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OPTIMAL EXPECTATIONS AND LIMITED MEDICAL TESTING: EVIDENCE FROM HUNTINGTON DISEASE

Emily Oster
Ira Shoulson
E. Ray Dorsey

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ABSTRACT

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Emily Oster
University of Chicago
Booth School of Business
5807 South Woodlawn Ave
Chicago, IL 60637
and NBER
eoster@uchicago.edu

E. Ray Dorsey
Johns Hopkins University
Department of Neurology
Meyer Bldg, Room 6-181
600 N. Wolfe Street
Baltimore, MD 21287
Ray.Dorsey@jhmi.edu

Ira Shoulson
University of Rochester
School of Medicine and Dentistry
Department of Neurology
601 Elmwood Ave, Box 673
Rochester, New York 14642
Ira.Shoulson@ctcc.rochester.edu

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Emily Oster*
University of Chicago and NBER

Ira Shoulson
University of Rochester

E. Ray Dorsey
Johns Hopkins University

Draft: November 17, 2011

Abstract

We use novel data to study the decision to undergo genetic testing by individuals at risk for Huntington disease (HD), a hereditary neurological disorder that reduces healthy life expectancy to about age 50. Although genetic testing is perfectly predictive and carries little financial or time cost, less than 10 percent of at-risk individuals are tested prior to the onset of symptoms. Testing rates are higher for individuals with higher *ex ante* risk of carrying the genetic expansion for HD. Untested individuals express optimistic beliefs about their probability of having HD and make fertility, savings, labor supply, and other decisions as if they do not have HD, even though individuals with confirmed HD behave quite differently. We show that these facts are qualitatively consistent with a model of optimal expectations (Brunnermeier and Parker, 2005) and can be reconciled quantitatively in this model with reasonable parameter values. This model nests the neoclassical framework and, we argue, provides strong evidence rejecting the assumptions of that framework. Finally, we briefly develop policy implications.

1 Introduction

Huntington disease (HD) is a degenerative neurological disorder with onset about age 40, a life expectancy of around 60 and a healthy life expectancy of 10 years fewer than that. HD is caused by an inherited expansion in the Huntingtin gene. Individuals with one parent with HD have a 50% chance of inheriting the expanded copy of the gene and developing the disease. Since the early 1990s a genetic test has been available. This blood DNA test can provide at-risk individuals with certainty (100% or 0%) about whether they will develop HD. This test would appear to have significant value;

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a variety of life choices (childbearing, marriage, retirement, education, participation in clinical research) are likely to be affected by HD status. Although HD is a rare disease, genetic testing for other conditions is becoming increasingly common, making our conclusions potentially more generalizable in the long run.

In this paper we explore the decision to undergo genetic testing. Our first contribution is to document a number of facts about genetic risk, behavior and genetic testing using a rich dataset of individuals at risk for HD. Our data covers 1001 at-risk individuals who had chosen not to undergo genetic testing prior to enrollment into an observational study. Over a ten year period we observe subsequent decisions by some research participants to pursue genetic testing for HD, yearly information on subjective and investigator-measured probability of carrying the HD expansion, and information on a variety of life events.

We begin by documenting low rates of genetic testing in our sample: fewer than 10% of individuals pursue predictive testing during the study. This echoes what has been seen in other contexts (Koszegi, 2003; Lerman et al, 1996; Thornton, 2008) and in other data on this population (Shoulson and Young, 2011). Also in line with other contexts, financial and time testing costs are relatively low, on the order of a few hundred dollars even if paid out of pocket.

Although predictive testing rates are low overall, we find that the probability of undergoing genetic testing is increasing with *ex ante* risk of carrying the HD expansion. This is true both in levels and in changes. In the cross section, individuals with higher objective probabilities of having HD (by virtue of emerging signs or symptoms) are more likely to pursue testing.[1] Further, testing appears to be commonly prompted by a *change* in symptoms which indicates increased likelihood of carrying the HD expansion. Moreover, we show that testing *explicitly for confirmation* in this context is fairly common. Depending on the dataset, as many as half or more of individuals will eventually be tested to "prove" what they know already from symptoms.

We next turn to describing beliefs and behaviors among untested individuals. First, we show that when asked about their chance of carrying the HD expansion, untested individuals report perceived probabilities which are much lower than their objective probability (determined by the investigator based on clinical signs). In many cases, the bias is extreme. For example, among untested individuals for whom a clinical investigator observes signs which represent "Certain Signs of

[1]This objective probability is based on investigator evaluations done as part of the study. The results of this evaluation are not transmitted to the patient.

HD (>99% confidence)," the average perceived chance of having HD is 52% and 11% percent of individuals in this group report believing there is *no* chance they carry the HD expansion.

Second, although behaviors (e.g., marriage, fertility, retirement choices) differ significantly for individuals who report certainty about either carrying or not carrying the affected gene, individuals who are uncertain almost always behave identically to those who are not carriers of the genetic expansion, rather than displaying intermediate behavior. For example, adjusting for age and gender[2], retirement is more than twice as likely for individuals who report knowing they carry the HD expansion versus those who are certain they do not. However, retirement rates for individuals with intermediate probabilities are identical to those who are certain they do not carry the expansion. This remains true even when we focus on individuals whose symptoms indicate a 90% or greater chance of HD. Although our primary descriptive analysis is limited to the HD case, in Appendix B we show suggestive evidence of similar patterns for both cancer screening and HIV testing. This suggests that explaining the patterns we observe for HD may also be informative in understanding the limited medical testing in those contexts.

Other authors have noted that the combination of low testing rates with low testing costs are a challenge to a standard neoclassical model, and suggested this behavior might be better modeled with a framework in which beliefs about the state impact utility directly (Koszegi, 2003; Caplin and Leahy, 2004; Caplin and Leahy, 2001). The facts here suggest that whatever model explains low testing rates – neoclassical or otherwise – should *also* accommodate the biased perception of risk, the fact that uncertain individuals behave in an overly optimistic way, and the result that testing is increasing in risk.

In Section 4 we suggest that an optimal expectations model, based on Brunnermeier and Parker (2005), provides a parsimonious way to explain the patterns in the data.[3] Section 4.1 describes the setup. There are three periods, a binary state ("sick" or "healthy") and a binary action choice. Individuals are endowed with some probability that they carry the HD gene. At time 0, they can choose whether to learn the true state, possibly for some real cost. An action is chosen at time 1

[2]We can also adjust for symptom levels, if any, with no impact on our results.

[3]We focus on a setup in which individuals make the choice about information seeking and actions on their own. This is related to a setting in which information can be conveyed by an agent who seeks to maximize utility of a principal (Koszegi, 2006). A major difference between our setup and the setup in Koszegi (2006) is that individuals here get utility from not only instrumental outcomes but also from their health status *per se*. In addition, there are several other models which are close in spirit to Brunnermeier and Parker (2005). These include Yariv (2005) and Mayraz (2011). The Benabou and Tirole (2002) model of self-confidence is also closely related, if slightly more distant.

and then the true state is revealed at time 2. At time 1, individuals experience utility associated with their anticipation of future consumption; at time 2, actual consumption utility is delivered. Consumption utility is maximized when the action is correctly matched to the realized state.

The key feature of this model is that if individuals are untested they have the option to choose their beliefs about the probability of each state, but are constrained to take actions consistent with those beliefs. Choosing an overly optimistic belief increases the time 1 anticipation utility but also increases the chance that the wrong action is chosen, with a time 2 utility cost. Overly optimistic beliefs may be optimal if the increase in anticipatory utility outweighs the decrease in consumption utility. If an individual chooses to test they cannot "unlearn" the true state, and therefore does not have the option to choose beliefs.

Section 4.2 relates the model to the facts in Section 3. We show that individuals in this model adopt overly optimistic beliefs in order to experience higher utility in the anticipation period. Having adopted such overly optimistic beliefs, individuals take overly optimistic actions, in accordance with these beliefs. These skewed choices of behavior naturally produce the result that testing is increasing in risk: as the objective risk increases and people continue to behave as if they do not carry the expansion, the utility loss from this behavior becomes larger and larger, increasing the incentive to test.

Once tested, individuals in this model can no longer manipulate their beliefs. This means that a significant "cost" of testing is the loss of the option to believe that you are healthy regardless of the true state; this cost may be so large that the value of testing is negative even ignoring any real costs. Even for those with a positive testing value, a very small real cost of testing may be sufficient to discourage testing. In an extension we show that it is possible to accommodate confirmatory testing in this model. That is, it is possible that individuals will not choose to test while uncertain but may choose to get a test to confirm status with some small benefit to "proof."

In Section 4.3 we estimate the model with heterogeneous agents and show that with reasonable parameter values we can match both the skewed action choices and the low testing rates we observe in the data. The estimation demonstrates that the low testing rates we see in the data can be generated with a testing cost that is about two orders of magnitude smaller than the utility cost of taking the wrong action.

In Section 5 we return to evaluating the standard, information-seeking, neoclassical framework.

As we note above, the combination of low testing rates with low testing costs seem like a threat to the standard model. However, in practice we observe many settings in which individuals are slow to take actions which benefit them (for example, poorly optimized retirement savings in Choi et al, 2011). We have only our estimate of the financial and time costs of testing, we do not observe the actual costs people experience. Given this, it seems hasty to reject this framework if the *only* issue is the need for high real testing costs.

If we assume individuals place no weight on anticipation, the optimal expectations model collapses to the neoclassical framework. We derive the predictions of the model in the case without anticipatory utility and evaluate the fit in light of the new facts in Section 3. We argue the neoclassical model fails qualitatively in two concrete ways: it cannot accommodate skewed beliefs or confirmatory testing. In addition, generating skewed action choices and testing increasing in risk require assumptions on the parameters which, although plausible, do not accord with intuition or other survey data. We also estimate the model and show that the fit of the model is worse than optimal expectations[4] and the parameter values which constitute the best fit seem problematic.

Overall, we argue the addition of these new facts more concretely rules out the neoclassical framework. In Appendix C we describe two other non-neoclassical models with anticipatory utility and relate them to our data. The first is an explicit model of wishful thinking (Mayraz, 2011), which is very similar in many ways to the optimal expectations framework and makes similar predictions. The second is a model with information-averse preferences (Koszegi, 2003), which we argue fits the data less well.

In the conclusion section, we briefly discuss welfare and policy. The patterns in the HD data also appear, at least suggestively, in data on HIV and cancer screening, suggesting this model may help explain resistance to testing in those more policy-relevant settings. To begin, we note that in this model individuals are not making mistakes. Their biased beliefs are optimal and a social planner would make them worse off by forcing them to test. However, when we consider a case like HIV in which testing may be socially valuable, it may be optimal to encourage individuals to test.

We use the estimated model in Section 4.3 to evaluate what policy levers might change testing rates. We find that lowering real testing costs would have limited impact on testing, increasing it only from 5% to 10% even at a cost of zero. This is due to the fact that, for many individuals, the

[4]We free up another parameter which we restricted in the optimal expectations estimation, in order for the models to have similar degrees of freedom.

anticipation value is so important that it swamps the impact of testing. In contrast, making the value of of correct actions more salient would have a larger impact. In some cases (e.g., HIV, cancer screening) this could include emphasizing actions individuals could take to improve their health if they were tested.

2 Background and Data on Huntington Disease

2.1 Huntington Disease Background[5]

Huntington disease (HD) is a degenerative neurological disorder that clinically affects an estimated 30,000 individuals in the United States. Individuals with the disease typically begin to manifest symptoms in early middle age (30-50). Symptoms include involuntary movement, impaired cognition and psychiatric disturbances. Individuals will need increasing levels of supportive and institutional care for many years. Death follows approximately 20 years after onset. A test for the HD genetic expansion was developed in 1993. Since everyone with the expansion will eventually develop HD, this test is perfectly predictive.

