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WILLINGNESS TO PAY FOR PREDICTIVE TESTS WITH NO IMMEDIATE TREATMENT IMPLICATIONS: A SURVEY OF U.S. RESIDENTS

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Keywords: willingness to pay, predictive tests, Alzheimer's disease, cancer, arthritis

ABSTRACT

We assessed how much, if anything, people would pay for a laboratory test that predicted their future disease status. A questionnaire was administered via an internet-based survey to a random sample of adult U.S. respondents. Each respondent answered questions about two different scenarios, each of which specified: one of four randomly selected diseases (Alzheimer's, arthritis, breast cancer, or prostate cancer); an ex ante risk of developing the disease (randomly designated 10% or 25%); and test accuracy (randomly designated perfect or "not perfectly accurate"). Willingness to pay (WTP) was elicited with a double-bounded, dichotomous-choice approach. Of 2,223 respondents who completed the survey, most (70-88%, depending on the scenario) were inclined to take the test. WTP was lower for Alzheimer's and higher for prostate cancer compared with arthritis, and rose somewhat with disease prevalence and for the perfect vs. imperfect test. Median WTP varied from $109 for the imperfect arthritis test to $263 for the perfect prostate cancer test. Respondents' preferences for predictive testing, even in the absence of direct treatment consequences, reflected health and non-health related factors, and suggests that conventional cost-effectiveness analyses may underestimate the value of testing.

1 INTRODUCTION

Predictive testing is one of the fastest growing areas of health care,(National Imaging Associates, 2008;Knechtges, 2007;PricewaterhouseCoopers, 2006) its growth spurred by technological advances that promise more accurate analysis of a patient's disease and prognosis, and the prospect of better care management.(Chan 2002;Hillman et al. 2005;Iglehart 2006;Maitino et al. 2003;Seshadri 2005) New applications have emerged for diseases from Alzheimer's to cancer to endocrine disorders.(Bossuyt, Verweire, & Blanckaert 2007;Cooke 2002;Kolata 2008) However, increased spending has led payers to ask more demanding questions about whether benefits of new tests are worth their costs and, if so, in what situations.

Economic evaluation of test information has typically relied on conventional methods of decision analysis and cost-effectiveness analysis.(Weinstein et al. 1980) Consensus panels have recommended quantifying health benefits using quality-adjusted life years (QALYs) that reflect changes in both longevity and quality of life, with "quality of life" quantified in a way that is consistent with preferences people have for different health states.(Singer & Applegate 2001;Weinstein et al. 1996) Published cost-utility analyses pertaining to in vitro or laboratory diagnostics increased from 1.8 per year in the 1990s to 13.4 annually between 2000 and 2008.(Tufts Medical Center 2010)

In this conventional framework, test information is valued only to the extent that it leads individuals and their agents to make better medical decisions.(Baker, Atlas, & Afendulis 2008;Grosse, Wordsworth, & Payne 2008) In practice, however, patients may value information from a test even when the information does not affect treatment.(Lee, Neumann, & Rizzo 2009) For example, test information may provide reassurance to patients and physicians that serious disease is absent,(Blackmore et al. 1999;Hillman, Amis, Weinreb, & Neiman 2005) especially

for those identified as at risk.(Asch, Patton, & Hershey 1990;Kenen 1996) A new test may be valuable because it provides quicker access to such information.(Baker, Atlas, & Afendulis 2008) In addition, research also shows that people dislike uncertainty(Shogren 2005;Viscusi, Magat, & Huber 1991) and so may prefer situations in which they have better information about their health or about their chances of developing a condition.(Ellsberg 1961)

Test information may be useful in both medical and non-medical decision making. For diseases that are treatable, such information is needed to guide medical treatment choices. Even for diseases that cannot be treated, test information may be helpful for non-medical decision making. For example, a patient who learns he has developed a life-threatening but untreatable disease may choose to use remaining time for travel or family engagements. Similarly, the patient might choose to alter employment, savings or other financial plans. Of course, test information may also induce harms unrelated to treatment consequences. The experience of being tested itself can cause anxiety and discomfort for patients.(Gyrd-Hansen & Rasmussen 1972)

