-text comments, at no real cost, from a substantial number of medical software downloaders/users. The survey has also offered some insight into why members of the public continue to turn to the Internet for medical information. Furthermore it has provided useful information about why people are actually downloading the AIDA v4.3a interactive educational "virtual diabetes patient" simulator.

INTRODUCTION

AIDA IS A FREWARE 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, via the Internet as a non-commercial contribution to continuing diabetes education. In the 7+ years since its original World Wide Web launch in March/April 1996 over 300,000 visits have been logged to the main AIDA Web pages at www.2aida.org, and over 60,000 copies of the program have been downloaded, *gratis*.

The AIDA software has been previously described in detail in this journal,¹ and elsewhere.²

Figure 1 demonstrates a little of what the

program can do. In the representation of an AIDA simulation shown, a baseline blood glucose simulation is displayed by the grey line for a twice-daily short- and intermediate-acting [Actrapid® and Lente® (Novo Nordisk)] insulin injection regimen. Superimposed in black, shown by the solid line on the top graph, is a simulation for educational use demonstrating the hyperglycaemia that would result from delaying the morning insulin injection until after breakfast.³ AIDA comes with 40 such sample case scenarios for simulation. Further cases can be created by users, and more examples of the sort of simulations that AIDA can offer can be found at www.2aida.org/demo on the Internet.

While other interactive simulators of glucose–insulin interaction in diabetes have been

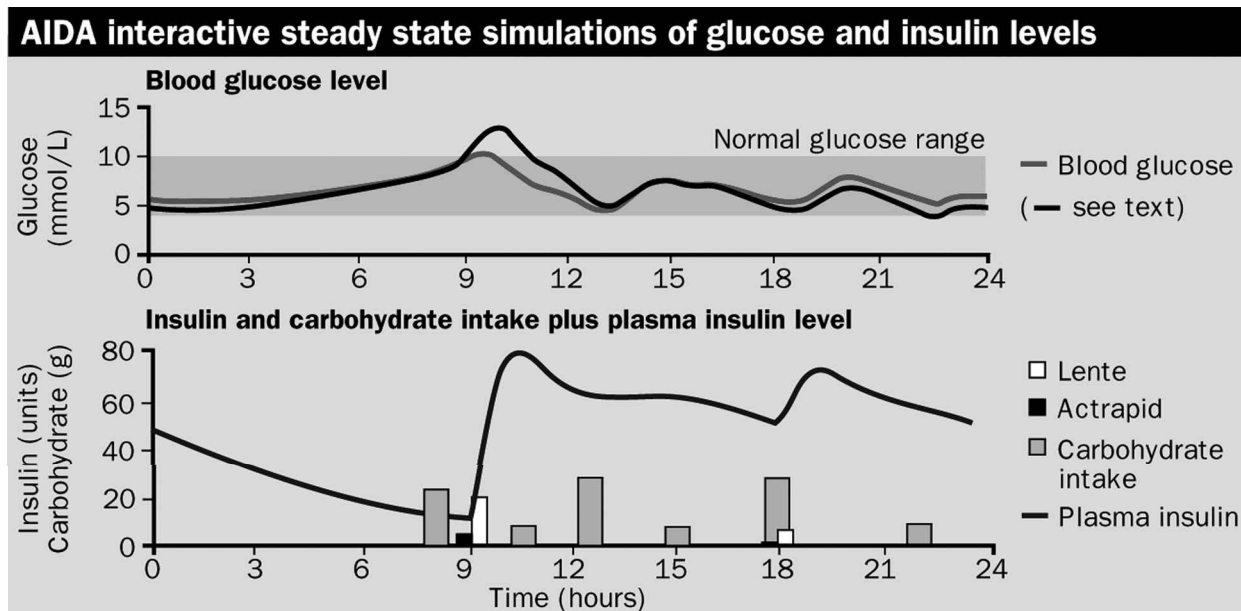


FIG. 1. In the representation of an AIDA simulation shown, a baseline blood glucose simulation is displayed by the grey line for a twice-daily short- and intermediate-acting (Actrapid and Lente) insulin injection regimen. Superimposed in black, shown by the solid line on the top graph, is a simulation for educational use demonstrating the hyperglycaemia that would result from delaying the morning insulin injection until after breakfast (1 mmol/L = 18 mg/dL). Reproduced from Lehmann³ with kind permission © The Lancet. Further examples of the sort of simulations that AIDA can offer can be found at www.2aida.org/demo on the Internet.

described in the literature,⁴⁻¹¹ 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^{6,8-10} 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.