HD is a genetic disorder due to an excessive expansion in the Huntingtin gene on chromosome 4; individuals with more than 40 repeats of a "C-A-G" (cytosine-adenine-guanine) sequence in this gene will inevitably develop HD unless they die from an unrelated cause prior to the expected onset of illness. The disease is inherited in an autosomal dominant manner: individuals who have a parent with HD have a 50% chance of having inherited the genetic expansion and subsequently developing the disease. There is no cure for HD or treatment that slows the progression, and symptomatic treatments are limited. The fact that HD has such clear and strong genetic predisposition means individuals are frequently aware of their family history and genetic risk.[6]

At birth, any individual with one parent with HD has a 50% chance of inheriting the HD expansion and eventually developing the disease. However, as they age individuals should update their probability (either up or down). The progression of HD is slow but steady, and timing of onset varies.[7] Early signs or features of HD may not be noticed by at-risk individuals, and early symptoms

[5]In this section we provide only a brief overview of Huntington disease; for a fuller clinical discussion, please see Shoulson and Young (2011).

[6]It is, of course, possible that people may not know of their risk until they are older, since parents' age of onset may be late or their parents may die of something other than HD before onset. In our sample, everyone enrolled knows of their risk since this is a condition for enrollment.

[7]Timing of onset has an inverse relationship with the extent of the CAG expansion. The greater the expansion, the

are not a perfect signal of HD. As symptoms develop, individuals should update their probability of carrying the gene slowly, generating variation in probability above 50%. On the other hand, as individuals age without symptoms, especially moving through middle age, it becomes progressively less likely that they carry the expansion. This generates variation in the range below 50%.

2.2 Data Description

The PHAROS (Prospective Huntington At Risk Observational Study) study was a prospective, observational study of individuals at risk for HD conducted by the Huntington Study Group (Huntington Study Group PHAROS Investigators, 2006). The study began in 1999 and included 1001 individuals at roughly 40 study sites in the United States and Canada. Individuals in the PHAROS study were interviewed at recruitment and then approximately every nine months afterward. Prospective clinical evaluation in the PHAROS study concluded in 2010. The PHAROS study enrolled individuals who were (at the time of enrollment) at risk for HD: that is, they had one parent (or first-degree relative) with HD, but had not pursued genetic testing. Participants in PHAROS are not a random sample of individuals at risk for HD. First, they needed to be willing to participate in the study, which may imply other differences. There is little we can do to address this.

In addition, participants had to be untested and not show signs of HD at the time of enrollment. This introduces two concerns. First, this sample may understate the general demand for testing, since individuals are selected based on not having tested up to enrollment. Empirically, this doesn't seem to be the case: testing rates in our sample are around 5%, similar to other data (Shoulson and Young, 2011). Second, if the type of individuals who test early are different from those who wait or do not test at all, we may draw conclusions which are not representative of the overall HD population. The low testing rates help us here: since only a small share of people test when young, our sample should be representative of most of the population (on this dimension, at least).

Participant visits during PHAROS contained two parts. First, individuals responded to a set of questionnaires, which collected information on demographics, life events and HD-specific behaviors and beliefs (e.g., genetic testing, perception of disease risk). Second, visits included a neurological exam with a series of motor, cognitive, behavioral and functional tests that looked at the individual

earlier the onset. Tested individuals would learn their CAG expansion count, which provides information on expected age of onset.

for signs of HD. Our analysis uses four elements of the data: investigator evaluation of the probability of carrying the HD expansion, individual subjective probability of carrying the HD expansion, information about HD testing and information on life events.

Investigator Evaluation of HD Status Individuals in PHAROS were given a series of clinical tests at each visit. These tests were designed to evaluate whether the individual was developing HD, and they include tests of motor and ocular performance, gait and involuntary movements such as chorea. Based on this test, individuals were given a motor score which could range from 0 through 154. In addition, at the end of the exam the investigators, who remained unaware of gene carrier status, make a composite judgment of confidence on a scale from 0 to 4. A 0 indicates "normal (no abnormalities)," a 1 indicates "non-specific motor abnormalities (less than 50% confidence of having HD)," a 2 indicates "motor abnormalities which may be a symptom of HD (50-89% confidence of having HD)," a 3 indicates "motor abnormalities that are likely signs of HD (90-98% confidence)" and a 4 indicates "motor abnormalities that are unequivocal signs of HD ($\geq$ 99% confidence of having HD)." We should note that given the construction of this sample, individuals who have no signs of HD at all (and are sufficiently young) are still at about 50% risk, since they have a parent with the HD expansion and could have inherited the expansion. Any clinical confidence score greater than zero indicates a higher likelihood than the nominal 50% risk.

The other source of objective variation in probability comes from age. As individuals age without signs or symptoms, they become less likely to carry the HD expansion. This generates variation in the probability below 50%: at birth, the probability is 50% and as people age without signs or symptoms, the probability drops. At-risk individuals who do not develop signs of HD by their late 60s and beyond are increasingly unlikely to carry the expansion.

Perceived Probability of HD Individual subjective probability of carrying the HD expansion is based on the following question: "On a scale of 0 to 100, today, how likely do you think it is that you carry the genetic mutation that causes HD? 0 = absolutely certain that you do not have the gene mutation that causes HD and 100 = absolutely certain that you do have the gene mutation that causes HD." Summary statistics for the motor score and perceived probability appear in Panel A of Table 1.

HD Testing and Gene Status Information on testing is drawn from a question, asked at each visit, about whether the individual has undergone HD testing since their last visit (everyone is

untested at enrollment into PHAROS, and roughly 10% chose to undergo testing during the sample period). Our primary use of the testing data is as an outcome; the share of individuals who choose to be tested is summarized in Panel A of Table 1. In addition, we use the behavior of individuals who report certainty about their status (either due to testing or early symptoms) to pin down optimal behavior for individuals who are either certain they do carry the HD expansion or certain they do not.[8]

Using the testing data for this latter purpose requires knowing individual test results. While everyone in the study consented to independent research analysis of their blood DNA sample as part of the study, these individual identifiable research results are never made available to anyone, either research participants or investigators. However, for individuals who chose to be tested outside the study we can infer their test result by using information from the investigator assessment or from their subjective probabilities (after testing, a large share of people report either 0% or 100% chance of carrying the HD expansion). The inference procedure is described in more detail in Oster et al (2010), and allows us to infer testing status for 80% of tested individuals.

Life Events Information on life events is drawn from a questionnaire entitled the "Life Experience Survey" which was administered (for most participants) five or six times over the 7-10 year study. This questionnaire listed a number of life events and asked the individual about whether they had experienced each event in the last year; a copy of the questionnaire is included as Appendix A. A number of these experiences do not qualify as "choices" – death of a spouse, changing sleeping habits, etc. We use data on a subset of events which do reflect choices. These are: marriage, pregnancy (either self or partner), divorce, getting a new job, reporting a major change in finances (including reports of borrowing), change in church activities, change in recreation and retirement.

These data do not cover all life experiences in which we might be interested. In addition, the survey did not probe in more depth about exactly *what* is implied by that behavior. In some cases, like "Made a Major Financial Change," it not entirely clear what happened. In the case of something like pregnancy, although the details of the experience may differ, it is clear what is meant when people report a "pregnancy." Despite these drawbacks, we believe that these data are informative about behavior. Summary statistics, reporting the share of individuals engaging in each behavior,

[8] A fundamental concern here is that those individuals who are tested behave differently than those who are not. This is worth keeping in mind, although in practice we will find the behavior among those who say they do not carry the HD expansion is very similar to those with intermediate risk suggesting, perhaps, that this is of limited concern.

are reported in Panel B of Table 1.

Demographics We will also use data on basic demographics – gender, age and education. These are summarized in Panel C of Table 1. The PHAROS sample is two-thirds women (this reflects desire to participate in the study, not anything about the gender distribution of HD, which is roughly equal) and fairly highly educated. The high education, in particular, prompts caution in extrapolating our results to the general population.

3 Descriptive Analysis: Testing, Risk, Beliefs and Behavior

In this section we describe several facts from the HD data. These will motivate the theory in Section 4.

HD Testing Rates and Testing Costs

We begin with the most basic fact about HD testing: it is uncommon. In the ten years that the PHAROS study has been running, about 7% of individuals with uncertain HD status have chosen to take an HD test.[9] Testing is even more limited, about 5%, when we focus on people who test prior to observing *any* signs or symptoms of HD. We might expect testing rates in this population to be especially low, given that a requirement for enrollment is that individuals are untested. However, the levels are very similar to what is seen in the HD population overall (Meyers, 2004).

Laboratory costs for an HD test are on the order of $200-$300. The actual financial costs may be higher, perhaps twice that, once you include consulting a neurologist and genetic counselor before testing, which most testing centers require. This testing would be covered by insurance, although in a large share of cases individuals report paying out of pocket for testing, likely to retain the option to keep their test results private (Oster et al, 2008).

Testing and Pre-Testing Risk

Although testing is low in general, testing rates appear to vary with individual *ex ante* risk of finding they carry the HD expansion. Figure 1 shows the probability of testing before the next PHAROS

[9] We refer here to testing outside of the sample. Everyone in our study is genotyped (the size of their Huntingtin gene is determined) as part of the study, but these results are never shared with the research participant of the investigator. In order to learn their HD status individuals must pursue genetic testing outside the study.

visit graphed against investigator diagnostic confidence score at the last visit. The pattern is increasing, with the highest probability of testing among those with an investigator score of 4. It is perhaps puzzling that people who should be nearly certain they carry the expansion nevertheless choose to test. However, as we will see below, in practice many of these individuals reportedly believe that their probability is lower, and are acting accordingly. This means they still perceive there to be information for them to learn.

Figure 2 shows the same result, but with coefficients adjusted for controls (listed in the notes). In addition to adjusting for standard demographics, the fact that we observe this investigator score at all visits means we can run these regressions with individual fixed effects. In both cases, the highest rates of testing are among individuals where the investigator records the highest confidence that they carry the HD expansion, and this is true with and without the individual fixed effects. Finally, Figure 3 shows the fixed effect analysis of Figure 2 in changes, graphing the chance of testing by the next visit against the change in investigator score between the last two visits. Again, this slopes up, demonstrating that individuals tend to test when new information points towards an increasing chance of carrying the expansion.

Finally, we explore age variation in testing. As individuals age without developing symptoms, their (objective) updated probability of carrying the HD expansion declines (from about 47% at age 25 to 10% by age 55). This allows us to look at whether testing becomes more common as people become more sure that they *do not* carry the expansion. Figure 4 shows the change of testing by the next visit by age group. Testing probability is not systematically varying with age.[10] Together with the evidence in Figures 2 and 3, this suggests that increases in risk above 50% prompt testing, although reductions in risk from 50% do not have a similar effect.

Even at the highest risk levels here, testing is still relatively uncommon. However, testing to confirm HD status once it is known is much more frequent. Of the people in our data with acknowledged symptoms of HD, 30% have undergone HD testing. And this is over only a few years of data. In another dataset (the COHORT study), confirmatory testing is more common. In those data, among individuals who notice symptoms without having been tested, 75% of them choose to have a confirmatory genetic test. In other words, the test is widely used but only after disease status

[10]One interpretation of this is that older people who are more interested in testing have been selected out of the sample (due to the requirement that individuals be untested at enrollment). Again, due to the genearlly limited testing in this population that seems unlikely to make a large difference.

is certain.

Perception of Risk

We turn now to beliefs and actions among individuals who remain untested. In our data, we observe both what individuals report to be their probability of carrying the HD expansion and the investigator evaluation of motor signs of HD. These signs are informative, but not unequivocal: some individuals without HD will show signs which could be consistent with the disease. More signs makes the diagnosis more certain. Based on data which includes motor signs of HD and actual gene status, we calculate the posterior probability of carrying the HD expansion by level of motor signs. Figure 5 shows the actual posterior chance of carrying the HD expansion (based on the informativeness of each level of symptoms) and individual self-perception. In addition, we graph the share of untested individuals at each level of motor signs who report there is *no* chance they carry the HD expansion.

Based on this figure, it is clear individuals are overly optimistic. Among those with very limited symptoms, the average reported risk is about 40%, similar to the 50% objective risk, although still lower. However, individuals update only very minimally with increasing symptoms. As the objective chance of carrying the HD expansion increases to 100%, the average subjective probability moves only from about 40% to just over 50%. Moreover, some individuals persist in reporting there is no chance that they carry the HD expansion, even when they have significant symptoms.[11]

Another simple way to express this is to report results from a regression of self-perception against actual risk (with some simple demographic controls). The coefficient is around 0.09, much less than the value of 1 which we would expect if self-perceptions and objective assessments were synchronous. Overall, this evidence supports the view that there is significant over-optimism among at-risk individuals.[12]

[11] One concern with this is that a large share of people are defaulting to 50%, and if we ignored individuals with a report of 50% we would see something differnet. This is not the case; leaving these individuals out the percieved risk in the lowest groups is around 37% and in the highest is around 52%, veyr similar to what we observe when including all the data.

