Use of the Internet to Study the Utility Values of the Public

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ABSTRACT

One of the most difficult tasks in cost-effectiveness analysis is the measurement of quality weights (utilities) for health states. The task is difficult because subjects often lack familiarity with health states they are asked to rate and because utilities measures such as the standard gamble, ask subjects to perform tasks that are complex and far from everyday experience. A large body of research suggests that computer methods can play an important role in explaining health states and measuring utilities. However, administering computer surveys to a "general public" sample, the most relevant sample for cost-effectiveness analysis, is logistically difficult. In this paper, we describe a software system designed to allow the study of general population preferences in a volunteer Internet survey panel. The approach, which relied on over sampling of ethnic groups and older members of the panel, produced a data set with an ethnically, chronologically and geographically diverse group of respondents, but was not successful in replicating the joint distribution of demographic patterns in the population.

INTRODUCTION

Some medical treatments increase the length of life of patients. Others primarily improve the quality of life. Many affect both. A widely used framework to integrate both quality of life and length of life benefits of treatments within economic analyses is the Quality Adjusted in Year model. In this model, a life of life with a health condition with a quality weight of 0.5 is equivalent to 1 year of life in perfect health (1). The source of quality weights for these economic analyses is a continuing controversy. Most researchers agree on the methods that should be used (either the standard gamble or the time trade-off approaches(2)) and on the population that should be surveyed (the preferences of the general public should be used in the initial modeling (1)).

Measuring the preferences of the public for many health conditions is a difficult task. Procedures for elicitation of values, such as the standard gamble or the time trade-off require the use of trained interviewers with props(2) or computer programs(3). Further, the disabilities caused by many diseases are not easily described and only infrequently seen by members of public. Members of the public may require intensive education to appreciate the implications of living with certain disorders.

One approach that may solve both of these problems is to use computer instruments with multimedia components to conduct preference surveys. Computer elicitation is a reliable approach to utility measurement(3). Previous work has shown that use of multimedia materials (sound, animations, graphics, and digital video to describe disease effects improves understand of those effects(4). Multimedia methods for description of health states were first used in a study of patients' values for adverse of effects of anti-psychotic drugs(5). Subsequently, we have used these methods to study patients and the public's values for a variety of other disorders(6-8).

While the use of computer programs to measure utilities and describe health states can solve two difficult technical problems, computer methods have their own logistical issues. How does one get a representative sample of the general public to complete a survey? In the past, the process of administering a computer has required researchers to bring computers to members of the public (in their homes and or shopping malls or other public places) or bring members of the public to research labs (through advertisements, incentives). Whatever methods are used, applying them over large geographic areas is difficult. Further, specific procedures for recruitment have their own limitations. Recruitment through advertising is inexpensive but produces a self-selected sample that may be biased in unknown ways. Recruitment and administration of surveys is in public places is impractical for computer surveys. Preference surveys tend to require intensive concentration for long periods of time (40 to 90 minutes is typical); administering such surveys in public places in impractical. Recruiting participants over the telephone (through random digit dialing) is an option, but since surveys cannot be administered over the phone, researchers must either go to the participant's home or offer sufficient incentives to bring the participant to the lab. Both options are expensive.

In this paper, we describe the use of a novel approach to the problem of measuring the general public's health state utilities for schizophrenia. Schizophrenia is a syndrome that is poorly understood by the public, that has a wide variety of manifestations. To measure utilities for states with this syndrome, we recruited attempted to recruit population with similar demographic characteristics to the U.S. population through selective sampling of a large online survey panel. We then administered a multimedia computer survey that illustrate typical features of the syndrome and elicited utility rates.

METHODS

To describe the effects of schizophrenia and measure preferences we developed 45-minute multimedia survey that used actors to portray various patterns of symptoms and elicited utilities for each pattern using the the standard gamble. The survey is described in detail elsewhere(9) and can be viewed at http://preferences.ucsd.edu/living. To conduct this study, we jointly developed a software application with a vendor with a large (500,000 plus) member panel of Internet users who had volunteered to participate in Internet survey research. The vendor (Greenfield Online, Wilton, CT) selected panel members with at least a 56K modem Internet connections at random to be invited to participate in the survey. After determining initial response rates, the vendor over-sampled ethnic and age groups in the panel with the aim of *produce a final sample with an age and ethnicity profile similar to that of the U.S. public.*

To recruit subjects, the vendor sent panel members an electronic mail message informing them of an opportunity to participate in a "health-related" study. A link in the Email sent respondents to the Greenfield site, where they were screened using a brief demographic survey. Respondents whose data matched that in the Greenfield database were referred for participation in the study. The Greenfield site assigned a unique numeric identifier to individuals subjects. This identifier passed to the main study web site and was recorded in the study database.