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), and via the program application itself. These are yielding useful information about what sort of people are downloading and using the software.^{12,13} In a recent pilot study we have also sought to try and identify why people have in the first place been turning to the Internet to download AIDA.¹⁴

A mention of study terminology may be helpful here. A pilot study is well recognised as being the initial experimental experience with a new approach. By contrast we regard a "proof-of-concept" study as aiming to reproduce the experimental approach of an initial pilot study, retrospectively, before proceeding onto larger-scale/longer-term studies—which may be conducted either retrospectively or prospectively. Connected with this, a proof-of-concept survey can be regarded as a second pilot study; the idea is to try and expand experience with running and analysing data from such an audit, before applying the approach more widely.

In order to continue to make efficient use of data from such audits and surveys, it is important for the analysis procedure adopted to be as straightforward, streamlined, and objective as possible. To achieve this a semi-automated process with as few manual or subjective steps as possible should be the optimum method of analysing such data. Therefore to ensure that the approach was as robust as possible, we have also now sought to semi-automate the data analysis process for this study.

METHODOLOGY

The data collection methodology has been previously described in detail elsewhere in this journal.¹⁴ For the current study the data collection approach was applied unchanged. However, what was refined was the data *analysis* methodology that was adopted. In the previous study a more manual, "hands on" approach was used. Potentially, though, this might be misconstrued as being prone to "biases" on the part of the researcher doing the analysis. By contrast, a semi-automated technique of data analysis should be less prone to any such potential errors, and therefore should allow more robust and objective comparisons to be made between surveys over time. The rationale behind this approach is that hopefully by removing any possible subjective component from the analysis, it will become more objective and robust.

Therefore for the current work we have sought to confirm the feasibility of undertaking a free-text survey about downloading of AIDA v4.3a via the Internet. For this proof-of-concept survey we were particularly keen to confirm the findings of an earlier pilot study¹⁴ and test out our approach to confirm why people are actually turning to the World Wide Web and downloading the AIDA software.

AIDA Website visitors were surveyed for a period of 5 months between October 3, 2001 and February 28, 2002. Responses were submitted by end users using a "guestbook"-type of free-text CGI-BIN script operating on the AIDA Web servers, as described previously.¹⁴ All comments were each individually stored in a dedicated HTML database at the AIDA Websites. The raw, source data for this pilot study—from both the main AIDA Website (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/why2 (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.)