[12] HD has mental as well as physical symptoms, so one possibility is that this apparent "bias" is simply due to confusion. However, the lack of updating of risk appears even among individuals with fairly low motor scores who are unlikely to be so impaired that they are unable to process the question. In addition, there is little reason to think this confusion would bias consistently downward.

Risk and Behavior

Our second new fact concerns behaviors undertaken by individuals with varying objective or subjective probabilities of carrying the HD expansion. To begin, Table 2 compares behaviors for those who report being certain about carrying the HD expansion and those who report being certain they do not carry the expansion. Column 1 shows means, and Column 2 shows regression coefficients adjusted for age, gender and education.[13] These groups do not differ on every action, but there are large significant differences in behavior for 5 of the 8 items. Unmarried individuals who know they carry the HD expansion are more likely to get married. Individuals who know they carry the HD expansion are more likely to get pregnant, marginally more likely to retire and much more likely to report major financial changes and changes in recreational activities. There are no differences in divorce, starting a new job or church attendance.

Although this is not the focus of the paper, we note that for the most part these patterns are what we would expect based on a life cycle model, especially retirement, financial changes and changes in recreation. The direction of the differences in marriage and pregnancy are, perhaps, surprising. It may be that the knowledge of a shortened lifespan advances forward the optimal timing of these activities in the life cycle. It is also worth noting that although these impacts are large and statistically significant, they are based on a small sample size and should therefore be taken with caution.

If we take the behavior of these individuals who are certain about their status as reflecting full-information choices, we can then ask where the behavior of uncertain individuals lies relative to these points. Of course, it is only meaningful to ask this about the subset of actions which differ in Table 2.[14] Graphical evidence on the behavior among uncertain individuals can be seen in Figure 6. This figure shows coefficients, adjusted for demographic controls, measuring differences across groups. In each case we show the coefficients for uncertain individuals and those who know they carry the HD expansion relative to those who are certain they do not carry the expansion. In all

[13]The sample of people who are sure they do carry the HD expansion includes individuals who have been tested and know they carry the HD expansion but do not have symptoms, as well as those who are certain they have the expansion due to symptom development. Given this, one concern is that behavior might be different since these individuals are actually sick and cannot engage in certain behaviors. In practice, this does not seem to impact our results: controlling for the degree of motor symptoms observed makes no difference.

[14]Since the choices are binary, it is difficult to understand what "intermediate" behavior would be. The simplest way to envision this is to imagine that learning they carry the HD expansion prompts 20% of people to get pregnant. Intermediate behavior would suggest that a 50% risk would push 10% of people into pregnancy.

cases, we see evidence that behavior differs for the two extreme groups (as in Table 2) but find the behavior of those individuals who remain untested mimics that of those who know they do not carry the HD expansion.

Table 3 shows further regression evidence in which untested individuals are differentiated based on their symptom level. This gives us some sense of whether individuals are at least more likely to engage in intermediate behaviors as their objective risk increases. This table indicates that actions among untested individuals are strongly skewed toward the expansion-negative optimal action. For marriage, retirement and financial changes there are no significant differences in behavior even up to the highest risk group. Individuals with motor scores above 11 have at least a 98% chance of carrying the HD expansion (see Figure 6) and yet seem to behave no differently from those who are certain they do not carry the expansion. For pregnancy and recreation there is some evidence that the highest risk group behaves more like those who are certain they do carry the expansion, although the behavior is consistently skewed up to the group for whom the investigator reports a 90-98% chance of carrying the expansion. When we aggregate (Column 6), we find no evidence of changes in behavior until the group with the highest motor scores and even this is not significant.

The evidence in this section comes only from HD. However, in Appendix B we look at two other contexts with low rates of medical testing: HIV testing and cancer screening. In each case we look for evidence in existing literature to speak to the patterns demonstrated above. Although our HD data is obviously richer and more complete, we find suggestive evidence of similar patterns in both other contexts. This suggests that whatever theory explains the patterns in the HD data may also explain low rates of medical testing in other, perhaps more policy relevant, contexts.

4 Theory: Optimal Expectations

Low medical testing rates in settings where the information seems extremely useful and the financial costs of testing are small seem to be a challenge to a standard neoclassical model of behavior (e.g., Koszegi, 2003; Caplin and Leahy, 2004). This has led to the suggestion that models of this behavior should incorporate some form of anticipatory utility (Caplin and Leahy, 2001), wherein individuals care about their expectations about the future in addition to their present consumption. The descriptive evidence in Section 3 presents several other, related, facts which such a model would

ideally accommodate.

In this section we outline an optimal expectations model, based on Brunnermeier and Parker (2005), which we argue provides a parsimonious explanation for both low testing rates and the facts described in Section 3. Our version of the theory hews closely to the original model, although we introduce the possibility of testing and learning the true state before the action is chosen. There are two key underpinnings of the model. First, individuals experience anticipatory utility. Second, as long as they are uncertain about the future state, individuals can hold beliefs about the state which differ from the true probabilities. Below, we describe the model and derive implications about beliefs, action choices and the relationship between testing and risk.

It is perhaps important to note that although the language used in this model indicates that individuals "choose" their beliefs, this need not be a description of the psychological process by which these beliefs occur. Individuals may "choose" beliefs, for example, by ignoring signs which would contradict their beliefs (as in Dawson et al, 2002). The key assumption in this model is that individuals act as if they hold beliefs which differ from the truth.

4.1 Setup

There is a binary state $s \in \{0, 1\}$ where $s = 1$ indicates the individual has the gene or disease (in this case, carries the HD expansion) and $s = 0$ indicates they do not. We refer to these states as "sick" and "healthy." Individuals have some exogenously given $p = E(s)$. The timing is as follows. At time 0, individuals choose whether or not to learn the true state through testing. This testing has a real cost, denoted C. At time 1, individuals choose a binary action $a \in \{0, 1\}$ and experience (discounted) utility associated with their expectation of time 2 consumption. *Ex post* individual consumption utility is maximized when action is matched to state. At time 2, the true state is revealed and individuals receive consumption utility, which is a function of the action and the true state.

The key assumption in this model is that if individuals do not learn the true state, they are able to adopt beliefs about the probability of each state at time 1. These chosen beliefs may differ from the true probability p. Actions are picked at time 1 based on these chosen beliefs only. Denote the chosen belief about the true state as π and utility given action a and realized state s as $u(a, s)$. Assume anticipation utility is down-weighted by a factor $\delta \in [0, 1]$.

Formally, individuals in this model choose time 1 beliefs $\pi \in [0,1]$ to maximize:

$$U(\pi|p) = \delta E(u(\hat{a},s)|\pi) + E(u(\hat{a},s)|p)$$

where $\hat{a}(\pi) = argmax_a E[u(a,s)|\pi]$. Because both actions and states are binary, we can write expected utility at time 2 as $E[u(\hat{a},s)|p] = pu(\hat{a},1) + (1-p)u(\hat{a},0)$, and similarly for π in the anticipation period.

If individuals know the true state, for example through testing, they are no longer free to choose beliefs. However, knowing the true state allows individuals to choose the *ex post* optimal action, so $a = s$, and two period utility is simply given by $(1+\delta)[pu(1,1) + (1-p)u(0,0)]$.

We define the following parameter values.

$$u(0,1) = -\Omega$$
$$u(1,1) = 0$$
$$u(1,0) = 1 - \Phi$$
$$u(0,0) = 1$$

Being healthy and taking the correct action has a value of 1; being sick and taking the state-matched action has a value of 0. Taking the wrong action in either case leads to a loss of utility. This loss is Φ if the state is "healthy" and Ω if the state is "sick". Defining separate parameter values allows for the losses to differ by state, although the simplest assumption is $\Omega = \Phi$. We assume that $\Phi, \Omega < 1$, implying that people value not having HD more than they value choosing the correct action.

4.2 Results: Optimal Expectations

As discussed, the timing in this model is such that beliefs are chosen at time 1 and actions result from those beliefs. Lemma 1 below describes what action will be chosen given chosen beliefs.

Lemma 1. $\hat{a}(\pi) = 0$ *if* $\pi \leq \frac{\Phi}{\Phi+\Omega}$ *and* $\hat{a}(\pi) = 1$ *if* $\pi > \frac{\Phi}{\Phi+\Omega}$.

Proof. Actions are chosen in this model based only on the period 1 anticipation utility.

The individual will choose $a = 0$ iff

$$\pi u(0,1) + (1-\pi)u(0,0) \geq \pi u(1,1) + (1-\pi)u(1,0)$$
$$\pi \leq \frac{\Phi}{\Phi + \Omega}$$

Note that under the symmetric assumption that $\Phi = \Omega$, this cutoff value is $\pi = .5$. □

Choice of Beliefs and Resulting Actions

We begin by deriving the implications of this model for the choice of beliefs and resulting actions. These appear in the following two propositions.

Proposition 1. Choice of Beliefs *Individuals will always choose beliefs such that $\pi \leq p$.*

Proof. Lemma 1 describes the choice of actions given the choice of beliefs. Given that result, utility is given by:

$$U = \begin{cases} \delta(1-\pi) + (1-p) - (\delta\pi + p)\Omega & \text{if } \pi \leq \frac{\Phi}{\Phi+\Omega} \\ (\delta(1-\pi) + (1-p))(1-\Phi) & \text{if } \pi > \frac{\Phi}{\Phi+\Omega} \end{cases}$$

We have assumed that $\Phi, \Omega < 1$, so the agent will only ever choose either $\pi = 0$ or $\pi = \frac{\Phi}{\Phi+\Omega}$. As long as the cutoff point at which people switch to belief $\pi = \frac{\Phi}{\Phi+\Omega}$ is above $p = \frac{\Phi}{\Phi+\Omega}$, we then have the result that $\pi < p$. Individuals will choose $\pi = 0$ if the following inequality holds

$$\delta + (1-p) - p\Omega \geq (\delta(\frac{\Omega}{\Phi+\Omega}) + (1-p))(1-\Phi)$$
$$p^* \leq \frac{\Phi}{\Phi+\Omega} + \frac{\delta\Phi(1-\Omega)}{(\Phi+\Omega)^2}$$

This implies they are choosing a value of $\pi = 0$ for $p \leq p^*$, with $p^* = \frac{\Phi}{\Phi+\Omega} + \frac{\delta\Phi(1-\Omega)}{(\Phi+\Omega)^2} > \frac{\Phi}{\Phi+\Omega}$. □

We note that in the case where $\Phi = \Omega$, the π cutoff is 0.5, so the proposition indicates that the actor in this model chooses $\pi = 0$ up to $p = .5 + \frac{\delta(1+\Phi)}{4\Phi}$ and $\pi = .5$ for values of p above that. Proposition 2 summarizes action choices.

Proposition 2. Choice of Action if Untested *Action $a = 0$ will be chosen for values of $p \leq p^*$ and action $a = 1$ will be chosen for values of $p > p^*$.*

Proof. This follows directly from the proof of Proposition 1. There, we showed that individuals will choose belief $\pi = 0$ up to a value of $p^* = \frac{\Phi}{\Phi+\Omega} + \frac{\delta\Phi(1+\Phi)}{(\Phi+\Omega)^2}$ and $\pi = \frac{\Phi}{\Phi+\Omega}$ for larger p. The agent chooses $a = 0$ in the first case and $a = 1$ in the latter case. □

Proposition 2 implies that individuals will take action $a = 0$ for some values of $p > .5$ as long as Ω is not much larger than Φ. In the simple case where $\Phi = \Omega$ we will see actions $a = 0$ for at least some values of $p > .5$, since $p^* = .5$. If $\Phi > \Omega$, this result is reinforced. It is only in cases where the cost to taking the wrong action if the true state is sick is much larger than if the true state is healthy that we might not see skewed actions.