Respondents who came to the study's web site were further screened for other computer software necessary for the study. Respondents who did not have appropriate software were directed to sites where they could download the software (all free) and return to complete the survey. We gave the following specifications, with links to download upgrades: The requirements for use of the survey included Internet Explorer 5.0 or higher, Netscape 4.08 (Netscape, Mountain View, CA), Flash 3 (Macromedia, San Francisco, CA), and Windows Media Player 6.4 (Microsoft, Redmond WA).

Potential participants with an adequate computer configuration completed online a standard human subjects consent form. Those electing to participate then viewed the survey. Participants were exposed to a digital video presentation with background material on the possible health effects of schizophrenia. They then viewed additional video materials illustrating specific patterns of disease effects. Each pattern was presented in scenes where a psychiatrist interviewed a model patient. After viewing each pattern, participants rated each the pattern using a visual analog scale followed by a standard gamble. At the end of the survey, subjects submitted their responses to the study database, where they were recorded.

Digital video materials depicting states were sent to subjects using a "streaming" video server. This server transmitted in the files in a specific format (Media Player) that allowed viewing of video materials while they were downloaded. The video materials were stored on a space leased from a second vendor who specialized in delivery of such materials on the web. An important limitation of the approach was the resources allowed only for use of one of the three common formats for "streamed" digital video. The specific format was selected because it is pre-installed on Windows operating system computers.

Even using the streaming video server, the video files had to be highly compressed resulting in some loss of image quality. Compression rates were set so that the video materials would play without interruption given full access to a 50 kilobit per second Internet connection.

Every few days, the main study web site transmitted the subject identifiers back to survey vendor. The survey vendor transmitted demographic information for these participants back to the site. The vendor also tracked response rates by age and ethnic group. This arrangement was designed to protect the privacy of survey panel members. The identity of subjects, while confirmed by the vendor, could not be discovered by the researchers.

An important aspect of this study was attempt to attain a sample which matched the demographic distribution of the U.S. population in age and minority representation using resampling methods. Using subject identifiers to determine the response rates of various groups, Greenfield online examined response rates and randomly selected additional participants from their panel to receive email invitations, deliberately over-sampling elderly and minority panel members.