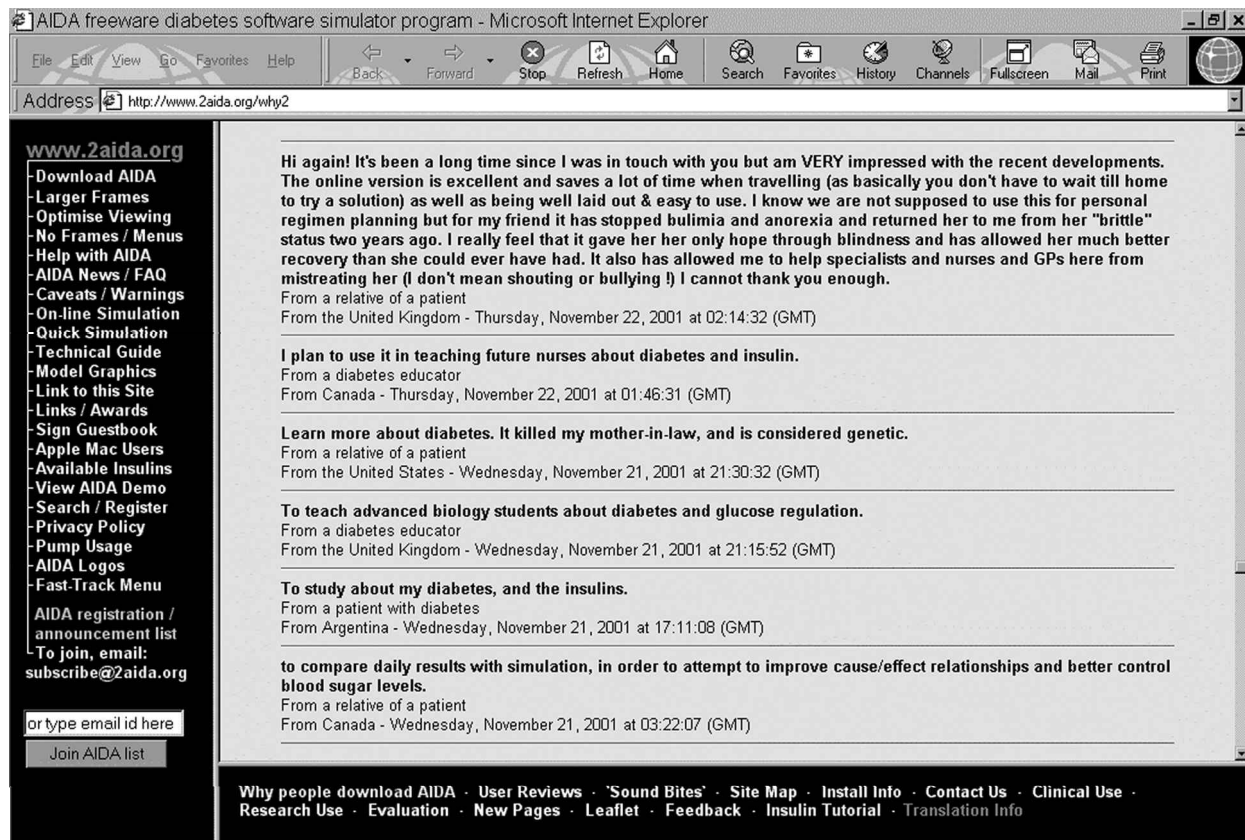


FIG. 2. Shows some of the respondents' comments as stored in the HTML database at the AIDA Website. These can be viewed directly at www.2aida.org/why2 on the Internet.

SEMI-AUTOMATED DATA ANALYSIS

A number of steps were taken to facilitate the semi-automated analysis of this dataset:

First, the why2.htm HTML Web page containing the downloader responses was saved in ASCII text format. This could then be imported into a standard spreadsheet like Microsoft Excel.TM *A priori*, from previous studies,¹²⁻¹⁴ eight categories of respondent had been predefined: (i) a patient with diabetes, (ii) a doctor, (iii) a relative of a patient, (iv) a student, (v) a diabetes educator, (vi) a pharmacist, (vii) a nurse, and (viii) none of the above. These corresponded to the predefined options that were made available on the HTML data submission form. As the data were being imported into an Excel spreadsheet, the descriptive category of the respondent could be separated from the other data using Excel import wizard delimiters. Similarly the respondent's country could

be separated from the free-text comments. In this way it was easy to sort the Excel database on the descriptive heading to establish the number of patients with diabetes, relatives, doctors, etc., who had been responding to this survey. In the same way, sorting the data on the country category enabled the number of respondents per country to be established.

Some other categories of description of a downloader's response could not be automated as they were more subjective, and therefore it necessarily remained a value judgement on the part of the person analysing the data as to which particular additional category could be applied. These alternative subcategories can be described as: (ix) "techies"—downloading AIDA for technical/information technology purposes; (x) people who missed the point as to what AIDA is about (e.g., wanting a program to download/graph blood glucose test data); (xi) people who just want to "try it and see";

and (xii) people who intended to try and adjust their carbohydrates and/or insulin doses using the program (AIDA is not meant for this).

For the purpose of selecting some free-text responses for publication (see Results below), a decision was taken only to consider comments that were ≥ 2 lines in length. This was not a completely arbitrary decision, as it was felt that longer items are usually more interesting and informative than more "monosyllabic" comments.

RESULTS

Four hundred proof-of-concept survey responses were received during the 5 months between October 3, 2001 and February 28, 2002. During this period there were 1,770 visits logged in total to the survey Web pages at the main AIDA Website, and the former AIDA U.S. mirror site, giving a response rate to this proof of concept survey of 22.6%.

Based on the automated data analysis, 208 responses (52.0%) were received from patients with diabetes, 50 (12.5%) from doctors, 49 (12.3%) from relatives of patients, 36 (9.0%) from students, 18 (4.5%) from diabetes educators, six (1.5%) from pharmacists, and four (1.0%) from nurses. Sixteen responses (4.0%) were received from people who regarded themselves as being in none of the aforementioned categories, and 13 (3.3%) respondents did not answer this question.

Based on the manual review of the responses, some three respondents (0.75%) could be described as "techies" downloading the software for some technical use, while some 13 respondents (3.25%) missed the point as to what AIDA was about, mainly wishing to use the software for downloading/graphing blood glucose data. Approximately 40 respondents (10.0%) were just downloading AIDA to "try it and see," with only one respondent (0.25%) possibly reporting planning to use the software for a nonintended purpose (e.g., to try adjusting his/her carbohydrate intake and/or insulin regimen).

Responses were received from end users in over 54 countries. However, nearly one-third of the responses ($n = 123$; 30.8%) came from the United States with a further 13.0% ($n = 52$) coming from the United Kingdom. Table 1 summarizes the number of responses per country with five or more respondents. For 92 responses (23.0%) 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 v4.3a software. Limited space precludes publication here of all the free-text comments—although these can be read directly at www.2aida.org/why2 on the Web. Nevertheless, a selection of the more substantial responses are documented below under separate headings for each of the groups of respondents.