Considering our base case of $\Phi = \Omega$, we have actions $a = 0$ occur for values of $p > .5$. The intuition behind the skewed action result is fairly straightforward. Skewed action choices are delivered by individuals' desire to "pretend" they do not have the disease. When individuals choose an overly optimistic belief, they benefit from experiencing positive anticipation: when they think about the future they experience anticipation of the ideal utility state, in which they are healthy and have taken the correct action. This overly optimistic belief has costs, however, since *ex post* actors experience a loss in consumption utility from having likely taken the wrong action.

To the extent that the anticipation gain outweighs the realized loss later, it will be optimal to adopt an overly optimistic belief. Conditional on having beliefs which lead to a given action, the actor will want beliefs to be as optimistic as possible. For any value of $\pi \leq \frac{\Phi}{\Phi+\Omega}$, they take action $a = 0$ and are paying the time 2 cost associated with the possibility of taking the wrong action. The anticipatory utility, however, is greatest for the value of $\pi = 0$, so this is what they will choose.

Testing and Risk

When evaluating the value of testing, individuals compare the utility delivered when tested to the utility delivered by their optimal choice while untested. The latter is described above. The utility if tested is given below:

$$U_{test} = (1+\delta)(pu(1,1) + (1-p)u(0,0)) - C = (1+\delta)(1-p) - C$$

where C is the real (financial or time) cost of testing. The value of testing (V_{test}) is the difference between this testing utility and the utility delivered if untested.

Given the beliefs and action choices described, Proposition 3 describes testing behavior.

Proposition 3. Testing Behavior *Define p^* as in Proposition 2. There are two cases, corresponding to a high and low anticipation value.*

Low Value of Anticipation:$\delta < \Omega$**.** *The following statements hold:*

1. *For values of $p \leq p^*$, the value of testing is positive if and only if $p(\Omega - \delta) > C$*
2. *For values of $p > p^*$, the value of testing is positive if and only if $\frac{\delta\Phi(1+\Omega)}{\Phi+\Omega} - p(\delta + \Omega) + \Phi > C$*

High Value of Anticipation:$\delta \geq \Omega$**.** *The value of testing is negative and decreasing in p at all values of p*

Proof. If $p \leq p^*$, individuals take action $a = 0$. If $p > p^*$ they take action $a = 1$. The value of testing for each range is given below.

$$V_{test} = p(\Omega - \delta) - C \text{ if } p \leq p^*$$
$$V_{test} = \frac{\delta\Phi(1+\Omega)}{\Phi+\Omega} - p(\delta + \Omega) + \Phi - C \text{ if } p > p^*$$

Low Value of Anticipation: $\delta < \Omega$. For $p \leq p^*$ and $a = 0$, the value of testing is increasing in p (since $\Omega - \delta > 0$), meaning it is maximized at p^*. For values of $p > p^*$ and action $a = 1$, the value of testing is decreasing in p (since $-(\delta + \Omega) < 0$), meaning it is maximized at the lowest value of p, namely p^*. The implications about value of testing come directly out of the testing values given above. Note that these conditions imply that value of testing is maximized at p^*.

High Value of Anticipation: $\delta \geq \Omega$. For $p \leq p^*$ and $a = 0$, V_{test} is decreasing in p, since $-(\delta + \Omega) < 0$. However, it is always negative: individuals with this set of parameter values will never choose to test. We note that at p^* the value of testing is the same in the $a = 0$ and $a = 1$ cases. This is because p^* is defined such that at that value the utility from the two actions is the same. The utility in the tested case is also the same, so the total value of testing is the same for action $a = 0$ and $a = 1$ at p^*. For values of $p > p^*$the value of testing is decreasing, and since it is negative at p^*, it is always negative.

□

Case 2 in Proposition 3 does not generate any variation in testing behavior. Individuals with this set of parameter values will never test at any value of p. Any variation in testing with p will therefore be driven by individuals with parameter values given in Case 1. These individuals may or may not choose to test. Their value of testing will be highest at p^*, defined as in Proposition 1, but if anticipation is important, it is possible that even this maximum value may be very small.

We can illustrate this result graphically. For simplicity, in these graphs we focus on the base case of symmetric losses: $\Phi = \Omega$. Consider first the impact of testing on time 1 anticipatory utility

only. This impact is the difference between the anticipatory utility *with* testing, which is $\delta[p(\Phi) + (1-p)(1+\Phi)]$, and the anticipatory utility without testing, which is $\delta(1+\Phi)$. These two utilities, and their difference, are graphed against p (for benchmark values of ψ and δ) in Figure 7.1. Up to p^*, utility without testing is constant (since people are just acting as if they are healthy and experiencing anticipation associated with that state), and utility with testing is decreasing in p. The difference $(-\delta p)$ is therefore also decreasing in p.

The second element is the impact of testing on time 2 consumption utility. This is the difference between realized utility with testing, which is $p(\Phi) + (1-p)(1+\Phi)$, and realized utility without testing, which is $(1-p)(1+\Phi)$. These utilities are graphed against p (with the same parameters as in Figure 7.1) in Figure 7.2. Both utility with and without testing are decreasing in p, but the utility without testing is decreasing faster. The time 2 difference in utilities is $p\Phi$, which is increasing in p up to p^*.

The total value of testing (ignoring the real cost) combines these two utilities. This is graphed in Figure 7.3, along with (for reference) the value of Φ. Because we have assumed that $\delta < \Phi$, the time 2 consumption utility dominates, and we observe that, overall, the value of testing is increasing in risk. However, because of the incorporation of the anticipatory utility, this testing value is much lower than it would be if we considered only the consumption utility as in the rational model. As p increases, it becomes more and more valuable to remain untested and pretend you are healthy, since testing is increasingly likely to lead to finding out you are sick. As Figure 7.3 illustrates, with this addition, even a very small real cost of testing could push people, especially those with low values of p, to not test. Effectively, a large portion of the cost of testing is the loss of the anticipatory utility.

Putting together the two cases in Proposition 3, we observe that as long as some individuals have values of $\delta < \Phi$, we will have testing increasing in risk. With a small real cost of testing, testing will have a negative value for some low levels of p and a positive value elsewhere. Any individuals with $\delta > \Phi$ will never test and so will not matter for the gradient (although they will lower the overall testing rate).

4.2.1 Extension: Confirmatory Testing

We consider now a simple extension to the model: adding the possibility of confirmatory testing. We add to the setup the assumption that if the individual does turn out to have HD, there will be an

incentive to undergo confirmatory testing, for example, to have "proof" for disability or other claims. Assume the value to this confirmation is Ψ. A reasonable assumption would appear to be that $\Psi < \Omega$. That is, if you turn out to carry the HD expansion, the value to taking the correct action at all times leading up to confirmation is higher than the value of the confirmation. This seems particularly true since even many of the actions one would take only when sick (draw down of long term care benefits, for example) do not actually require a genetic confirmation. The value of this confirmation is therefore likely quite small.

Importantly, we are considering here an individual who has accepted (through medical diagnosis) that $p = 1$; that is, that they are sick. This individual has no option to choose beliefs which differ from the true p, so that "cost" of testing is eliminated. Propositions 1 and 2 are identical with this modification. The key follow-up question is under what conditions will individuals test for confirmation but *not* engage in predictive testing. Are there parameter values such that people will avoid testing for all $p < 1$ and yet still be willing to test once they are sure they have the gene? The condition is summarized in Proposition 4.

Proposition 4. Confirmatory and Informative Testing *Assume p^* is given as in Proposition 2. Individuals will engage in confirmatory but not predictive testing if $\Psi > C$ and one of the two following conditions holds:*

$$\delta \geq \Omega$$
$$\delta < \Omega \text{ and } C > \frac{\Phi^2(\Omega - \delta) + (1-\delta)\Phi\Omega^2 + \delta^2\Phi(\Omega - 1)}{\Omega(\Phi + \Omega) + \delta\Phi(\Omega - 1)}$$

Proof. Confirmatory without predictive testing requires that individuals experience all values of p up to $p = 1$ without testing, but they do want to test once there is no anticipation loss. The condition for wanting to test later is simply $\Psi > C$. The condition for preferring confirmatory to predictive testing is $C > \frac{p(\Omega-\delta)}{(1-p)}$. If $\delta > \Omega$ then the right hand side is negative and any positive value of C will satisfy this.

If $\delta < \Omega$ we note that the value of testing is highest at p^*. If the cost C exceeds the value at p^*, this will hold. Simplified, the condition for this is given above. Note that combined with the condition for ever wanting to test, this implies that Ψ is also greater than that expression. □

This proposition suggests there are parameter values under which individuals will engage in confirmatory but not predictive testing. Even though the value of confirmation is assumed to be small ($\Psi < \Omega$), the existence of δ means that this condition may hold. Put simply: with

confirmatory testing the real costs are the same, and the benefits are lower. However, when testing for confirmation individuals do not experience the cost associated with having to face the truth. If this cost is important enough as a restriction on testing predictively, it may be that confirmatory testing is a good idea and predictive testing is not.

In Propositions 1-4 we show that the general form of the optimal expectations model is able match the qualitative evidence in Section 3. In Section 4.3 below we estimate the model, and argue that we are able to fit the fact quantitatively as well.

4.3 Estimation of Optimal Expectations

The intuition behind the optimal expectations model is appealing, and it is qualitatively predictive. A key question, however, is whether *in practice* the low testing rates we observe can be explained in this model with only a small cost of testing. In this section we estimate the model, imposing the assumption that the cost of testing is small. We fit the behavioral moments in the data: the action choices and testing rates.

We focus on matching the average action, based on Column 6 of Table 3. We define the action taken by individuals who are certain they carry the expansion as "1" and the action taken by those who are certain they do not carry the expansion as "0". For both actions and testing we define groups based individual motor score. We match 10 moments of the data which are shown in Columns 1 and 2 in Panel B of Table 4.

We assume $C_i \sim \text{Unif}[0, 0.01]$. This puts a constraint on the real testing costs relative to the difference in maximum utility in the healthy versus sick cases (defined in Section 4.1 as equal to 1). What we *do not* constrain is the cost of testing relative to the lost utility from taking the wrong action. That will be fit by the data. In this sense, the data will tell us whether the cost of testing is small: it will tell us the size of the cost *relative to* the cost of taking the wrong action. In terms of estimation, we could set the cost lower, which would result in a similar fit with smaller estimated values for Φ_i.

We assume symmetry: $\Phi_i = \Omega_i$. We estimate a distribution of Φ_i ($\Phi_i \sim \text{Unif}[\alpha, \alpha + \beta]$), and a single value for δ. To review, individuals will choose to take action $a = 1$ if
$(2p_i - 1 - .5\delta)\Phi_i - .5\delta > 0$. The conditions for testing are:

$$p_i(\Phi_i - \delta) - C_i > 0 \text{ if } a = 0$$
$$\frac{\delta(1+\Phi_i)}{2} - p_i(\delta + \Phi_i) + \Phi_i - C_i > 0 \text{ if } a = 1$$

Table 4 shows the best fit parameters and the estimated moments of the data. The estimated moments are, again, a close fit to the actual moments in the data. The parameter values indicate a compressed distribution of Φ_i very close in value to δ. This means that most individuals are either (a) never interested in testing since $\delta > \Phi$ or (b) close to indifferent about testing, so a small cost can push them not to test. This is consistent with the intuition outlined in Section 4: much of the cost of testing is simply that if the individual tests they may spend the next period anticipating bad health later. The estimated values of α and β suggest that the utility loss from taking the wrong action is about 180 times higher than the real cost of testing.

The estimated model produces the result that beliefs are skewed. In fact, beliefs are more skewed than in the data. As the model is set up, all individuals who take action $a = 0$ should report beliefs $\pi = 0$. In practice, we observe skewed beliefs clustered around $\pi = .4$. This is perhaps not surprising. People may find 50% to be a focal point, since that is their objective probability of HD at birth. We could potentially accommodate this in the model by introducing some psychic cost of reporting a probability which is very far from the truth, or by suggesting that reporting any probability less than $\pi = .5$ reflects an individual thinking they do not carry the expansion. We note that the average individual in all groups except the highest risk one reports a probability $\pi < .5$, consistent with the latter interpretation and the fact that these groups take actions $a = 0$.