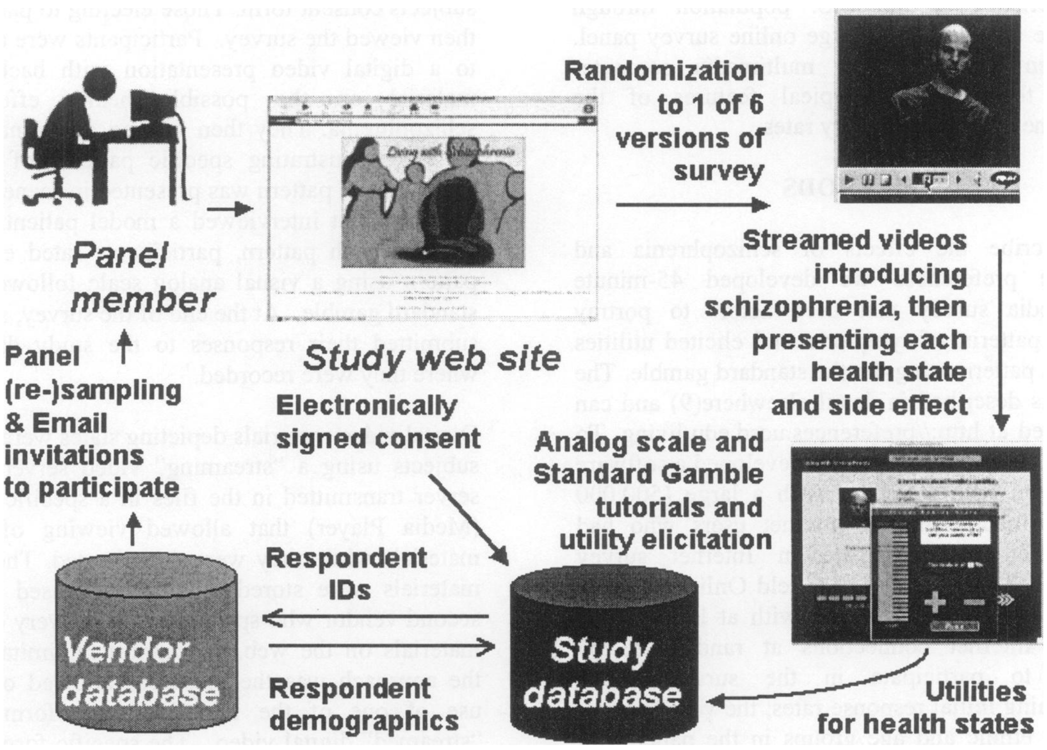


Figure 1. Design of the software systems used for administering the survey.

The process of sampling, recruitment, confirmation of identity, administration of the survey, and re-sampling of the survey panel, as described above, is shown in Figure 1. Subjects who completed the survey received $10. All procedures were approved by the University of California, San Diego, Human Subjects Committee.

Data analysis

To assess respondent bias, we determined the response rate in several ways. We compared the demographics of subjects invited, those who entered our website, those who signed the consent form, and those who completed the study. From survey logs we determined where people dropped out of the survey after signing the consent form. To assess potential biases in the method, we compared the demographic profile of respondents to the U.S. population, focusing on whether certain groups may have been excluded by this approach.

RESULTS

Greenfield Online e-mailed an announcement of the study to a total of 30,104 persons over 18 years old who were sampled from their panel. Of these, 1631 (5.4%) entered our site, 1302 (78.8% of those who entered the site) signed an on-line consent form and were passed to a page where their equipment was tested for compatibility. Response rates to email differed by age and ethnicity and ranged from 3.5% in African Americans to 11.5% in Caucasians and from 2.4% in 18 to 24 year olds to 13% in those over 55. The entire survey was completed by 640 subjects (49.2% of those who signed the consent). The completion rate also varied by age from 59.4% for those under 35 years of age and 42.1% for those 35 or over; and varied by ethnicity from 38.5% for African-Americans to 68.1% for Asian-Americans.

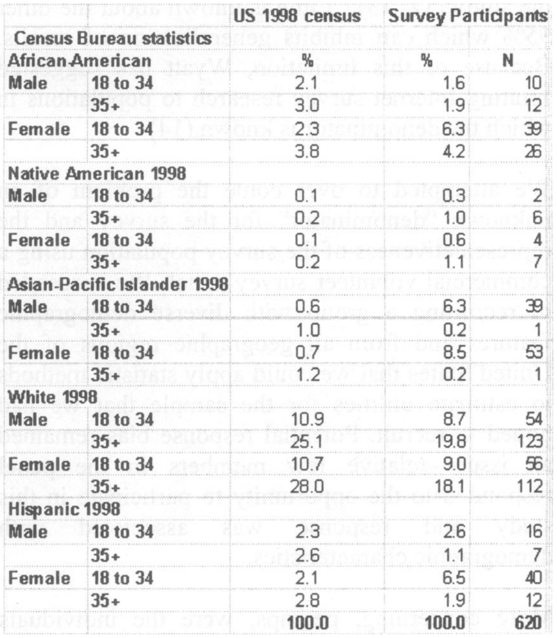
Participant characteristics
The population completing the survey was 43% males; 54% were Caucasians, with the largest minority groups (Latinos, African-Americans and Asians) ranging from 12% and 15% of the sample. The population tended to be young, but older panel members were also reached, with 16% over 55. Most respondents (80%) had completed more than high school education. The distribution of household income level and the region of residence in the United States were broad.

There were associations between demographic factors, email response rates and completion rates are a potentially important a limitation of this method. Efforts at over-sampling by invitation to minority and elderly subjects resulted in over sampling of some combinations of ages and ethnic types and under sampling of others as shown in Table 1. Certain demographic groups are almost completely missing from the sample. Others are highly over-represented, due to efforts to attempt to balance the survey on age or ethnic grounds.