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

Country	Number of responses ^a	Percentage (of 400 total)
United States	123	30.8
United Kingdom	52	13.0
Canada	19	4.8
India	13	3.3
Australia	7	1.8
Denmark	6	1.5
Greece	5	1.3
Brazil	5	1.3

^aOf 230 responses (57.5%) from eight countries. The remaining 170 responses (42.5%) from over 46 other countries (with four or fewer responses per country) are not shown. No country was specified for 92 responses (23.0%).

HOW DO YOU SEE YOURSELF MAYBE MAKING USE OF THE AIDA SOFTWARE?

Downloader comments from patients with diabetes

From the USA: I am always looking for ways to improve my life. I wish to use this program to see what benefits it may provide.

From Chile: I think will use them to analyse my glycemic results & take rational decisions about my insulin therapy.

No country specified: Take care of myself and distribute the knowledge to other people who are suffering.

From the USA: Recently put on medication for type II diabetes. Told to lose weight, etc. I know I have a reaction to certain "hidden sugar" foods—often in "low-fat" or "lite" foods. So losing weight, reducing sugar, eating right, taking medication—even with advice from a doctor specializing in diabetes, and a skinny dietician who basically says "don't eat," I want a better handle on myself as I go through the highs and lows, ups and downs . . . "a level playing field?"

From Australia: Run simulated models for planned changes to my routines, etc., along with consultation with my health professionals.

From the USA: Simulate action of 4 insulin types ranging from Humalog through Ultralente humulin. To help me better predict response with fairly complicated routine. I'm type II with a glycohemoglobin of 7.2 and absolutely no diet compliance. I've just added the UL [ultralente] to work toward an under 7.0 glycohemoglobin number.

From New Zealand: I wish to control my diabetes a lot better as I have been having bad episodes and my helpers are not sure what is causing them so I am keen to try anything that will help me.

From the UK: Run simulations prior to discussion with my diabetic adviser specialist nurse as a basis for discussion and advice.

From the USA: I need some encouragement in my therapy for diabetes and any help is appreciated. I think this will give me that help.

From the USA: I'm new to diabetes and new to this software, so I'm looking for ANY assis-

tance in dealing with my blood sugar testing and my diabetes in general, so I honestly cannot tell you how I plan to use this software except that I'll use it to do all I can to help myself survive diabetes! I also am interested because the software for my Blood Sugar Monitor is WAY out of my reach financially and I hope this may do some of the same things, even if I have to enter the information from my monitor manually. Thanks!

From the USA: Learn more about interactions between dosages of insulin, timing of insulin and carbohydrate counting.

From the USA: Get information about the effect of different types and doses of insulin on blood sugar levels.

From the USA: I hope I can balance my carbohydrate intake to the amount of insulin I am taking. I may be alerted to the timing of my insulin injections.

No country specified: I would like to see as to how it can help me with running a normal life. I have been a diabetic now for 38 years and am beginning to get trouble with my legs and feet. Also sexual problems. I'm only 55 years old thus I'm trying to get some help. Thank you for your interest.

From the UK: I have type 2 diabetes, and am at the moment on unsuccessful oral medication, I expect to be switching to insulin soon. Any information about the way a body (generic) body reacts is interesting to me.

From Costa Rica: By using it I'll try to understand better the interaction between different insulins and the food I eat, and then find the best dose to maintain the best control possible in my blood glucose levels.

From Canada: I am a patient who was extremely active all of his life. I competed nationally and internationally in wrestling and other combative arts (kickboxing only locally). The physical stress is tremendous and took some dietary planning even prior to my diagnosis with diabetes. At 25 years of age I was diagnosed with Diabetes type 1 Mellitus. I am pretty disciplined and test myself regularly and never miss my injections. I take 3 Humalog injections per day and 1 Humulin at night. I base my injections on what I eat (and that may change day to day). I am now 26 and $1/2$ (I've had diabetes for a little over a year), and it's

out of control. At dinner time, based on carbohydrate counting I took ten units of insulin, and it took my reading from 12 mmol/L [216 mg/dL] at dinner time to 14 mmol/L [252 mg/dL] at supper time. For supper, based on carbohydrate counting again, I took a little more to supplement the fact that I was "twice" over normal level, and 5 hours later, I felt pleasant and great but my readings were off the scale. I was above 33.3 mmol/L [599 mg/dL]. I did quality assurance tests on my glucometer, and re-tested myself, but everything pointed to me being extremely high. I now don't train as much or as heavy because I have taken extreme lows while exercising heavy. I am new to this and I hope AIDA can help me with the following: 1.) Help me take better control of my glucose readings. 2.) Provide information to predict based on carbohydrate counting, and history of current readings, approximations of how much Humalog to take. 3.) How much Humulin (nighttime slow acting) to take (bolus rate stuff). 4.) How to predict changes when I exercise. 5.) How I could change my diet to reach normal weight levels again (I've lost over 10 lbs, and 26 at 120 lbs is bothersome). BASICALLY 6.) Give me some of my freedom back through control. I feel like diabetes is holding me hostage to everything I've ever done.

