

# Who Participates in Internet-Based Self-Management Programs? A Study Among Novice Computer Users in a Primary Care Setting

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## PURPOSE

**T**he purpose of this study was to evaluate the participation rates and factors associated with nonparticipation among primary care patients who were invited to join an Internet-based self-management research program.

## METHODS

Primary care providers invited their patients with type 2 diabetes to participate in an Internet-based diabetes self-management support program. Research staff contacted these patients by phone to assess their eligibility and interest in participating. Reasons for declining were assessed and demographic/medical status information was collected.

## RESULTS

Of the eligible patients, 60% participated in the program. No significant differences were found between participants and decliners in gender, insulin use, computer familiarity, or computer ownership. There were significant differences in age and years since diagnosis. Participants were slightly younger and had diabetes for a fewer number of years than nonparticipants. Nonparticipation was not related to computer or Internet issues.

## CONCLUSIONS

Most older diabetes patients without previous Internet experience will take part in Internet-based self-management support programs if barriers to participation are addressed.

Diabetes management requires a high level of patient involvement in the treatment regimen<sup>1-3</sup> and a complex interplay of medical factors (eg, medication taking, blood glucose monitoring) and lifestyle factors (eg, diet, physical activity).<sup>4,5</sup> These activities are referred to as diabetes self-management because the patient has the primary responsibility for handling them.<sup>6</sup>

There are 4 major limitations to diabetes self-management education and research that is conducted in individual, small group, or classroom settings. The first limitation is cost. As discussed by Kaplan and Davis,<sup>7</sup> the time costs are considerable for both multidisciplinary staff members and patients. A second limitation is the disappointing penetration or reach of such diabetes education programs.<sup>8,9</sup> There are considerable barriers for patients who attend multisession education classes, including convenience, transportation, and competing time commitments. While comprehensive diabetes education programs such as those recommended by the American Diabetes Association standards<sup>10</sup> are beneficial, there is one important limitation: these programs reach only a minority of persons in need of self-management education and support.<sup>8,11,12</sup> Harris et al<sup>12</sup> reported that 2 national surveys of probability samples of diabetes patients revealed that less than 60% of type 1 patients, less than half of insulin-treated type 2 patients, and less than a quarter of noninsulin-treated type 2 patients had ever had a diabetes education course or class. A recent large-scale survey<sup>13</sup> found that only 44% of type 2 patients had ever received diabetes education training. The third limitation to diabetes self-management education is that ongoing contact and support appear to be necessary for long-term maintenance, especially in lifestyle areas such as nutrition.<sup>14-16</sup> The feasibility of providing frequent contact with healthcare professionals over a long time is limited given the decreasing healthcare resources.

A fourth limitation of the vast majority of diabetes education research studies is that they have been conducted with highly motivated, self-selected samples.<sup>9,17,18</sup> Even among the most recent and sophisticated studies of diabetes self-management, information on participation has been collected in only approximately 44% of the studies since 1997,<sup>9</sup> which raises concerns about generalization of effects. Even among studies that reported participation rates, few compared the characteristics of participants and nonparticipants to determine the representativeness of the sample compared with the target population.

#### INTERACTIVE INTERNET TECHNOLOGY

Most communication technologies (eg, telephone, radio) have had far-reaching, transformative consequences, and computer-based telecommunications will likely have an equally profound impact.<sup>19,20</sup> Within the past few years, the Internet has emerged as a fundamental information medium with an increasing impact on health care. The rapid growth of the Internet to 112 million US users by the year 2000 shifted the demographics of those using the Internet to more closely resemble those of the average American. Current Internet penetration is 30% of all households, with 51% of those planning to get Internet access being over the age of 35 and almost half (49%) having a high school education or less.<sup>21</sup>