Contingent valuation (CV) or willingness to pay (WTP) surveys offer researchers substantial flexibility to investigate the value of a wide range of health and non-health benefits resulting from predictive tests. The WTP literature in health care has grown over the past few decades, with applications to different disease areas, treatment modalities, and survey methods (Blumenschein & Johannesson 1999;Diener, O'Brien, & Gafni 1998;Lachaine 2006;Olsen & Smith 2001;Rodriguez-Monguio, Otero, & Rovira 2003;Sach, Smith, & Whynes 2007). Several dozen WTP studies on a range of diagnostic and predictive tests have been published in a variety of clinical areas and modalities.(Appel et al. 1990;Berwick & Weinstein 1985;Brooks et al. 2005;Carlos et al. 2002;Caughey et al. 2004;Cho et al. 2000;Donaldson et al. 1995;Fauli & Thue

2008;Frew, Wolstenholme, & Whynes 2001;Hirth et al. 1999;Hirth et al. 2000;Lata, Binkley, & Elliott 2002;Liang et al. 2003;Miedzybrodzka et al. 1995;Mushlin et al. 1994b;Mushlin et al. 2005;Neumann et al. 2001;Papatheofanis 1998;Papatheofanis 2000;Phillips et al. 2006;Raab et al. 2002;Ryan et al. 2005;Salkeld et al. 2003;Schiffner et al. 2003;Shih et al. 2007;Tarasiuk et al. 2003;Wagner et al. 2001;Whynes, Frew, & Wolstenholme 2003;Wordsworth, Ryan, & Waugh 2001;Yasunaga et al. 2006a;Yasunaga et al. 2006b;Yasunaga et al. 2007;Yasunaga 2008) They have generally found that people have positive WTP for test information, even in the absence of treatment consequences. However, most of the studies relied on small convenience samples. Moreover, they vary considerably with respect to the methods they use to estimate WTP.

We conducted a population-based survey to investigate people's willingness to pay for predictive testing. We assessed whether and how much people would pay for a predictive laboratory test under conditions in which the test information had no immediate treatment implications. We also examined how preferences varied with disease type, disease prevalence, and test accuracy.

2 DATA AND METHODS

2.1 Survey design

We presented respondents with hypothetical scenarios in which they were asked to imagine that in the course of a regular check up, their physician told them they were healthy, but that someone their age had a chance (e.g., 25%) of one day contracting a particular disease (e.g., Alzheimer's) (Figure 1). Respondents were told that the doctor mentioned a new blood test that would tell respondents whether or not they would one day develop the disease. Patients would have to pay for the test themselves, however, because insurance did not cover it.

Respondents were told to assume that they could not prevent the disease from occurring, but that for people who eventually acquired the disease, treatments were available that might help. The scenario stated at the outset that questions were based on hypothetical or imaginary situations and that responses were confidential. The questionnaire included a pictogram illustrating the disease risk.

Willingness to pay for the test was elicited using a double-bounded, dichotomous-choice approach, which presented respondents with a binary (yes/no) bidding game, with respondents randomized to one of several initial starting bids ($50, $150, $300, $500).(Hanemann, Loomis, & Kanninen 1991) Respondents answering "yes" to the first question were asked if they would pay twice the initial price. Respondents answering "no" were asked if they would pay half the initial price. If the second response was "no," the subject was asked if they would be willing to take the test for free.

This bidding-game format is believed to produce less biased responses than open-ended and payment-card formats, because respondents have no incentive to misrepresent their preferences.(Hanemann, Loomis, & Kanninen 1991) A survey using this format elicits the respondent's upper and lower bounds on their willingness to pay, determined by the smallest bid to which they respond "no" and the largest bid to which they respond "yes" (the lower bound is assumed to be zero for respondents who answer "no" to both questions, and the upper bound is undefined for those who answer "yes" to both). By presenting this series of questions to many respondents, it is possible to estimate the distribution of willingness to pay for the test.

Each respondent answered questions about two different disease scenarios, each of which specified one of four randomly selected diseases: Alzheimer's disease, arthritis, breast cancer (female respondents only), and prostate cancer (male respondents only). Each scenario also

specified an ex ante risk of developing the disease in the future (randomly designated either 10% or 25%), and about test accuracy (randomly designated perfect or "not perfectly accurate"). Figure 2 illustrates the survey design and details the number of respondents randomized to each scenario.