From Australia: I am having trouble controlling my blood sugar levels, they are erratic and often too high or hypo[glycaemic]. My specialist tells me to do one thing or the other and I would like to satisfy myself on the effects of different insulin regimens. I have been a type 1 diabetic for 24 years now and had no trouble until about 5/6 years ago when my glucose levels started to play up. I hope to learn something from this programme. Thank you. Kindest Regards.

From the USA: Get a better understanding of the relationship between insulin dosage and glucometer readings so that I can discuss insulin type and dosage more effectively with my internist for tight control of my diabetes.

From the USA: I have lots of experience working with and building simulations of complex systems and they have been a wonderful way to understand the system.

From the USA: Have a finer tuning of the

amount of insulin I need to avoid blood glucose levels that are too high or too low.

From the USA: I would like to learn and apply a Pocket PC capable software for diabetic athletes that would enable them to calculate glucose clearance rates, consumption needs and BG [blood glucose] control during long distance, multiday events where nutrition intakes are limited to endurance sport type bars, drinks, etc.

From the UK: I am testing my blood sugar about 6 times a day to reduce HbA1c [glycosylated hemoglobin] as much as possible. I am hoping that this simulation gives me some more insight to better adjust my dosages of Insulatard and Humalog.

From the USA: Learn more about insulin control. I also need to learn more about the diet. As usual everything I like is probably off limits. Ha! Thank you for making these things available.

From the USA: I am an out of control diabetic, whose doctor is of little help in this matter. I hope your software will help me to control my diabetes.

From Spain: It is a tool that I was searching for a long time ago. I think it can help me to control my diabetes and improve my knowledge of the actions of the different variables. I will do a correct use of this software and I thank you very much. Yours sincerely.

From Canada: See how (physician-prescribed) changes to my insulin dose and regimen look on the graph. Also, run "what if" scenarios that I can discuss with my physician if any look promising.

From the UK: Try and work out the best insulin regime. At the moment I just inject Novorapid 4× a day and I am hyper[glycaemic]. Previously I injected Humulin I 2× a day and was hypo[glycaemic]. I am going to try a mix of the two to see what it comes up with.

No country specified: I'd be curious to see how this software compares to the type provided by the blood glucose meter manufacturers.

From Botswana: I download it for a friend who discovered 2 weeks ago the diabetes. I only want to help him. The funniest thing is, he works in a hospital laboratory and did thousands of tests for diabetes but he never thought.

. . . Anyway I only try to help him with something.

From France: I began a basal-bolus insulin treatment last Friday (October, 5th) and I would like to understand the action of my new insulins better. Thanks a lot.

From the UK: Not quite sure at the moment—only been diabetic for about 3 months. Probably to get a better understanding of the interaction of diet and insulin and see how it compares with what I have experienced so far.

From the USA: I'll use it mostly for educational purposes in learning how to better control my diabetes.

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:

Downloader comments from relatives of patients

From the USA: I have a foster child diagnosed with juvenile diabetes. I want her to try this to see what could happen under certain circumstances.

From Canada: To compare daily results with simulation, in order to attempt to improve cause/effect relationships and better control blood sugar levels.

From the USA: Married to a man with 2 diabetic Type 1 girls. Plan to work with the girls to educate ourselves in order to start controlling their diabetes. This software is one of the many resources we will be and are using to educate us.

From the USA: To do some modeling of my daughter's glucose levels and insulin usage. I will not be using this to necessarily plan her dosage or carbohydrate intake.

From Canada: Understand the effects of changes in diet and insulin. With a better understanding of the interactions, we can stay within the range better and hopefully find ways to lower the total amount of insulin used.

From Belgium: Do some experimenting I can't do on living patients. After all I don't want anyone to get hurt.

From the UK: My father has just been diagnosed with diabetes. He has begun medication but I thought, seeing as he is quite down about

it, I could provide him with some information to look at. He likes using the computer. It will hopefully keep him busy and provide practical information.

From South Africa: This is actually for my wife who has been a diabetic since she was 12 years old. Her specialist told her that she obtained a glucometer in the [United] States that downloads her sugar readings on a computer and the computer automatically projects a graph based on the old sliding scale. I would love to get her something like that but even if it were available here in South Africa, we probably wouldn't be able to afford it. So I would like to see what this programme can do, because if it can help my wife, she will tell her specialist and we could help a lot more people here in South Africa with it.

From Denmark: Study it and discuss it with friends and relatives who have diabetic children and so on. Mostly to learn something about the subject.

From the USA: Use as basic education tool for a family member's caregiver. Will review with the patient's internist overseeing management of her diabetes to obtain his recommendations.