With regard to patients using the Internet, approximately 19 million people search the Internet regularly for health and medical information.<sup>22</sup> CommerceNet and Nielsen Media Research<sup>23</sup> conducted an Internet demographics survey and found that access to the Internet increased 50% in a 6-month period, from 14% (August 1995) to 22% (March 1996). The growing use of the Internet for information and support is converging with another powerful trend, the increase in patient initiative for exploring healthcare options and taking greater responsibility for healthcare decision making. Patients and their supporters are connecting and interacting on the Internet to find medical information, verify it with experts, and share it with one another in large, supportive communities. The 7th Annual Graphics, Visualization, and Usability (GVU) Survey<sup>24</sup> found that 38% of users access health/medical information at least once a month. HealthMed retrievers who access the Internet specifically seeking medical information or advice comprise 49% of US Internet users.<sup>25</sup>

#### USING THE INTERNET FOR TYPE 2 SELF-MANAGEMENT EDUCATION

Reaching patients who do not usually participate in self-management training is an especially important issue if we are to come close to achieving national goals of reducing healthcare disparities.<sup>26</sup> The issue of the percent and characteristics of patients who will participate in Internet-based interventions is a particularly important area to investigate. Claims, largely unsupported by data, have been made on both sides of this issue. Some have claimed that the Internet can remove most of the barriers to participation and, given its ability to reach consumers on demand and at distance, can help reduce disparities in access to care and education.

Others remain skeptical, however, and are concerned that less advantaged groups will not have access to this medium, and that only technologically sophisticated, wealthier individuals will use such services.<sup>27,28</sup>

This project was designed to investigate some of these participation issues. The first step was to remove one of the major obstacles to Internet participation—access—by providing patients the opportunity for free, unlimited access to the Diabetes Network Web site for 1 year using a home computer provided by the project. Eliminating this barrier permitted the investigation of recruitment and participation, that is, the extent of interest in and willingness to participate in an Internet-based self-management support research project. To study the appeal of an Internet-based program among those who had no previous Internet experience, one of the few criteria required for inclusion was lack of Internet access at the time of screening. Also, a defined population of primary care patients with type 2 diabetes was used for recruitment.

The purposes of this paper are to (1) characterize participation rates and describe the participants in the Diabetes-Network (D-Net) diabetes support program, (2) report the representativeness of participants, and (3) identify reasons for nonparticipation.