We asked respondents who answered 'YES' to either the first or second bid question to select from multiple options what actions they would take if the test reported they would develop disease (e.g., get their finances in order). We also asked respondents about whom they would tell in the event of a positive test result, and how worried they would be that others (e.g., their employer) would gain access to the test information. Finally, we elicited information on demographic/socio-economic information, health status (personal history related to the health conditions described in the test scenarios), and a series of questions on risk attitudes (e.g., do you wear a seatbelt?). The survey instrument is available from the authors upon request.

2.2 Fielding the survey

The questionnaire was administered via the internet to a national panel of adult U.S. residents maintained by a survey research firm, Knowledge Networks (Menlo Park, California). Panel members are recruited using probability sampling and Knowledge Networks maintains various procedures to achieve sample representativeness and to prevent self-selection bias (J.Michael Dennis 2010). The survey panels resemble US Census benchmarks for primary demographics. Panelists were selected at random to receive an e-mail invitation to the survey. To prevent respondents from completing the survey more than once, each invitation contained a unique password. Reminder invitations were sent out at 2-4 day intervals to improve response rates.

A sample of 4,262 panelists was drawn from the weighted Knowledge Networks panel using probability proportional to size (PPS) sampling methods; 1,906 responded to the invitation and qualified for the study, yielding a total of 1,837 completed surveys. (Of these, 1,463 responded to the WTP questions reported on in this paper; the remainder were randomly assigned to questions about other topics that are not included in this analysis.) The survey was pre-tested on 29 respondents and pilot-tested on a sample of 193 respondents to assess the clarity of wording, to verify proper question branching and skip patterns, and to test the appropriateness of the starting bids. Specifically, we conducted an initial pretest with 29 cases using $50/$100 as the initial bids. Because a relatively high percentage of respondents were willing to pay for the test at these levels, we used $50/$500 as the initial bids for the follow-up pilot test of 386 cases. Pilot-test results suggested these values reasonably captured the WTP distribution and so we used $50/$150/$300/$500 as the initial bids in the main study. Because the pilot test revealed no problems with the questionnaire, we included these respondents in the final analyses. We excluded respondents who stated they had ever been diagnosed with any of four diseases studied. The survey required approximately 15 minutes to complete.

2.3 Analysis

The double-bounded, dichotomous-choice format permits an analysis of the willingness-to-pay data as a survival analysis with censoring.(Hanemann, Loomis, & Kanninen 1991) Although a respondent's exact WTP is not observed, it is assumed to lie above any bid amount to which she replied ''yes'' and below any bid amount to which she replied ''no''.

We implemented a two-part model to estimate WTP.(Hammitt & Zhou 2006) The first model component used logistic regression (proc LOGISTIC, SAS version 9.2, Cary, NC) to estimate the probability that WTP > 0. We assumed WTP to be zero if the respondent rejected

the two bids offered and answered "no" to the follow up question asking if the respondent would take the test for free. Other respondents were assumed to have a non-zero WTP with bounds determined by their responses to the bid questions.

The second model component limited attention to respondents with WTP > 0. We used maximum likelihood regression (SAS proc LIFEREG) to estimate median and mean WTP values for these respondents assuming WTP followed a lognormal distribution.

We conducted two sets of regressions to predict WTP. The first set included our main predictors of WTP, namely disease type (four values), prior disease risk (two values), and test accuracy (two values). We estimated the median WTP for the complete population (zero and non-zero respondents) to be the $50 - p$ percentile of the WTP distribution for the non-zero respondents, where *p* is the percent of the population with zero WTP. We computed mean WTP as the product of $(1 - p)$ and the arithmetic mean WTP for non-zero respondents.

We conducted a second set of regression analyses to determine if other factors influenced WTP. This set incorporated main predictors for WTP from the first analysis as well as several adjusters, including log income (continuous), education (four categories), gender, and age (continuous). We added these independent variables to test the credibility of the survey (e.g., WTP should increase with income and test accuracy) and to learn something about how WTP varies with individual characteristics (e.g., sociodemographic variables and respondent attitudes). We also calculated and included in the regression a "risk score," which is an aggregation of responses to questions indicative of respondent risk tolerance. Its value is the sum of points awarded based on responses to each of five questions (e.g., do you were a seatbelt?) (see footnote to Table 1).