As a final note, we consider the possibility of confirmatory testing with these parameter values. For the majority of individuals, $\delta > \Phi$, which would imply that we could rationalize confirmatory testing without predictive testing for any value of $\Psi > C$. Even for individuals in this setting for whom $\delta > \Phi$, we would expect confirmatory testing without predictive testing as long as $\Psi > .01$. In other words, it is easy to explain this pattern in the data in this setting: the value of anticipation is sufficiently high that predictive testing is very unappealing, although once this is turned off individuals may well want to test as long as there is some value to having proof.

5 Neoclassical Case

The evidence above suggests that both qualitatively and quantitatively, the optimal expectations model can fit the patterns we observe in the data. What we do not answer above is whether we could do as well, or almost as well, with the neoclassical, no-anticipatory-utility version of the model *if* we were willing to assume a higher cost of testing. That is, we can ask whether the only thing ruling out the neoclassical model is the need for a high cost of testing. If that is the case, the conclusion that people want to avoid information seems hasty; perhaps our impression of the cost is skewed.

To begin, Proposition 5 below summarizes the results of the model under the assumption of no anticipation.

Proposition 5. *Assume that $\delta = 0$. Then:*

1. *Self-reported beliefs are accurate ($\pi = p$).*
2. *Action $a = 0$ is taken as long as $p < p^*$ where $p^* = \frac{\Phi}{\Phi+\Omega}$. Note $p^* > .5$ iff $\Phi > \Omega$.*
3. *The value of testing is increasing in p for values of $p < p^*$ and decreasing in p for values of $p \geq p^*$. This value is positive if $p < p^*$ and $p\Omega > C$ or if $p \geq p^*$ and $\Phi - p\Omega > C$.*
4. *Confirmatory testing will occur without predictive testing if and only if $\Psi > \Phi$.*

Proof. These conditions follow directly from Propositions 1-4, with the assumption in each case that $\delta = 0$.

□

Qualitative Evidence

We begin by evaluating the qualitative evidence for the statements in Proposition 5.

Beliefs The neoclassical case does not accommodate the overly-optimistic self-reported beliefs that we observe in the data. Without an anticipation period there is simply no sense in which individuals can hold beliefs which are different from the truth.

Confirmatory Testing We have assumed that $\Psi < \Omega$. That is, the value to confirmation is smaller than the value to all actions which could be taken while uncertain. The neoclassical case allows for confirmatory testing only if $\Psi > \Phi$. Further, note that this model generates skewed actions only if $\Phi > \Omega$, so observing confirmatory testing would require $\Psi > \Omega$, which is in violation of the

assumption. We should note that this *could* occur if we allowed for the possibility that confirmation is more valuable than all choices up to that point, although this seems implausible.

Actions and Testing Skewed action choices and the claim that testing is increasing in risk are both delivered in the model by a $p^* > .5$. As stated above, this will occur only if $\Phi > \Omega$, implying that it is much worse to take the wrong action if the true state turns out be "healthy" than if it turns out to be "sick." To deliver the actual patterns in the data this asymmetry needs to be quite large: in order to have skewed actions up to $p = .9$, as we observe in the data, it must be the case that $\Phi \geq 9\Omega$.

We can frame the required difference in terms of timing. For example, we observe in the data that individuals who carry the HD expansion choose to retire earlier than those who do not. The data we observe would be generated, therefore, if people felt it was much worse to retire too early than to retire too late. In principle, there is nothing that rules this out. One way to evaluate whether this is plausible in practice is through introspection. In the case of retirement, perhaps this assumption seems reasonable. For fertility, maybe less so: given the behavior of individuals at the two extremes, generating the data in this model requires that it is much worse to have children too early than to wait too long. An alternative to introspection, perhaps slightly more compelling, is to survey individuals from the general population about these options.

We ran a simple survey through Amazon's Mechanical Turk marketplace, asking 300 individuals from the general population about the timing of marriage, childbearing and retirement. For simplicity, we looked for direction rather than intensity of preference. Individuals were asked to imagine their optimal age for marriage, childbearing or retirement. We then asked them whether, if their optimal age was not possible, they would prefer to undertake the action too early relative to their optimal or too late.

The data does not support the view that losses are asymmetric. On all three outcomes, individuals are fairly evenly split between preferring to undertake the action too early versus too late: 55% prefer too late on marriage, 57% on childbearing and 50% on retirement. Of course it remains possible these preferences are different in the HD population, or the asymmetry in losses arises directly from being sick rather than from timing, but this certainly does not provide positive evidence in support of any asymmetry.

Impact of Testing Costs As a final piece of qualitative evidence, we note that in the neoclassical case, avoidance of testing is driven only by cost. If the cost of testing were zero, everyone would test.

Moreover, changes in the cost of testing should have a large impact on testing behavior. This need not be true in the case with anticipation; there, our estimation suggests a large share of people avoid testing solely due to anticipation concerns and would not test even with a cost of 0.

There are two things in the data which call into question the prediction of responsiveness to testing costs. The first comes from the comparison between Canada and the US. Real costs of testing in Canada are likely to be lower still than those in the US; with a national health care and disability plan, there is no concern about loss or denial of insurance with testing. This both removes one cost of testing *and* makes it less likely people will feel they need to pay out-of-pocket to keep their test results anonymous (Oster et al, 2008). Despite this lower cost, predictive testing rates are only slightly higher in Canada: in our data, about 7% versus 5% in the US.

The second piece of evidence comes from reported reasons for avoiding testing. At enrollment into the PHAROS study individuals are asked why they have not undergone genetic testing. They are provided with a list of possible reasons and asked to indicate the importance of each reason. One of the reasons given is, "The financial costs of testing are too high" and another is "The testing process takes a long time." Only 20% of individuals report that financial costs are a "Somewhat" or "Extremely" important reason to avoid testing and only 8% of individuals report that time costs are an important reason. In contrast, 60% of people say that a preference for living with uncertainty is an important reason for not testing. This suggests that relatively few people perceive real testing costs to be a barrier to testing.

Quantitative Evidence

To get a quantitative sense of the neoclassical model fit to the data, we can estimate the model from Section 4.3 with the restriction that $\delta = 0$. To allow for similar degrees of freedom we fit different minimum values for Ω_i and Φ_i (when estimating with a free δ we constrained these to be equal). In particular, we estimate $\Phi_i \sim \text{Unif}[\alpha, \alpha+\beta]$ and $\Omega_i \sim \text{Unif}[\lambda, \lambda+\beta]$. We match the same moments as in Section 4.3.

The results (parameters and moments) are shown in Table 4. This model is a slightly less good fit to the data than the optimal expectations model; the best fit testing rates are still slightly too high. The parameters of the data are noisier and imply extreme asymmetry. Comparing the estimated distributions of Φ and Ω we find the parameters suggest it is *ten thousand* times worse in

terms of lost utility to take the wrong action if the true state turns out to be "healthy" than if it turns out to be "sick".

The parameters also imply large testing costs. Recall that we pinned down the average testing cost of $C = 0.005$, and we interpret this magnitude *relative to* the costs of taking the wrong action. In this case, the real costs of testing must large: be about 6 times higher than the cost of taking the wrong actions if the true state is "sick." Finally, we note that to incorporate confirmatory testing here it must be the case that there is some $\Psi > \Phi$. The high degree of asymmetry here means that Φ is very large relative to Ω. Therefore, in order to explain the existence of confirmatory testing it must be the case that the benefit to confirmation when sick is ten thousand times greater than the benefit to taking all the correct actions up to that point.

The evidence here shows that the fit of the restricted model is worse (despite having the same number of free parameters). More problematic, the estimated parameter values seem implausible. In combination with the qualitative evidence, some of which directly contradicts the findings, we argue that we reject the neoclassical model as an explanation for these facts. In some sense this is not surprising. However, our rejection here is more complete: even if one thinks that real testing cost are large, the other evidence seems to rule out this explanation.

Alternative Non-Neoclassical Models

Having rejected the neoclassical case, we note that the optimal expectations model is not the only non-neoclassical candidate to explain these facts. In Appendix C we describe two other models. We begin with a model of wishful thinking (Mayraz, 2011). We find this model produces implications very similar to the optimal expectations case, and in this sense is a plausible alternative. Little in our data distinguishes these two models; the one feature leading us to weakly favor optimal expectations is that the Mayraz (2011) model requires higher real costs of testing to explain low testing rates, and has difficulty accommodating confirmatory testing. Second, we describe a model with anticipatory utility and information-averse preferences (Koszegi, 2003). This model fails to match the bias in reported beliefs, and requires the same asymmetry in utility losses which is necessary to explain behavior in the neoclassical case. We therefore argue the data more strongly rejects this alternative.

6 Conclusion and Policy

The central puzzle with which we began this paper is low rates of medical testing. The analysis of HD data here demonstrates several additional stylized facts about testing and behavior: individuals have downward-biased beliefs about their risk of being sick, they take actions which would be appropriate if they were healthy and testing rates are increasing with *ex ante* risk. We argue that these facts are well explained by an optimal expectations model (Brunnermeier and Parker, 2005).

In addition to fitting the facts in theory, we show that this model can match the data with seemingly reasonable parameter values. In particular, even if we assume very low real costs of testing, we can produce low testing rates. This model also features an appealing psychological intuition. The primary reason for testing avoidance in this case can be summarized, colloquially, as not wanting to live with the anticipation of future ill-health. This intuition aligns closely with a literature in psychology in which individuals facing bad news look for reasons to avoid believing it (see, for example, Dawson, Gilovich and Regan, 2002).

Although the data analysis in this paper focuses on HD, we show evidence (in Appendix B) that similar patterns exist in cancer screening and HIV testing. This suggests that the theory we suggest here may explain not just the HD case but low demand for medical information more generally. In a number of these other settings, low testing rates are of some policy concern. We can use our analysis to ask the question of how testing rates might be increased, if that is socially desirable. It is important to note that in the optimal expectations world, the individual choice to avoid testing is privately optimal. They are not making a mistake, nor do they lack information: individuals are avoiding testing because they prefer to consume happiness in the anticipation period. Given this fact, we should be wary of inadvertent revelation of information about genetic status, since it may make individuals worse off.

There are two reasons why higher testing rates could be socially optimal even if *not* privately. The first is in a case like HIV, for example, where testing might lead to better treatment and less disease spread. Because of the contagious nature of this disease, revealing individual status may encourage them to protect their partners, which has social value. Second, even if the disease is not contagious, overly optimistic individuals may be socially costly for other reasons. For example, over-optimism may lead people to under-save for bad health, and then the burden falls on the

government. In either case, a social planner may want to encourage testing.

Using the estimated model from Section 4.3, we can run several counterfactuals to illustrate what interventions might increase testing rates under this model. These results are shown in Table 5. Row (1) reports the baseline probability of testing with the simulated best-fit parameters. Rows (2) and (3) report simulated testing rates with changes in the cost of testing. These results illustrate that while testing rates are responsive to changes in cost, they are not very responsive since for many people the true "cost" of testing is the loss in the ability to ignore their status. Even at a cost of zero, only around 10% of individuals would be tested. Doubling the cost of testing reduces testing rates by about half.

The alternative to changing testing costs is to change the weight on anticipation or the utility loss from taking the wrong action.Rows (4)-(7) of Table 5 show the impact of these changes. Testing rates are much more sensitive to these alterations than to the cost of testing. Less anticipation (a lower value of δ in the model) or greater value on taking the correct action (higher α) will dramatically increase the cost of testing.

The results in Table 5 suggest that under this model it may be difficult to have a large impact on testing rates by changing the real cost of testing. However, either making the future more salient or emphasizing the value of changing life choices in response to medical information could be more effective at encouraging testing. This, of course, predicts the obvious comparative static that if there is a treatment or cure, which will impact the value of taking the correct action, people will test more.

As a final note, the key assumption in the optimal expectations framework is that, once tested, individuals are no longer able to change their beliefs. This seems like an appropriate assumption in cases like HD (or HIV) where the test is fully accurate. A different assumption may be appropriate in cases where the test is not fully accurate. In this case we could imagine that the test restricts belief manipulation to some extent, but not completely. This modification could be an interesting extension to the model.