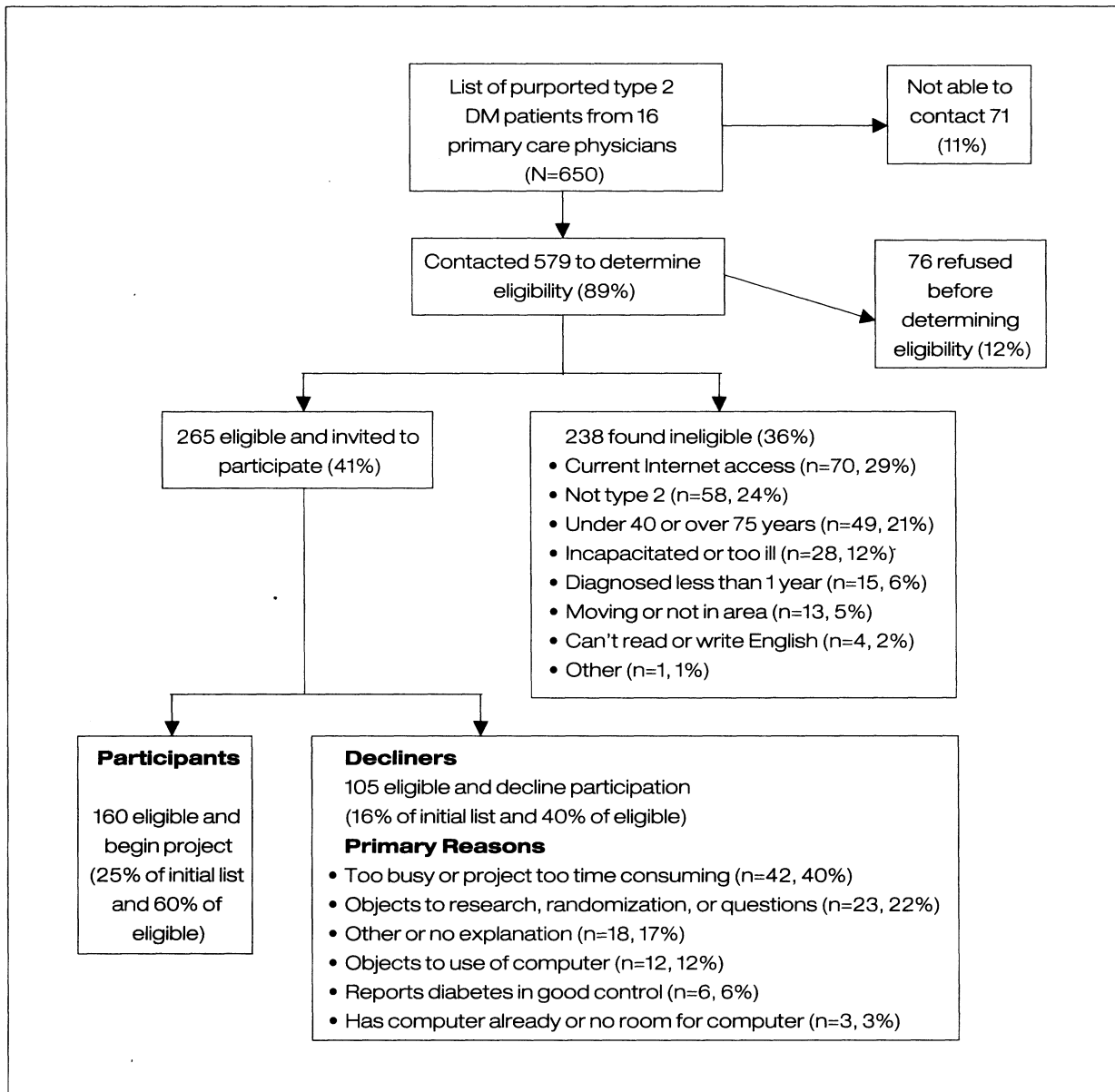
#### METHODS

Specific components of the D-Net intervention were peer social support and personalized dietary intervention facilitated by a professional mediator. All participants were provided with computers by the project that were specialized for diabetes self-management and Internet access. To help participants feel more comfortable learning to use the D-Net computers, the project used simplified computers, provided complete computer installation and extensive training (eg, 2 to 6 hours), and employed a simplified customization of the Internet Web site. The home-based intervention was free of charge, convenient (eg, the participants were loaned a specialized computer for 10 months to 1 year), and designed to mitigate frequent participation barriers such as cost, transportation, child care, travel costs, and work schedules.

#### RECRUITMENT RESULTS

Recruitment procedures began with a letter to patients from 1 of 16 primary care physicians (including 3 specializing in diabetes). The practices had an average of 40.6 type 2 patients (SD=49.1). The primary care physicians sent invitation letters to 650 patients listed as having type 2 diabetes. The letter described the project, enclosed a stamped “decline participation” return postcard, and informed the patients that a research project staff member would contact them to ascertain their willingness to participate. Prospective participants who did not want contact with project staff mailed the decliner postcard. The following eligibility requirements were established: aged 40 to 75, from the local area, have a telephone, able to read and write English, novice computer users, and diagnosed with type 2 diabetes mellitus for at least 1 year. *Novice computer use* was defined as the self-reported absence of Internet use. Of the 650 patients who were mailed letters, 71 (11%) could not be contacted, 76 (12%) returned the decliner postcard, and 238 were found to be ineligible (see the Figure). Of the 265 patients who were eligible to participate, 105 (40%) declined and 160 (60%) were enrolled in the program and completed baseline measures.