3 RESULTS

Table 1 reports sample statistics. Table 2 reports the proportion of respondents who would take the test (including those who would take it only if it were free), and the mean and median WTP for all respondents, including those who would *not* take the test even if it were free. A majority of respondents were inclined to take the predictive test across all diseases and scenarios, with proportions varying from 70% to 88%. Inclination to take the test was highest for prostate cancer (85-88%, depending on disease risk and test accuracy) and lowest for Alzheimer's disease (70-75%). A higher ex ante risk of disease (25% *vs.* 10%) was associated with a somewhat higher WTP, and WTP was somewhat higher for the perfect than the imperfect test. Mean WTP ranged from $320 for an imperfect arthritis test to $622 for an perfect prostrate cancer test.

Table 3 presents the multivariate regression results. We present the impact on the probability that subjects are inclined to take the test and the impact of various characteristics on the natural log of the geometric mean WTP among these subjects. Respondents who would take the test include those who were willing to pay for testing as well as those who would take it if it were free. We present a "simple" model, which contains the disease type, disease risk, and test accuracy, and an "expanded" model, which also includes income, education, gender, age, and risk score. The proportion of respondents inclined to take the test was significantly smaller for Alzheimer's and higher for prostate cancer than for arthritis. This proportion was also significantly higher for the perfect than the imperfect test. Older respondents, females, those with a bachelor's degree or higher, and those with a lower risk score (i.e., exhibiting less risk taking behavior) were significantly less likely to want the test even if it were free.

Restricting attention to only those respondents inclined to take the test, willingness to pay was significantly higher for breast cancer, Alzheimer's and prostate cancer than for arthritis. WTP rose with income and was lower for females and those with lower risk scores.

Regarding what they would do with a positive test, respondents most frequently stated that they were very likely or somewhat likely to obtain a second medical opinion (59%) or seek medical care from a medical specialist (59%) (responses were not mutually exclusive) (Table 4). Other popular responses included signing an advance directive document (51%), spending more time with family (51%), getting finances in order (48%), and traveling more (31%). Frequencies were considerably higher for the Alzheimer's disease and cancer scenarios than for arthritis. Less common responses were seeking help from a medical professional (27%), changing jobs (7%), and quitting work (7%).

Asked whom they would tell if they received a positive test, respondents most often stated they would definitely or probably tell their spouse (69%), other family members or relatives (55%), close friends (50%), or children (49%) (Table 4). Fewer would tell their clergy member (34%) or co-workers (22%). Percentages were generally lower for the Alzheimer's scenario. In terms of concerns about people gaining access to the information, respondents worried most about insurance companies (37%), followed by the government (28%), and their employers (24%). Concerns were highest for Alzheimer's relative to other diseases.

4 DISCUSSION

4.1 Preferences for predictive testing

Observers have long argued that conventional techniques of economic evaluation may insufficiently capture the value of predictive testing because people prefer information, even if it has no bearing on subsequent treatment.(Asch, Patton, & Hershey 1990;Baker, Atlas, & Afendulis 2008;Fryback & Thornbury 1991;Grosse, Wordsworth, & Payne 2008) Our study tested this presumption empirically and contributes to the field by employing a multi-faceted experimental design in a large population-based internet survey.

The results suggest that most people prefer to take predictive tests even in the absence of direct treatment consequences -- and that they are willing to pay reasonably large amounts for the opportunity. The results hold across multiple diseases, whether or not the test is perfectly accurate, and for different ex ante probabilities regarding the risk of developing the disease in the future.

Our study thus adds to research indicating that people desire information for its own sake. Researchers have found that people generally prefer to learn their disease status or predisposition for conditions including Alzheimer's, cancer, cystic fibrosis, and Huntington's disease.(Babul et al. 1993;Bratt et al. 2000;Cairns, Shackley, & Hundley 1996;Erde, Nadal, & Scholl 1988;Green et al. 1997;Neumann et al. 2001;Van Bebber et al. 2007) Berwick and Weinstein(Berwick & Weinstein 1985) found that 44% of women respondents valued ultrasound in pregnancy for reasons unrelated to treatment. Schwartz and colleagues reported that cancer screening was favored by two-thirds of respondents even in the absence of treatment options.(Schwartz et al. 2004) Studies of prenatal screening have reported that WTP estimates are not very sensitive to whether or not a woman plans to terminate an affected pregnancy.(Donaldson, Shackley,

Abdalla, & Miedzybrodzka 1995;Donaldson, Shackley, & Abdalla 1997;Hammitt & Zhou 2006;Shackley 1996)