DISCUSSION

This study is one of the first attempts to recruit a sample with demographics that are similar to the U.S. population for health policy research using a commercial Internet survey vendor. Certain biases are inherent with using the Internet for research and with the specific survey administration procedures used in this study. While the majority of Americans have access to computers at home or work (69%) and use the Internet (56%) (10), penetration of Internet use is lower in African American (40%) and Hispanic ethnic groups (50%) and in persons with low income and or educational levels. By working with a vendor with a large database of Internet users willing to participate in survey studies, we were able to recruit and administer a complex multimedia utility survey to a sample with high proportions of minority and aged participants, by selectively re-sampling from this database. However, we were not able to achieve a population mix similar to U.S. demographics using this approach.

This survey required use of "streaming" media to play digital video descriptions of health states. This complicated recruitment because the technology is not widely used (36% in a recent report from Nielsen Media). Several different variants of the video viewing, web browsing, and Flash software are available, therefore the proportion with any one variant is considerably less. Limitations on our budget prevented fielding of surveys with multiple types of streaming media. However, this might have been a wise investment in hindsight.



		US 1998 census	Survey Participants	
Census Bureau statistics				
African-American		%	%	N
Male	18 to 34	2.1	1.6	10
	35+	3.0	1.9	12
Female	18 to 34	2.3	6.3	39
	35+	3.8	4.2	26
Native American 1998				
Male	18 to 34	0.1	0.3	2
	35+	0.2	1.0	6
Female	18 to 34	0.1	0.6	4
	35+	0.2	1.1	7
Asian-Pacific Islander 1998				
Male	18 to 34	0.6	6.3	39
	35+	1.0	0.2	1
Female	18 to 34	0.7	8.5	53
	35+	1.2	0.2	1
White 1998				
Male	18 to 34	10.9	8.7	54
	35+	25.1	19.8	123
Female	18 to 34	10.7	9.0	56
	35+	28.0	18.1	112
Hispanic 1998				
Male	18 to 34	2.3	2.6	16
	35+	2.6	1.1	7
Female	18 to 34	2.1	6.5	40
	35+	2.8	1.9	12
		100.0	**100.0**	**620**

Table 1. Differences between the survey population and U.S. demographics.

The survey screened potential enrollees for the appropriate software and an appropriately fast (56K) Internet connection. Potential subjects who came to the site without the appropriate software installed on their computers were encouraged to obtain this from the Microsoft web site. Nonetheless, the relatively high drop-out rate between initial contact with our site and completion of the survey is in part attributable to the survey's software requirements.

Our previous efforts to use the Internet for research on preferences for health outcomes, and most other work by medical researchers have focused on patient populations on the Internet. Recruitment strategies have relied upon use of search engines or newsgroups to recruit subjects. This approach can result spectrum biases. Patients enrolling our previous online studies have tended to have high levels of disease symptoms that decrease with follow up(11).

What is difficult to determine in most Internet surveys is the degree of selection bias inherent in the approach. Surveys that solicit participants via search engines, email and hyperlinks produce samples where much is known about the participants, but little known about the population from which they were recruited. In our previous work, we have observed that about 5% of persons who view a web page describing a study, enroll in the study (12, 13). Little is known about the other 95% which can inhibits generalization of results. Because of this limitation, Wyatt has suggested limiting Internet survey research to populations in which the denominator is known.(14)

We attempted to over come the problem of an unknown "denominator" for the survey and the representativeness of the survey population using a commercial volunteer survey panel. We succeeded in recruiting a group with diverse demographic features and from all geographic regions of the United States that we could apply statistic methods to estimate utilities for the sample that we had hoped to recruit. Potential response bias remained an issue—relative few members in the panel responded to the opportunity to participate in this study and response was associated with demographic characteristics.

More concerning, perhaps, were the individuals under represented in the panel and among respondents—elderly from certain minority groups and persons of lower educational levels, missing from the survey. These groups may have systematic differences in preferences that would bias results. Fortunately, there is no work that suggests educational level is an important determinant of utility for health states. Because elderly minority group members are by definition a small portion of the total population, the degree of bias introduced into estimates of mean population utilities by omission is probably small.

CONCLUSIONS

Advances in Internet survey methodologies offer opportunities to investigators to collect data from members of the public to study their preferences and utilities at low cost relative to conventional survey methods. Use of the Internet may be particularly important if computer tools are required for administration of the survey due to the complex nature of questions or description of health impairments under study, precluding the use telephone or mail survey methods. Unless the panel is strictly representative, there will be biases in the approach and further study is required to assess how may impact the generalizability.

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