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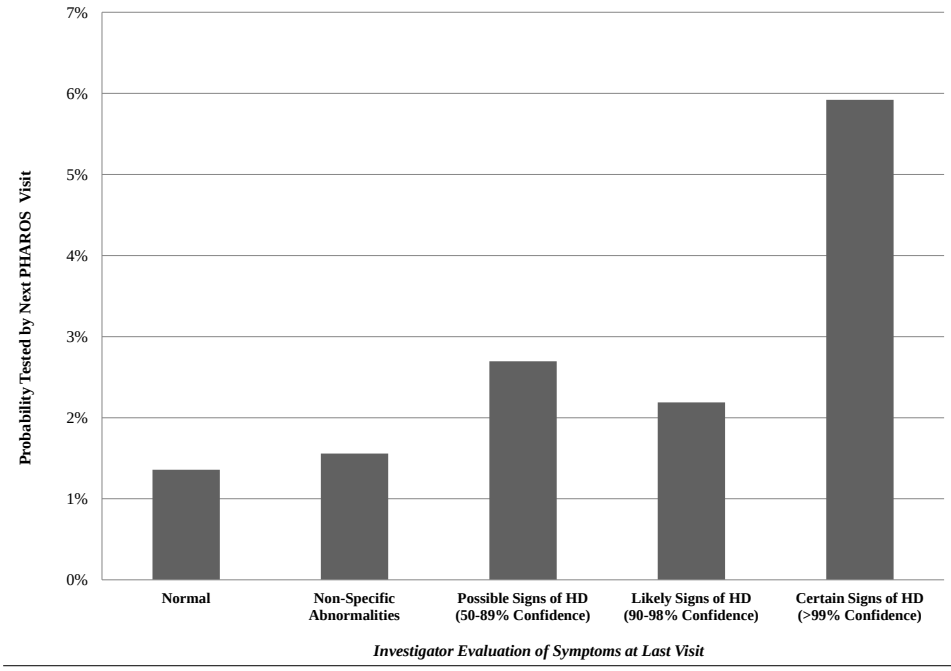
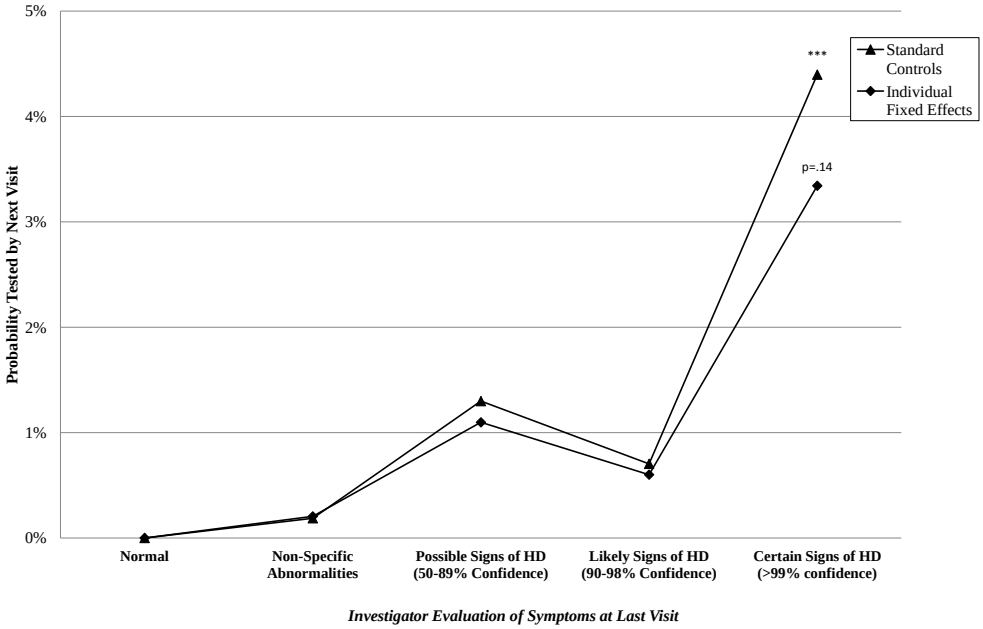
Figure 1:
Testing Behavior by Investigator Evaluation of Risk



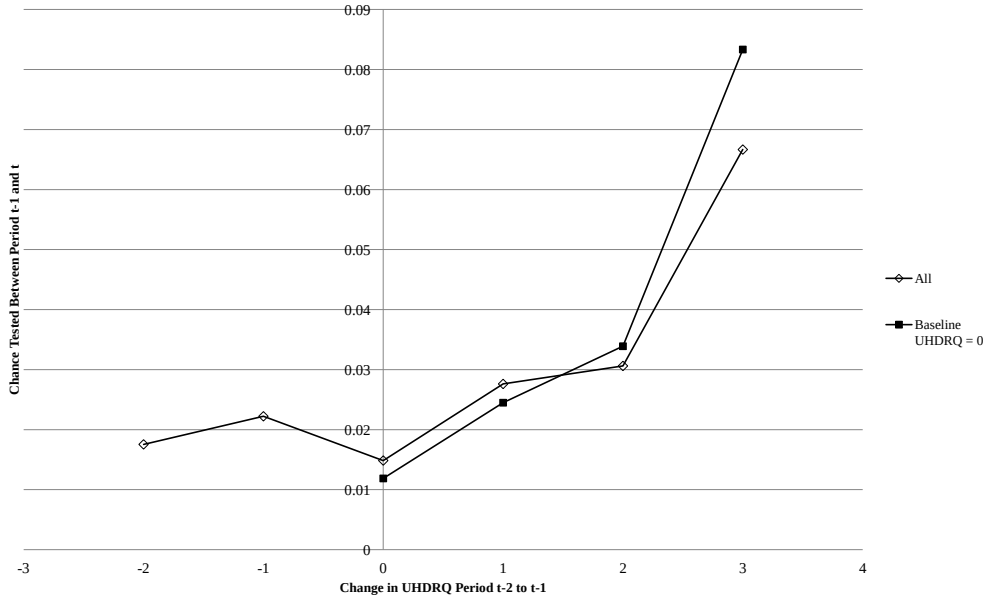
Notes: This figure shows the chance of genetic testing by the next PHAROS visit grouped based on investigator-evaluated disease status.

Figure 2:
Testing Behavior by Investigator Assessment of Disease State
(Regression Adjusted for Controls)



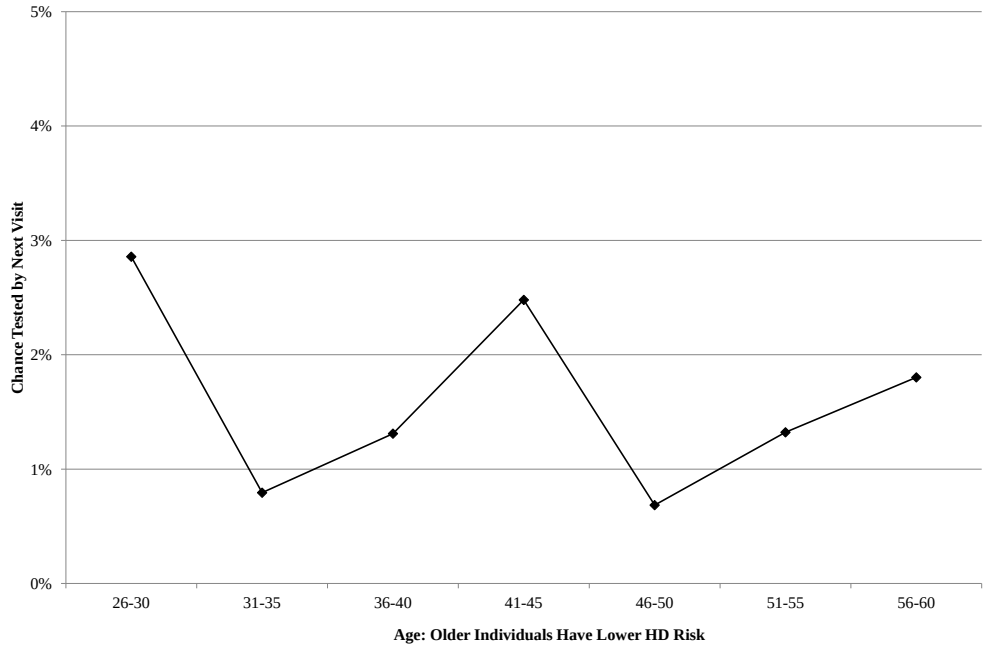
Notes: This graph shows the impact of symptom levels on testing, adjusting for age, education and gender. *** significantly different from those assessed "Normal" at 1% level.

Figure 3:
Testing Behavior by Change in Investigator Score



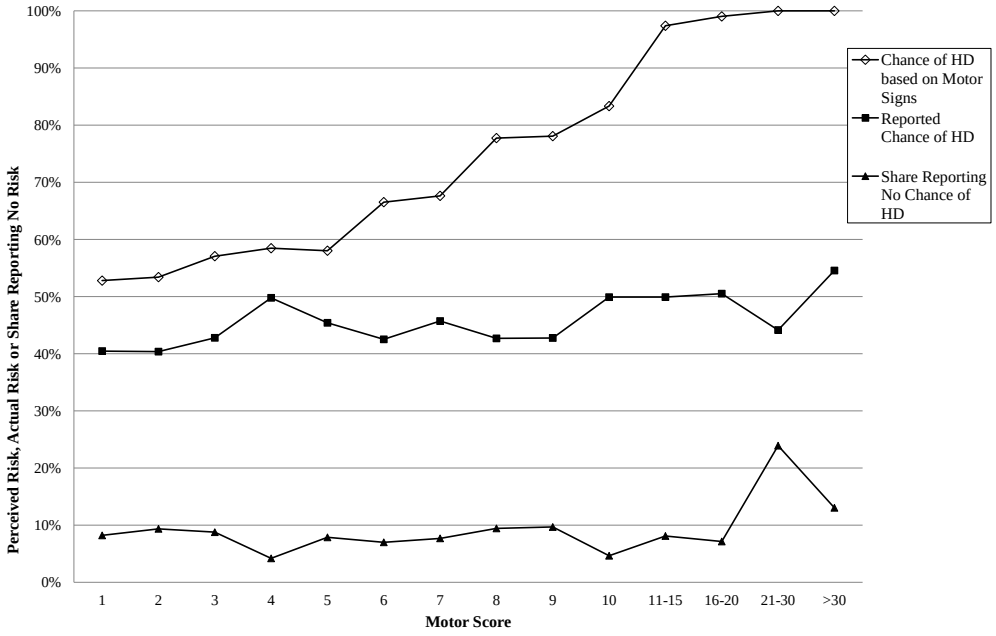
Notes: This graph shows the relationship between changes in investigator confidence about disease status and subsequent testing. Investigator confidence is on a range from 0 to 4 with 0 indicating no evidence of HD and 4 indicating HD with >99% confidence. The X-axis shows changes between visits t-2 and t-1 and the Y-axis shows the chance tested between visits t-1 and t.

Figure 4:
Testing Behavior by Age among Individuals with No Symptoms



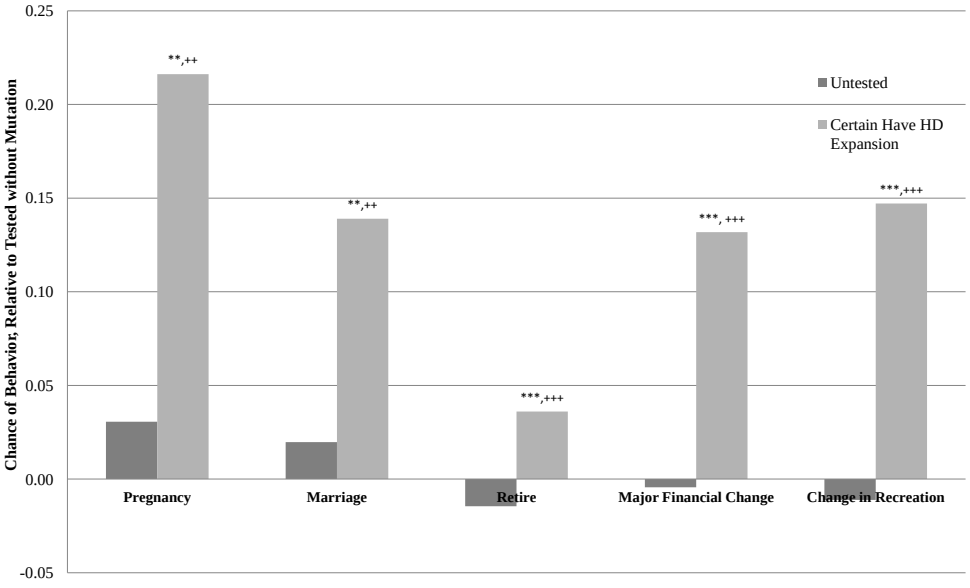
Notes: This graph shows testing rates by age among individuals with no symptoms. As individuals age their risk falls, from around 50% for the youngest group to 5-10% for the oldest.