This "value of knowing" seems in part a desire for reassurance that one does not have a particular disease. Studies report, for example, that many persons at low risk of hereditary cancer would seek testing as a means of obtaining reassurance.(Andrykowski et al. 1997)

However, it also suggests a desire for information even in the face of possible bad news. Research has demonstrated that people dislike ambiguous situations (in which the probabilities of different outcomes are unknown or uncertain) (Shogren 2005;Viscusi, Magat, & Huber 1991) and so may prefer situations in which they have better information, even if negative, about their health or their chances of developing a condition.(Ellsberg 1961) One study of people who had undergone genetic testing to determine their risk for developing Huntington's disease found that those who learned they had a very high likelihood of developing the condition were happier a year after testing than those who had not learned their risk.(Wiggins et al. 1992) A study of Alzheimer's genotype disclosure in asymptomatic adults who had a parent with Alzheimer's disease found that disclosure provided a psychological benefit to those who were negative for a susceptibility gene and caused only transient, modest distress to those with a positive result.(Green et al. 2009) The authors concluded that the data supported disclosing information to people who requested it, despite the frightening nature of the disease and the fact that disclosure has no clear medical benefit. Mushlin et al.(Mushlin et al. 1994a) found that even people receiving positive test results became less anxious upon diagnosis, despite the new knowledge that they had a chronic disease. The psychologist Daniel Gilbert(Gilbert 2009) has observed "people find uncertainty more painful than the things they're uncertain about and people feel worse when something bad *might* occur than when something bad *will* occur."

Consistent with other research, our study suggests that people also value test information because it might alter their behavior.(Neumann et al. 2001;Payne et al. 2007;Van Bebber, Liang, Phillips, Marshall, Walsh, & Kulin 2007) Despite being told to assume that there was no way to prevent the disease, many respondents noted that they would seek a second opinion or consult a specialist, perhaps to confirm or refute the test results. However, respondents also valued predictive information because of a host of non-health related reasons, such as spending more time with family and attending to personal finances. Most said they would share the news with their spouse, family members and friends, suggesting possible "spillover" effects, which could be particularly important for genetic testing.(Basu & Meltzer 2005;Grosse, Wordsworth, & Payne 2008) Most were not worried about others receiving access to the information.

The inclination to take and pay for testing was particularly strong for the breast and prostate cancer scenarios, which may reflect the heightened dread that cancer evokes relative to other conditions.(Hammitt & Liu 2004;Sunstein CR 1997) and perhaps a disbelief in our claim in the hypothetical scenario that the cancers could not be prevented. Among those who wanted test information, WTP was highest for the breast cancer scenario, which suggests a particular salience for that condition. Fewer people wanted the Alzheimer's test, which suggests fear of living with the prospect of dementia.(Neumann et al. 2001)Respondents were somewhat more inclined to take and to pay for the perfectly accurate vs. the imperfect test.(Hirth et al. 1999;Neumann et al. 2001)

We also found considerable heterogeneity among respondents. Notably, about a quarter of the sample elected not to take the predictive test, perhaps because of anxiety or confusion about testing and/or concerns about living with the burden of disease.(Benkendorf et al. 1997;Drickamer & Lachs 1992;Kahn 1997;Maguire et al. 1996;Roberts 2000;Van Bebber,

Liang, Phillips, Marshall, Walsh, & Kulin 2007;Welkenhuysen, Evers-Kiebooms, & Van den 1997;Wroe, Salkovskis, & Rimes 1998) Generally, women, more educated and older individuals and those with healthier behaviors were less inclined to obtain testing. As expected, WTP increased with disease risk and income, and was higher for the perfect than the imperfect test. WTP was smaller for females and those with higher education, age, and risk score, consistent with some prior studies (Neumann et al., 2001), though the literature on the influence of these variables seems mixed (Frew et al., 2001; Caughey, 2004; Yasunaga, 2006; Raab, 2004; Yasunaga, 2009; Lacour, 2008) .