From Romania: Try to understand workings of various types of insulin and ask doctor to manage my results. I have a child 4 years old and measurements go up and down, almost unpredictable. Thank you.

From Iceland: See if it can be of help for my husband and son who both have type II diabetes mellitus.

From Yugoslavia: To help in teaching my child and to compare with my evaluation of insulin application.

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:

Downloader comments from doctors

From the USA: Want to try it and see what it can do. Have had various patients come to me with printouts from the program, and asking various questions about diabetes, based on what the software has showed, so I thought I should check this out myself.

From India: Check out if AIDA medical software really helps doctors, as my colleagues say.

From the UK: Firstly I look into the software and its level of helping the general public. Basically now there is a very much general public awareness about diabetes and heart diseases. I will teach my patients and the young doctors about the levels of insulin and also about its effects.

From Bahrain: I would like first to try it on myself, as I am diabetic (type 1) on multiple injections regimen. Then as a family doctor, I will use it for educating my type 1 patients.

From the USA: I had gestational diabetes with both my pregnancies and I'm at risk of developing diabetes. I would like to take control of my diet and watch my glucose levels.

From Canada: Seeing if this might help some patients . . . seeing how I do in adjusting insulin . . . look at the limitation of mixed insulin.

From Estonia: To get a new information to myself. To get new tips treating and educating patients. Maybe get some practical exercises for teaching students.

No country specified: Train and instruct nurses as to the proper use of management skills and time and good practice towards diabetes patients.

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

Downloader comments from students

From Pakistan: Understand the procedure involved in diabetes . . . experiment with insulin doses . . . help my relatives who are diabetics, and believe me there are many. . . .

From the USA: I will show it to my class. I'm doing a presentation on children with diabetes and this software sounds excellent. I really think it will help them understand what diabetes is.

From Greece: I am studying in Greek university to be a dietician for diabetic patients and I consider that this software will be very useful to me.

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

Downloader comments from diabetes educators

From the USA: I'm recently certified as a diabetes educator and my job will be expanded. I plan to use this as a tool to practice insulin dose changes.

From the USA: Test my brain against this for my problem patients! Educate patients.

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).

From the USA: Examine the information to see if it could be recommended as an adjunct to diabetes education.

From Belgium: My girlfriend is a nurse who specializes in diabetes patients. I want to show her the software, she might learn from using it.

Downloader comments from a pharmacist

From India: Basically I am a B.Pharm. graduate running a WHO GMP standardised factory near Chennai. I have excellent rapport with medical profession in South India, where as most of the interiors/towns of South India lack Internet facilities, therefore I am planning interactive website for doctors and so that they can educate the patients through your AIDA software. In fact we are rice-eating population and the incidence of diabetes is more in South India. Because of lack of facilities in towns, where few computer, browsing centres are just coming-up, I thought if you can support me by your esteemed software I can make doctors to use the simulation for patients benefits, it is not only a service but 2,000 strong elite doctors are becoming subscribed members in this proposed site, here-in some doctors participate in equities. I just want to initiate the use of your software by so many medical practitioners who are unaware in the interior towns of South India. I will be grateful if you can give options for customizing according to the patients condition/case profile. Though you are promoting for patients, but in the present circumstances I will ask the doctors to do this for the patients which then will catch like a fire. Anyhow thanks for the useful software. Because of this

most of the doctors/members will visit your site would give way for furthering our ties for useful services.

Not all the downloaders fitted into the above prespecified categories. There follows a comment from a downloader who was not a patient, relative, or health-carer—illustrating the use that people have found for the software, even in schools:

Downloader comment from none of the prespecified categories

From the UK: I am a computer and biology teacher and am looking for software to improve courses and educate pupils on a variety of topics.

Unfortunately, despite all the information given at the Website, a number of downloaders did seem 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:

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

From Germany: Hello! Please excuse my bad English, but I'm German. I use the diabetes software named CAMIT. The reports are very difficult and my doctor could not understand its reports. I look for better reports. Also I look for a possibility to export my list to Microsoft Excel.

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

Usage with pets

From the USA: To try to assist in regulating my dog who has diabetes. While it won't serve as my main guide, it will help in providing analyses based on the different variables I can plug into the program.

From the USA: I am working with several medical schools on various training projects, and would like to see what you have done with this. As a byline, I have a cat with a serious diabetes condition. Thus, I rather fall into two of the categories below.

Interestingly there were some respondents who reported having downloaded AIDA before:

Downloader comments from people who were downloading a new/updated copy of AIDA

From the USA: I have been a user of the software in the past and it worked to lower my blood sugar from 11 mmol/L [198 mg/dL] down to 6.2 mmol/L [112 mg/dL]. Thank you.