Figure 5:
Perceived and Actual Risk of HD, by Motor Score



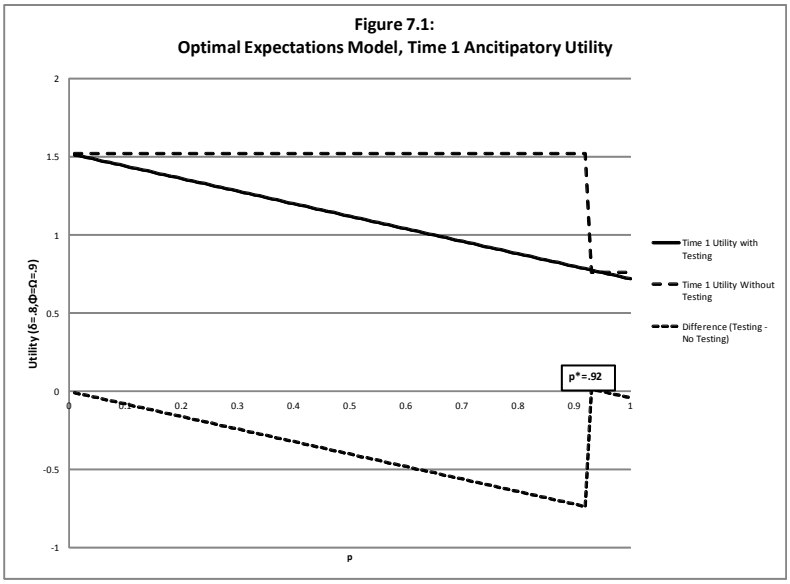
Notes: This figure shows the reported chance of HD (individual perception) and the actual posterior chance of HD by motor score.

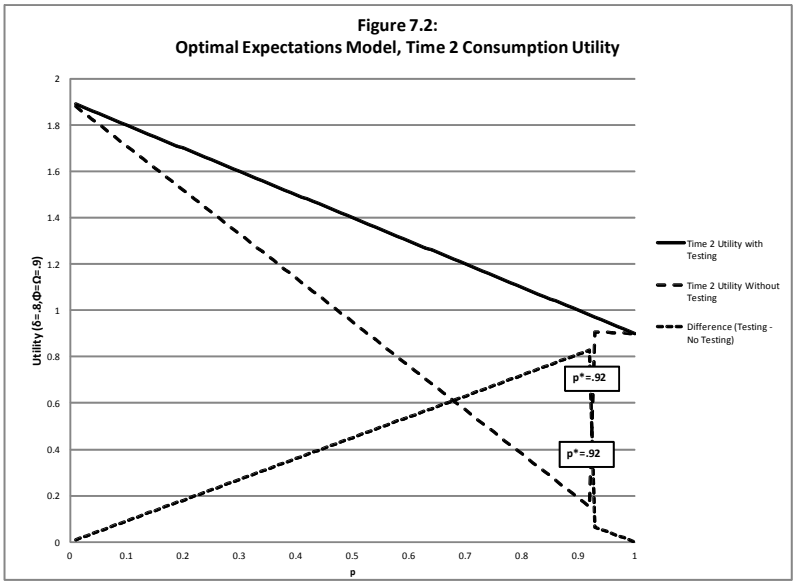
Figure 6:
Behavior Choice Relative to Individuals Without HD Expnansion



Notes: The bars shows differences in behavior relative to individuals who report they do not carry the HD expansion. Untested individuals include only individuals who report being uncertan about their stauts. Those who carry the mutation know that they carry it either through testing or through early symptoms. The regression adjusts for age ,gender and education. The regression for pregnancy restricts to people under 40 and also adjusts for number of existing children. ** ,***significantly different from those without mutation at 5% and 1% levels. ++,+++ significantly different from untested group at 5% and 1% levels.

Figure 7: Optimal Expectation Model, Graphical Intuition





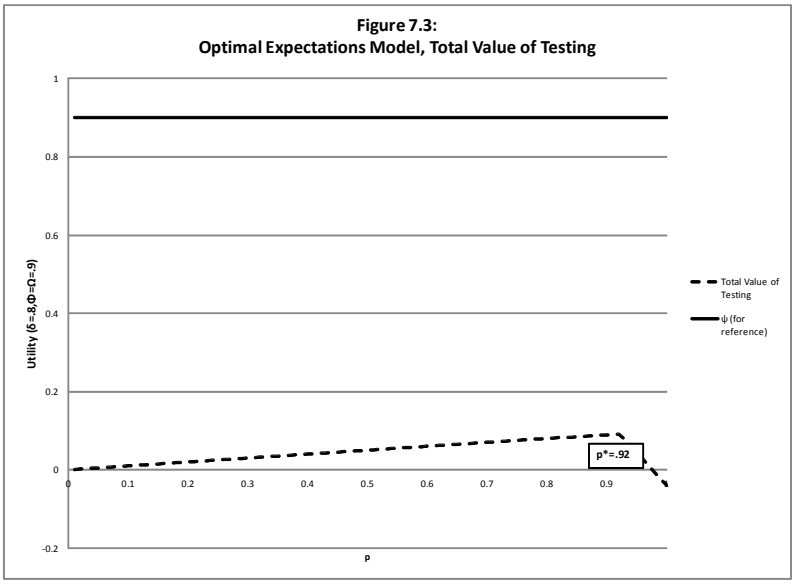


Table 1: ***Summary Statistics***

Panel A: HD Status Variables			
	Mean	*Std. Dev.*	*# of Obs.*
Motor Score (0-100)	4.00	6.66	3267
Doctor Evaluation of Risk (0-4 Scale)	0.634	0.999	6501
Perceived Chance of HD Mutation (untested)	42.9%	24.7%	2768
Tested (0/1)	4.6%	20.9%	6779
Tested Positive (0/1) (if test status inferred)	57.4%	49.5%	287
Panel B: Life Experience Summary Statistics			
	Mean	*Std. Dev.*	*# of Obs.*
Pregnant (Self or Partner), Under 40	11.4%	31.8%	865
Get Married (if unmarried)	14.5%	35.3%	884
Get Divorced	2.7%	16.1%	3633
New Job	14.6%	35.3%	3050
Retire	1.2%	10.7%	3057
Major Financial Change	38.9%	48.7%	3218
Change in Church Attendance	8.5%	27.9%	3161
Change in Recreation Activities	19.4%	39.5%	3159
Panel C: Demographic Summary Statistics			
	Mean	*Std. Dev.*	*# of Obs.*
Age	41.8	7.3	1001
Male (0/1)	29.3%	45.5%	1001
Education (years)	14.9	2.6	1001

Notes: This table shows simple summary statistics from the PHAROS data. In Panels A and B an observation is an individual-year, since perceived probability and doctor score can both vary across visits for a given individual and actions are chosen in multiple years. In Panel C there is just one observation per individual. Oster et al (2010) detail the methodology for inferring test results for tested individuals.

Table 2: ***Behavior Among Individuals with Certain HD Status***

	Difference in Mean Probability	*Coefficient Adjusted for Controls*
	With HD Mutation - Without HD Mutation (1)	*With HD Mutation Relative to Without Mutation* (2)
Pregnant (Self or Partner), Under 40	0.141**	0.223*
Get Married (if Unmarried)	0.140*	0.168**
Get Divorced	0.019	0.013
New Job	0.003	-0.0164
Retire	0.034*	0.031
Major Financial Change	0.162***	0.132**
Change in Church Attendance	0.015	0.0172
Change in Recreation Activities	0.167***	0.123***

Notes: This table shows, for each action, the relative probability of taking the action in the last year for individuals who are certain they do or do not carry the HD mutation. Column 1 shows the basic difference in means (significance from t-tests); Column 2 shows the coefficients from a regression adjusting for simple controls (gender, education, age and previous children in the case of pregnancy). *significant at 10% **significant at 5% ***significant at 1%.

Table 3: ***Behavior by HD Symptom Levels***

	(1)	(2)	(3)	(4)	(5)	(6)
Dependent Variable:	Pregnancy (Self or Partner)	Get Married	Retire	Major Finance Change	Change in Recreation	All Behaviors
Sample:	*Age<40*	*Unmarried*	*All*	*All*	*All*	*All*
Uncertain, Motor=0	.0455	.0251	-.0083	.0020	-.0374	-.0055
	(.052)	(.047)	(.008)	(.032)	(.026)	(.014)
Uncertain, Motor 1-3	-.0073	.0227	-.0128	-.0043	-.0392	-.0055
	(.054)	(.049)	(.008)	(.034)	(.028)	(014)
Uncertain, Motor 4-6	.064	.0390	-.0207**	-.0152	.0108	.0001
	(.062)	(.054)	(.009)	(.039)	(.031)	(.017)
Uncertain, Motor 7-10	.0319	-.0214	-.0211**	-.0302	.0249	-.0042
	(.077)	(.057)	(.010)	(.043)	(.035)	(.019)
Uncertain, Motor >11	.1176	-.0035	.0108	.0093	.0563	.0226
	(.08)	(.055)	(.010)	(.043)	(.035)	(.022)
Certain Carry Mutation	.2148**	.1212**	.0353***	.1446***	.1442***	.1100***
	(.090)	(.062)	(.012)	(.050)	(.040)	(.024)
General Controls	YES	YES	YES	YES	YES	YES
# Children	YES	NO	NO	NO	NO	NO
# of Observations	505	593	2878	3029	2977	9251

Notes: This table reports estimates of differences in behavior for individuals with varying risk of HD. The omitted category is individuals who are certain they do not carry the mutation. Uncertain individuals are those who report an intermediate probability of carrying the mutation; we differentiate them by their doctor-assigned motor score, which ranges from 0 (no symptoms) up to 100 (which would indicate extremely advanced HD). The true updated probability of HD for each motor score group can be seen in Figure 6. The certain group contains those individuals who report being sure they carry the HD mutation. General controls are: fixed effects for ten year age group, gender, years of education. When we estimate impacts on pregnancy we also control for the number of existing children. The final column estimates the impact on all behaviors together, with the data stacked so the observation is an individual-behavior. In this case we control for dummies for each behavior and cluster the standard errors by individual. Standard errors in parentheses. *significant at 10% **significant at 5% ***significant at 1%.

Table 4: ***Estimated Parameter Values and Moments***

Panel A: Estimated Parameter Values						
	Optimal Expectations		*Neoclassical Model*			
	Mean	*95% CI*	*Mean*	*95% CI*		
α	.856	(.855,.857)	10.006	(7.41,568.4)		
$\alpha + \beta$	.958	(.956,.959)	10.008	(7.41,568.4)		
δ	.968	(.967,.969)				
λ			.00009	(2.30e-5,.0006)		
$\lambda + \beta$			.0017	(.00056,.0036)		
Panel B: Moments						
	Moments in Data		*Optimal Expectations*		*Neoclassical Model*	
Motor Score Group	*Behavior*	*Testing*	*Behavior*	*Testing*	*Behavior*	*Testing*
0 ($p = .4$)	0.00	1.49%	0.000	2.05%	0.000	3.71%
1-3 ($p = .54$)	0.00	0.86%	0.000	2.72%	0.000	5.03%
4-6 ($p = .6$)	0.0006	2.3%	0.000	3.25%	0.000	5.74%
7-10 ($p = .75$)	0.00	4.0%	0.000	4.23%	0.000	6.99%
>11 ($p = .98$)	0.204	4.6%	0.210	2.99%	0.225	8.04%

Notes: This table shows estimated parameter values (Panel A) and moments (both behavior and testing) from the data and the estimated model (Panel B). Estimation is done using method of simulated moments in Matlab. In the optimal expectations model, $\Phi_i \tilde{}$Unif$[\alpha, \alpha + \beta]$. In the neoclassical model, $\Phi_i \sim$ Unif$[\alpha, \alpha+\beta]$ and $\Omega_i \sim$ Unif$[\lambda, \lambda + \beta]$.