4.2 Implications

Health technology assessment (HTA) agencies worldwide are intensifying their scrutiny of predictive tests by requesting evidence that testing not merely increases accuracy, but also improves patient outcomes and has evidence of cost-effectiveness.(Neumann & Tunis 2010) Conceivably, predictive testing will reduce some costs -- e.g., decreased anxiety may reduce some subsequent health care utilization,(Esfandyari & Harewood 2007) -- though in most situations net costs will likely rise.(Baker, Atlas, & Afendulis 2008)

Our study suggests that HTA organizations might better account for individuals' "value of knowing".(Lee, Neumann, & Rizzo 2009) Most cost-effectiveness analyses have not included non-health outcomes or preferences for information.(Asch & Hershey 1995;Asch, Patton, & Hershey 1990;Grosse, Wordsworth, & Payne 2008;Hirth et al. 1999) To be sure, how to incorporate these preferences into cost-effectiveness analyses and into health policies raises challenges. There are also questions about whether and to what extent patients should pay themselves for these non-health outcomes. In addition, we did not directly evaluate the fact that for some respondents, receiving the information might generate disutility. These individuals

have WTP less than zero and, in theory, would need to be compensated to receive the test and hear its results. For those with WTP<0, conventional analyses would *overvalue* predictive tests and the relevant question is how much clinical value are people willing to trade in order to accept the disutility of knowing the information.

4.3 Limitations

It is well known that results from contingent valuation (CV) surveys are influenced by factors ranging from scenario richness and presentation (e.g., how believable and realistic the scenario is and the sequence in which items are presented) to the payment vehicle, expression of risk, time period of valuation, and survey administration.(Hanley, Ryan, & Wright 2003;Smith 2003;Smith 2008) Responses can be insensitive to the scope of the good or project being valued. People tend to state a similar willingness to pay for any given magnitude of risk reduction(Hammitt & Graham 1999) and tend to exaggerate valuations of the specific intervention that respondents are asked about, relative to interventions that respondents are not asked about.(Cookson 2003;Hanley, Ryan, & Wright 2003) Some studies have found much higher hypothetical than real WTP.(Hanley, Ryan, & Wright 2003)

Our study has a number of limitations, including standard concerns about the hypothetical nature of the vignettes and possible framing effects. We did not include detail on the nature of the test, such as waiting time for results, for example.(Grosse, Wordsworth, & Payne 2008) Studies have found that patients' acceptance of a test can depend on a test's duration and unpleasantness, and the anxiety resulting from extended waiting times.(Schonenberger et al. 2007;Swan et al. 2000)

Conceivably, some respondents might have been confused by the wording of the questionnaire. For example, some subjects may have believed that the test would help them

obtain those treatments in a timely fashion – as perhaps suggested by the fact that the most common responses to the information were to seek second opinions and specialty care (59% each). In addition, it is possible that the estimated WTP did not differ much between respondents told that the test was perfectly accurate and those that were told it was imperfect because respondents discounted the assumption of perfect accuracy. That is, respondents familiar with existing tests might know that no predictive test (other than perhaps for Huntington disease) is close to perfect and thus might reasonably ignore or heavily discount that piece of information.

4.4 Future research

Grosse et al.,(Grosse, Wordsworth, & Payne 2008) observe that the potential of WTP estimates to inform health care policy has remained largely unfulfilled because of difficulties applying the technique in practice, and that most published CV studies in health care remain experimental in nature.(Grosse, Wordsworth, & Payne 2008) Still, interest in CV methodology endures because it permits a more comprehensive valuation of health benefits than do QALYs.(Olsen & Smith 2001) CV requires that people express preferences in the single dimension of money, but it does not restrict the attributes of the intervention over which the respondent may have preferences, e.g., one can incorporate preferences for non-health as well as health attributes of the intervention (Olsen & Smith 2001) In the case of predictive information, CV offers a clear potential advantage because of the importance of non-health outcomes, such as the value of knowing. Our study demonstrated face validity in that WTP moved in the expected directions with disease risk, test accuracy, income, and individuals' risk scores.

CV research has enjoyed broader acceptance among academic economists and policy makers in environmental and transport economics(Hanley, Ryan, & Wright 2003;Smith 2003) and the potential remains for its application in health care. The field has been aided by advances in techniques for collecting and analyzing data, including use of the double-bounded dichotomous choice and the use of parametric and semi-parametric approaches to estimating the distribution of WTP.(Hanemann, Loomis, & Kanninen 1991) To build on the work presented here, future researchers could assess other conditions and scenarios and explore further why people want information(Hanley, Ryan, & Wright 2003) Our study highlights the fact that the desire for this information can be an important component of value.