From the UK: Hi again! It's been a long time since I was in touch with you but am VERY impressed with the recent developments. The on-line version is excellent and saves a lot of time when travelling (as basically you don't have to wait till home to try a solution) as well as being well laid out & easy to use. I know we are not supposed to use this for personal regimen planning but for my friend it has stopped bulimia and anorexia and returned her to me from her "brittle" status two years ago. I really feel that it gave her her only hope through blindness and has allowed her much better recovery than she could ever have had. It also has allowed me to help specialists and nurses and GPs here from mistreating her (I don't mean shouting or bullying!) I cannot thank you enough.

From Turkey: Examine the nature of this "wonderful" disease. I had learnt about the effective timings of the carbohydrate intake with the previous DOS version (v4.0). . . and other variables that affects the blood sugar level. Thank you for making this available for free.

From Denmark: I have used previous versions of AIDA to check simulated results relative to clinical research data and alternative model based analysis.

From the USA: I plan to use the AIDA diabetes software simulator to help give me an idea about how and when my insulin is working in relation to food eaten, and exercise undertaken. I have used it before and it is a great help to me. Of course I do not go by the simulation alone in relation to insulin dosages, but like I said it helps me to understand certain qualities of different insulins in different situations.

DISCUSSION

Generally in medicine there is a growing movement to involve patients more in their health care. This is particularly the case in diabetes. Such moves to involve patients, in the

case of AIDA, involve securing feedback from users of the program, which can assist in the further refinement and development of the simulator. A large number of downloads of the AIDA software have been logged on the Internet. However, up to now, apart from user testimonials about the program¹⁵⁻¹⁸—and *ad hoc* comments received by the system developers via electronic mail¹⁹⁻²¹—there has been relatively little formal assessment as to who has actually been downloading or making use of the simulator or, more importantly, *why*.¹⁴

In the section above selected comments left by visitors at the AIDA Websites 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. Interestingly, in the previous pilot study,¹⁴ some of the respondents clearly missed the point about AIDA, and what it is meant for. As a result, the information—particularly the caveats—provided at the AIDA Website have been strengthened. Since then there seem to have been fewer people downloading the software quoting reasons that are not supported by the program.

The majority of respondents in this proof-of-concept survey seemed to expect to derive some benefit from their use of the simulator—and for the correct, intended purpose of the program. Their comments also mirror those of independent healthcare 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/reviews on the Web. However, while intuitively the benefits of such an interactive educational diabetes simulation approach may seem self-evident, as before,¹⁴ 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.²²⁻²⁴

For the current survey it was felt to be informative to confirm *why* people are in the first place actually turning to the AIDA site and downloading the program. In this respect, the current study has re-affirmed the feasibility of using the Internet to solicit free-text comments from substantial numbers of users/download-

ers of diabetes software. It has also provided useful and interesting information—highlighting that over half the respondents [257 (64.3%)] 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^{12,13} that so many patients and their relatives are turning to the Internet for diabetes-related information and guidance.

No survey would be complete without some assessment of the limitations of the approach. The most obvious limitation in this study 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, and repeat downloads, as have been overviewed above, do imply that people are making use of the program—and that is why they are telling others—and visiting the Website again to download the latest release of AIDA.

Furthermore, as has been outlined previously elsewhere²⁵ 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, which does seem to indicate substantial on-going interest in the program.

Semi-automated analysis

Some interesting issues for consideration—which may be useful for future surveys—have also come out of the current semi-automated data analysis. In this work it was not possible to automatically identify “missed the point” and “try it and see” replies—as these were not (and in some cases could not be) precoded. Therefore this involved manually reviewing the data. We found during this work that au-

tomated methods are much more robust and amenable to repeat implementation if as much of the data as possible has been pre-categorised. This implies that planning ahead to classify data items correctly is of some importance. However, in addition to this there will always be an interpretation step required, if one seeks to get the maximum amount possible out of the data that has been collected.

Nevertheless one issue to be considered with trying to categorise and semi-automate the analysis of such survey data is that some of the survey responses may cover more than one category and it may well not be possible to “pigeon-hole” these just one way. Given this, as intimated above, some human review of the data—albeit subjective—may be necessary simply to extract as much useful information as possible from the dataset.

Therefore perhaps two levels of analysis are needed—the first semi-automated, and the second slightly more subjective. In this respect the human review of the dataset obviously permits greater flexibility, which in turn allows interesting insights and comments to be extracted from a larger dataset, in a way that may not be so practicable using a semi-automated method. By contrast the semi-automatic process basically aims to establish as much information as possible—particularly about respondent demographics which do not require any special interpretation—with the minimum user/researcher interaction.