Analyses were conducted to evaluate differences between those eligible and agreeing to participate (participants, n=160) and those eligible but declining to participate (decliners, n=105) on a series of demographic, medical status, and computer use variables (see the Table). Chi-square (for categorical variables) and *t*-tests (for continuous variables) comparing demographic variables found no significant differences between participants and decliners in gender, insulin use (used as a proxy measure of disease severity), and, most importantly, computer familiarity and computer ownership. There were statistically significant but modest differences in age and the number of years since diagnosis. Using a Bonferroni correction to adjust for the number of analyses, the values were nonsignificant at the  $P<.007$  level ( $.05/7=.007$ ). Participants were slightly younger (59 vs 62 years) and had diabetes a fewer number of years (10 vs 13 years). One might suspect that age and



Sequence of steps in recruitment for the D-Net project.

### Characteristics of Participants and Those Eligible Who Declined Participation

Patient Characteristics	Eligible/Participated (n=160)	Eligible/Declined (n=105)
Age, * y, mean (SD)	59.2 (9.6)	62.1 (9.2)
Female, %	53.1 0 missing	54.4 2 missing
Own computer, %	44.4 0 not reported	33.3 57 not reported
Familiar with computers, <sup>†</sup> mean (SD)	1.7 (0.68) 0 not reported	1.4 (0.62) 57 not reported
Years diagnosed,* mean (SD)	9.5 (7.7) 0 not reported	13.4 (11.6) 56 not reported
Treatment, %		
Diet/exercise	10	9
Oral meds	53	51
Insulin	20	28
Both	17 0 not reported	13 58 not reported

\* $P < .05$ .

<sup>†</sup>1=not at all to 4=extremely.

years since diagnosis would be related; that is, older patients would be more likely to have diabetes for a longer time than younger patients. A test of this relationship found that while the correlation was significant, the magnitude was very weak ( $r=0.18$ ,  $P<.01$ ). Most decliners cited refusal reasons related to research participation (62%), whereas only 15 people reported their refusal was related to computers (15%). A complete listing of refusal reasons is shown in the Figure.

#### DISCUSSION

Research frequently does not address the issues of sample representativeness.<sup>9</sup> For example, the Diabetes Control and Complications Trial<sup>29</sup> (DCCT) studied a very motivated patient population without any complications. While the DCCT findings are impressive, many diabetes educators might find it daunting to replicate its results under conditions in the real world. Innovative approaches result from applied research on interventions that can be used with a high percentage of patients and that can incorporate representative samples. These approaches are likely to be adopted since they have been tested with a representative sample of the targeted client population. In this study, a sample of computer novices with type 2 diabetes were recruited from primary care physicians. The sample was highly representative of people who might need and seek the self-management information and strategies used in the

project. Results show that there were some weak relationships between 2 demographic variables to participation—age and years with diabetes—that were predictive of interest in interactive Internet interventions. These findings suggest a slightly increased interest in technological interventions in younger populations. The participation rate (60%) and representativeness were similar to but slightly less encouraging than what has been observed with medical office-based touchscreen computer-assisted self-management support.<sup>18</sup> However, this Internet-based program was more intensive in terms of time and intrusiveness because it was home-based, which may explain the difference.

Widespread dissemination of health-related information through the Internet is a trend and opportunity facing diabetes educators today. Many patients are becoming more actively involved in their health and entering healthcare settings with information collected over the Internet.<sup>24</sup> Given this trend, this Internet intervention can complement medical treatment of diabetes by providing personally tailored lifestyle interventions and social support via a computer accessible from patients' homes. This approach allowed a small number of staff to serve patients from a variety of providers and clinics, and could become a generalizable model for use in managed and primary care settings, or other situations in which population-based care is implemented for an entire panel of patients.

Evidence-based self-management support services can be provided in an appealing, attractive, and low-cost manner via an Internet Web site. Participants can access educational and support resources from the privacy of their own homes, as their schedule permits, and receive ongoing rather than time-limited support to address the critical issues of relapse and maintenance of behavior change.<sup>30</sup> The results from this study show that interactive Internet interventions can appeal to a wide range of type 2 patients regardless of gender, disease severity (as measured by insulin use), and computer familiarity, thus mirroring the general public's adoption of the Internet. Future research is needed to evaluate whether the Internet modality can maintain participation on an ongoing basis and help patients initiate and maintain meaningful behavior changes.

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