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Table 1: Sample statistics

Gender	Male (51%)				
Age (Mean ±SD)	43 (±16.2)				
Education					
Less than High School	11%				
High School	30%				
Some College	29%				
Bachelor's degree or higher	31%				
Household Income (annual)					
Less than $20,000	14%				
$20,000 to 39,999	23%				
$40,000 to 59,999	18%				
$60,000 to 84,999	21%				
More than $85,000	25%				
Risk Score* (Mean ±SD)	11±(4.0) (95% range: 5-18)				
	Always	Usually	Sometimes	Rarely	Never
Wear seatbelt	83%	9%	4%	2%	1%
Eat healthy diet	15%	47%	31%	6%	1%
Annual check-up	39%	18%	16%	15%	12%
Smoke	44%	12%	20%	7%	16%
Exercise regularly	56% (Yes)				

*The Risk Score is an aggregation of responses to questions indicative of respondent risk tolerance. Its value is the sum of points awarded based on responses to each of five questions. For each question, a higher point score indicates greater tolerance of risk, or engagement in more risky behaviors. For example, we ask respondents whether they wear a seatbelt always (1 point), usually (2 points), sometimes (3 points), rarely (4 points), or never (5 points). Other questions ask about diet, how often the respondent gets an annual checkup, smoking, and exercise. For regular exercise question, we only have yes (1 point) and No (5 points).

Table 2. Proportion of respondents who would take the test and willingness to pay for all respondents [(a)]

	Disease Risk 10%		Disease Risk 25%	
Test Accuracy / Disease	Perfect	Imperfect	Perfect	Imperfect
Alzheimer's Disease				
Pct who would take test[(a)]	74.0%	70.4%	74.8%	71.2%
Median – all respondents[(a)]	$153	$120	$162	$128
Mean – all respondents[(a)]	$479	$409	$500	$428
Arthritis				
Pct who would take test[(a)]	80.2%	77.2%	80.8%	77.9%
Median – all respondents[(a)]	$135	$109	$142	$116
Mean – all respondents[(a)]	$370	$320	$385	$333
Breast Cancer				
Pct who would take test[(a)]	81.9%	79.0%	82.4%	79.7%
Median – all respondents[(a)]	$221	$181	$232	$191
Mean – all respondents[(a)]	$587	$508	$610	$529
Prostate Cancer				
Pct who would take test if free[(a)]	87.5%	85.4%	88.0%	85.9%
Median – all respondents[(a)]	$251	$212	$263	$222
Mean – all respondents[(a)]	$600	$526	$622	$546

Notes:(a) The percentage of respondents who would take the test, includes those who would only take it if it were free, as well as those who were willing to pay for testing. "All respondents" refers to both those who would take the test if it were free and those who would not. The mean reported here reflects the assumption that the test is worth zero to respondents who would not take it even if it were free. The median reported here reflects the assumption that the test is worth no more than zero to this group.

Table 3. Regression Results

	Probability Subject Would Take Test				Natural log of the geometric mean WTP			
	Simple model		Expanded model		Simple model		Expanded model	
Variables	**Estimate**	**SD**	**Estimate**	**SD**	**Estimate**	**SD**	**Estimate**	**SD**
Intercept	1.22***	0.046	2.45***	0.67	5.38***	0.10	3.73***	0.55
Disease								
Alzheimer's disease	-0.35***	0.072	-0.36***	0.073	0.34***	0.12	0.31***	0.11
Prostate cancer	0.55***	0.087	0.46***	0.11	0.40***	0.11	0.22*	0.12
Breast cancer	0.11	0.080	0.21**	0.099	0.44***	0.11	0.65***	0.12
Arthritis (ref.)								
Prior risk								
25%	0.040	0.044	0.031	0.045	0.032	0.075	0.038	0.073
10% (ref.)								
Test Accuracy								
Perfect	0.18***	0.045	0.18***	0.045	0.032	0.075	0.11	0.073
Imperfect (ref.)								
LN Income			-0.0089	0.056			0.20***	0.046
Education								
High school			0.056	0.077			-0.085	0.14
Some college			-0.11	0.079			0.046	0.14
Bachelor's degree or higher			-0.17**	0.083			0.14	0.14
Less than high school (ref.)								
Gender								
Female			-0.13**	0.058			-0.39***	0.11
Male (ref.)								
Age (Years)			-0.012***	0.0029			0.0003	0.0024
Risk Score			-0.052***	0.012			-0.032***	0.010