As such, this report also provides some insight into how much it is possible to extrapolate a survey analysis beyond the bounds of its original data collection, by interpreting some of the free-text comments. Furthermore it shows that although free-text data collection offers the maximum freedom for the *respondent*, it does lead to some issues that need to be considered when it comes to analysing such data, implicitly placing some constraints on the data analysis/interpretation that can be adopted. In addition some of the responses clearly require an element of human interpretation to draw useful conclusions from what is being said by downloaders.

In summary, it is a learning point from this study that if the data collection methodology incorporates sensible data coding into appro-

priate categories at the beginning, prior to the study, then more appropriate semi-automated analysis becomes possible later, with less “researcher involved” steps.

As an aside, it is interesting that a number of people with non-insulin-dependent (type 2) diabetes mellitus (NIDDM) report downloading and using the AIDA v4 program—even though NIDDM is not explicitly catered for in this version of the AIDA model. We have observed in a number of previous surveys of user comments^{17,21} that people with NIDDM have been using AIDA and report finding it of benefit. This perhaps is not surprising, as to some extent the basic principles of learning about balancing insulin and diet in diabetes are very similar in insulin-dependent (type 1) diabetes mellitus and insulin-treated NIDDM.

A future version of AIDA aims to incorporate the option of including endogenous insulin secretion in the model to improve the realism of the simulations for patients with NIDDM. Further information about this, and future versions of AIDA, can be obtained by sending a blank e-mail note to subscribe@2aida.org to join the low volume AIDA registration/announcement list.

Possible self-selection biases

The author has heard a number of times from diabetes health-care professionals as to what they think patients do, or do not, require from a program like AIDA. These comments, although entirely well intentioned, interestingly do not seem to correspond so well with what patients themselves are saying they want or need from AIDA.

In this respect, one thing that comes out of these surveys,¹²⁻¹⁴ repeatedly, is the desire for information that some people with diabetes mellitus, and their relatives, have. Occasionally we—as health-care professionals—may not fully appreciate this. Although there are clearly, unfortunately, some people with diabetes who attend diabetes clinics who have little or no interest in their disease or its complications—there are also many people with considerable interest. How self-selected the group who visit the AIDA Websites and download the AIDA program are, remains difficult

to assess. But from the absolute number of responses received there are clearly a substantial number of people around the world that seem to have interest in this approach.

One issue of importance to us is whether, in these surveys,¹²⁻¹⁴ we are simply hearing from the relatively enthusiastic and positive downloaders with less enthusiastic users simply not bothering to reply? We think not, given the large numbers of responses received (1,360 in our first download pilot survey in 1999/2000¹² and 2,437 in our second survey in 2000/2001,¹³ plus 642 free-text comments in a subset pilot study,¹⁴ as well as 400 further comments in this current proof-of-concept study). Therefore, there would appear to be a sizeable number of enthusiastic AIDA downloaders/users visiting the AIDA Websites. This observation is supported by the large (and growing) number of members of the opt-in AIDA registration/announcement list. This is accessible directly via www.2aida.org/register on the Web and currently has >2,400 subscribers.

Given the above, consideration of any possible respondent "bias" would only seem to really affect estimates of the *proportion* of AIDA downloaders/users that our surveys represent. (Attempts to extrapolate the findings of a particular audit study to *all* AIDA downloads during that period will always have difficulties.) By contrast, the surveys do seem to reveal a substantial number (in absolute terms) of enthusiastic downloaders/users. Therefore all we can say for sure is that there are thousands of people around the world who have been making use of AIDA, and seeming to find it of benefit. However, exactly how many thousands of *active* users is very much harder to establish, given our current survey tools. In this respect all we can easily monitor is the total number of program downloads from the AIDA Websites, which seems to carry on rising month on month.

Lastly we may also wish to consider whether the responses we are receiving in these surveys are honest and truthful. However, once again, it is the absolute number of positive respondents that seems to highlight the honest nature of the replies. In this respect, if we only had a small number of downloaders, perhaps a few self-selected respondents could bias the over-

all perspective—but with thousands of replies being received this of course becomes very much more difficult—common themes showing through in any analysis of the responses.¹²⁻¹⁴

Obviously there remains much that we need to learn about how to evaluate computer programs like AIDA. However, it is not just about randomised controlled trials (RCTs). While RCTs are clearly of importance,²² and remain the gold standard method of evaluation of such a program,^{23,24} we also need to survey users and learn from their feedback to close the audit/feedback loop. In this respect understanding the issues surrounding the analysis of data provided by such surveys is of interest and importance to us, in order to get the most out of such data collection exercises. Clearly similar survey approaches could be adopted for other diabetes software, and we would encourage other program developers to consider this for their own applications.

Finally, this study obviously only answers some questions that we may wish to ask about why people are continuing to download the AIDA software. Further studies are very clearly required to provide additional insight into usage of the program. Nevertheless it has been interesting to establish how people think they might benefit from downloading and using the existing AIDA v4.3a software.

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.

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