Note: * p<0.10; ** p<0.05; ***p<0.01

Table 4. Attitudes about testing

	Overall	Disease			
		Alzheimer's	Arthritis	Prostate Cancer	Breast Cancer
What would you do with a positive test?[1]					
Get a second medical opinion	59%	53%	31%	61%	59%
Seek medical care from a medical specialist	59%	50%	36%	61%	59%
Sign a document specifying how you want to be treated if you became ill	51%	53%	24%	50%	53%
Spend more time with your family	51%	51%	27%	49%	55%
Get your finances in order	48%	43%	25%	48%	50%
Travel more	31%	42%	21%	28%	33%
Seek help from a mental health professional	27%	37%	6%	23%	31%
Change jobs	7%	3%	3%	6%	8%
Quit working/retire	7%	9%	7%	7%	6%
Who would you tell?[2]					
Spouse or partner	69%	55%	67%	73%	66%
Other family members or relatives	55%	48%	57%	58%	53%
Close friends	50%	40%	48%	50%	52%
Children	49%	46%	65%	53%	45%
Minister/rabbi/clergy member	34%	25%	31%	36%	33%
Co-workers	22%	10%	32%	23%	22%
How worried are you about people gaining access?[3]					
Insurance company	37%	45%	38%	37%	37%
The government	28%	34%	17%	28%	27%
Employer	24%	28%	27%	23%	24%

Note: The table excludes individuals who were "not applicable" respondents (e.g., those who were not employed were excluded from the question about how worried they would be that their employer would gain access to test information).

1. Includes those responding "Very likely" or "Somewhat likely"
2. Includes those responding "Definitely would tell" or "Probably would tell"
3. Respondents were asked whether they were "worried" or "not worried"

Table Legends:

Table 1:
Characteristics of the survey sample

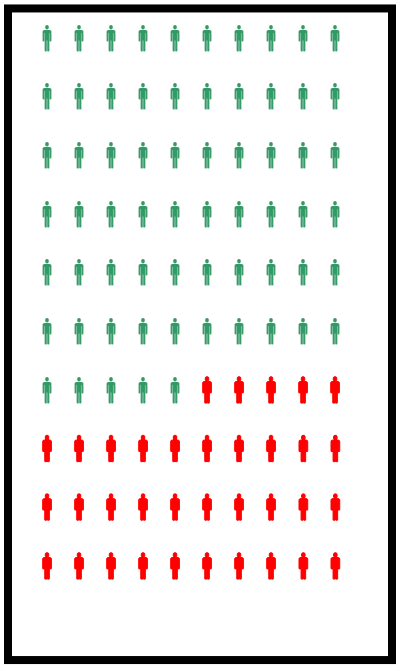
Table 2:
Proportion of respondents who would take the test and willingness to pay for all respondents

Table 3:
Results of the 2-part regression model

Table 4:
Survey respondent attitudes about testing

Figure 1: Sample Scenario

Imagine that you go to the doctor for your regular check up. Your doctor tells you that you are healthy but that someone your age has a 25% chance of some day getting Alzheimer's disease. The people in red represent the number out of 100 that might get Alzheimer's disease.



As you may know, Alzheimer's disease is a disease of memory that worsens over time. Most people who get Alzheimer's disease are over age 65.

The doctor tells you that a new blood test is available that will tell you now whether or not you will one day develop Alzheimer's disease. The test is 100% accurate. You will have to pay for the test yourself because insurance does not pay for it.

Assume for this scenario that you cannot prevent the disease from occurring. For people who get the disease, there are treatments available that may help.

Would you want to take the test if it cost you $50?

Figure 2: Survey Design

	Willingness to Pay			
Disease Risk	25%	10%	25%	10%
Test Accuracy	Perfect	Perfect	Imperfect	Imperfect
Disease				
Alzheimer's Disease	193	193	193	193
Arthritis	192	189	190	191
Prostate Cancer	159	186	159	184
Breast Cancer	166	165	165	208

Note: 1,463 respondents were randomized to answer questions about two of 16 scenarios each of which contained one of four diseases (Alzheimer's disease, arthritis, breast cancer or prostate cancer), a disease risk (10% or 25%) and information about test accuracy (perfect test, "not perfectly accurate"). The figure shows the sample allocated to each of the 16 scenarios.