Table 5: ***Counterfactuals***

	Change in Model	Simulated Testing Rate
(1)	No Change	2.39%
(2)	Zero Cost of Testing	9.05%
(3)	Double Testing Cost	1.14%
(4)	$\delta = 1$	0%
(5)	$\delta = .9$	54.7%
(6)	$\alpha = .8$	0%
(7)	$\alpha = .9$	30.8%

Notes: This table shows the simulated testing rate (average across all individuals) for the parameter values in Table 4 (row 1) and variations (rows 2-7). The baseline cost of testing is $C = .01$.

Appendix A: Life Events Questionnaire

INSTRUCTIONS: Listed below are a number of events, which can bring about change in the lives of those who experience them. Please mark **"YES"** for the events that you have experienced in the *last year*.

Also, for each item marked **"Yes"** below, indicate the extent to which you viewed the event as having either a positive or negative impact on your life at the time the event occurred.

	Yes	No	Extremely Negative	Moderately Negative	Slightly Negative	No Impact	Slightly Positive	Moderately Positive	Extremely Positive
1. Marriage	○	○	○	○	○	○	○	○	○
2. Detention in jail or comparable institution	○	○	○	○	○	○	○	○	○
3. Death of spouse	○	○	○	○	○	○	○	○	○
4. Major change in sleeping habits (If **No** go to #5)	○	○	○	○	○	○	○	○	○
4a. If Yes, in question 4, trouble falling asleep	○	○	○	○	○	○	○	○	○
4b. If Yes, in question 4, trouble staying asleep	○	○	○	○	○	○	○	○	○
4c. If Yes, in question 4, early morning wakening	○	○	○	○	○	○	○	○	○
5. Death of close family member:	○	○							
If Yes, complete remainder of question.									
○ Mother Affected by HD?	○	○	○	○	○	○	○	○	○
○ Father Affected by HD?	○	○	○	○	○	○	○	○	○
○ Brother Affected by HD?	○	○	○	○	○	○	○	○	○
○ Sister Affected by HD?	○	○	○	○	○	○	○	○	○
○ Grandmother Affected by HD?	○	○	○	○	○	○	○	○	○
○ Grandfather Affected by HD?	○	○	○	○	○	○	○	○	○
○ Other (specify): [ ] Affected by HD?	○	○	○	○	○	○	○	○	○
6. Major change in eating habits (If **No** go to #7)	○	○	○	○	○	○	○	○	○
6a. If Yes, in question 6, have you lost more than 10% of your previous body weight?	○	○	○	○	○	○	○	○	○
6b. If Yes, in question 6, have you gained more than 10% of your previous body weight?	○	○	○	○	○	○	○	○	○
7. Foreclosure on mortgage or loan	○	○	○	○	○	○	○	○	○

	Yes	No	Extremely Negative	Moderately Negative	Slightly Negative	No Impact	Slightly Positive	Moderately Positive	Extremely Positive
8. Death of a close friend	○	○	○	○	○	○	○	○	○
9. Outstanding personal achievement	○	○	○	○	○	○	○	○	○
10. Minor law violations (i.e. traffic ticket)	○	○	○	○	○	○	○	○	○
11. Wife / girlfriend's pregnancy	○	○	○	○	○	○	○	○	○
12. Your own pregnancy	○	○	○	○	○	○	○	○	○
13. Change in work situations (responsibilities, hours, etc.)	○	○	○	○	○	○	○	○	○
14. New job	○	○	○	○	○	○	○	○	○
15. Serious illness or injury of close family member:									
15a. Mother	○	○	○	○	○	○	○	○	○
15b. Father	○	○	○	○	○	○	○	○	○
15c. Brother	○	○	○	○	○	○	○	○	○
15d. Sister	○	○	○	○	○	○	○	○	○
15e. Grandmother	○	○	○	○	○	○	○	○	○
15f. Grandfather	○	○	○	○	○	○	○	○	○
15g. Other (specify):	○	○	○	○	○	○	○	○	○
16. Sexual difficulties	○	○	○	○	○	○	○	○	○
17. Trouble with employer (i.e. danger of losing job)	○	○	○	○	○	○	○	○	○
18. Trouble with in-laws	○	○	○	○	○	○	○	○	○
19. Major change in financial status	○	○	○	○	○	○	○	○	○
20. Major changes in closeness of family members	○	○	○	○	○	○	○	○	○
21. Gaining a new family member (i.e. birth, adoption, family member moving in)	○	○	○	○	○	○	○	○	○
22. Change of residence	○	○	○	○	○	○	○	○	○
23. Marital separation from spouse, due to conflict	○	○	○	○	○	○	○	○	○
24. Major change in church activities	○	○	○	○	○	○	○	○	○
25. Marital reconciliation with mate	○	○	○	○	○	○	○	○	○
26. Major change in number of arguments with spouse	○	○	○	○	○	○	○	○	○
27. Change in wife's work outside the home	○	○	○	○	○	○	○	○	○
28. Change in husband's work	○	○	○	○	○	○	○	○	○
29. Major change in usual type and/or amount of recreation	○	○	○	○	○	○	○	○	○
30. Borrowing more than $10,000	○	○	○	○	○	○	○	○	○

	Yes	No	Extremely Negative	Moderately Negative	Slightly Negative	No Impact	Slightly Positive	Moderately Positive	Extremely Positive
31. Borrowing less than $10,000	○	○	○	○	○	○	○	○	○
32. Being fired from job	○	○	○	○	○	○	○	○	○
33. Wife / girlfriend having an abortion	○	○	○	○	○	○	○	○	○
34. Having an abortion	○	○	○	○	○	○	○	○	○
35. Major personal illness or injury	○	○	○	○	○	○	○	○	○
36. Major change in social activities (i.e. parties, movies, visiting - increased or decreased participation)	○	○	○	○	○	○	○	○	○
37. Major changes in living conditions of family (i.e. building new home, remodeling)	○	○	○	○	○	○	○	○	○
38. Divorce	○	○	○	○	○	○	○	○	○
39. Serious injury or illness of close friend	○	○	○	○	○	○	○	○	○
40. Retirement from work	○	○	○	○	○	○	○	○	○
41. Son or daughter leaving home	○	○	○	○	○	○	○	○	○
42. Ending of formal schooling	○	○	○	○	○	○	○	○	○
43. Separation from spouse, due to work, travel, etc.	○	○	○	○	○	○	○	○	○
44. Engagement	○	○	○	○	○	○	○	○	○
45. Breaking up with boyfriend / girlfriend	○	○	○	○	○	○	○	○	○
46. Leaving home for the first time	○	○	○	○	○	○	○	○	○
47. Reconciliation with boyfriend / girlfriend	○	○	○	○	○	○	○	○	○
48. Taking on major care - taking responsibilities for a family member (If **No** go to question 49)	○	○	○	○	○	○	○	○	○
48a. If Yes, in question 48, who?									
48b. If Yes, in question 48, is this person affected with HD?	○	○	○	○	○	○	○	○	○
Other experiences having an impact on your life: (please list and rate)									
49.	○	○	○	○	○	○	○	○	○
50.	○	○	○	○	○	○	○	○	○
51.	○	○	○	○	○	○	○	○	○
52. Have you made a living will?	○	○							
53. Have you made arrangements for durable (enduring) power of attorney?	○	○							

Appendix B: HIV and Cancer Screening

In this appendix we discuss patterns of behavior in HIV testing and cancer screening and ask whether we see patterns similar to those in our HD data.

HIV testing and cancer screening are both cases in which the demand for medical testing seems surprisingly low. Although cancer screening has improved dramatically in the past decades, and is useful in catching cancer at an early stage, many people do not get this screening with the recommended frequency. In the case of HIV, even in the US where good treatments are available, public health officials have struggled to get people to engage in HIV testing. In Africa, where rates of HIV are much higher but treatments are limited, testing is even less common. These low testing rates extend to testing for genetic markers for cancer risk (Lerman et al, 1996).

As with HD, the real costs of testing seem not to be the limiting factor on testing. Lerman et al (1996) report that 40% of individuals who were tested for the BRCA1 mutation did not choose to receive their results even though the cost was zero and they were already at a counseling session. In the case of HIV, Thornton (2008) pays individuals to receive their HIV test results in Malawi, and finds that 20% of people avoid their results even if they are paid to get them.

Although the data are less comprehensive than in the HD case, an expanding literature in these two cases also provides some evidence on the relationship between risk and testing, and on behavior chosen by untested people relative to those who are tested. The one thing we have only limited evidence on is the relationship between subjective and objective probability. In these two settings, the objective probability is not well defined, and few studies ask for details on subjective chance of illness. One exception are data from HIV positive individuals reported in Thornton (2011). She finds that two years after being told they were HIV positive, about 70% of individuals report "no likelihood" or "low likelihood" of having HIV. This suggests significant down-weighting relative to their actual risk, similar to what we see in HD.

Risk and Actions among Untested Individuals

For both cancer screening and HIV testing, the primary non-testing behaviors researchers focus on are health-related. In the case of cancer and BRCA testing, the natural question is how cancer screening behavior differs for individuals with positive and negative BRCA1 test results, and how these behaviors compare to at-risk individuals who are untested or who do not get test results.

Schwartz et al (2003) study prophylactic ovary removal for individuals after BRCA testing; carriers of the BRCA1 mutation are more likely to develop ovarian cancer in addition to breast cancer. These authors find similar rates of prophylactic ovary removal for those individuals who have a negative test result and those without test results (2% and 5% respectively), but higher rates (27%) for those who have a positive test result. Note that *none* of these individuals (even those with a positive test result) actually have cancer, just a marker for increased risk.

Foster et al (2007) compare carrier and non-carriers of the BRCA1 mutation on rates of mammography, ovarian ultrasound and other preventative behaviors. The individuals in this study are questioned about behaviors before testing and after testing, with the latter dependent on carrier status. The data suggest that there are limited differences between baseline behavior and the subsequent behavior of non-carriers, but very large changes in behavior for those who are carriers of the mutation. This suggests screening behavior is different for individuals with differing test results, but that those with intermediate risk tend to behave like those without the genetic mutation rather than undertaking some intermediate behavior.

A similar result is seen in the case of HIV when the outcome is sexual behavior. For example,

Thornton (2008) uses a randomized evaluation in Malawi to estimate the impact of learning HIV status on risky behavior and condom purchases. She finds evidence that those who learn about a positive test result purchase more condoms, but there is no difference between those who learn about a negative result and those who remain uninformed. She also finds a large (but not significant) decrease in risky sexual behavior for individuals who test positive. A meta-analysis of data from the US from 1985 to 1997 (Weinhardt et al, 1999) shows similar patterns. Risky behavior (lack of condom use, unprotected sex) is similar for untested individuals and those with a negative test result; those with a positive test result have significantly less risky behavior.

Overall, in both cases, the data suggest that behaviors are very different for individuals with differing test results, as we would expect. We also consistently observe that individuals with intermediate risk do not undertake some intermediate level of behavior: they appear to behave much more similar to individuals who have a negative test result. This suggests some "skewing" of actions toward what would be optimal in the good state.

Risk and Testing Behavior

Among the most informative genetic screens for cancer is the test for the BRCA1 or BRCA2 mutation, which are a strong predictors of both breast and ovarian cancer. Penentrance of these markers is high: 80% of women with the BRCA1 mutation will develop breast cancer if they live to age 80. A simple way to measure *ex ante* risk is with the number of relatives impacted by breast cancer: the more relatives with cancer, the more likely that it is genetic. In a number of studies of testing behavior, it appears that testing is increasing with risk, as measured by number of family members impacted (Lerman et al, 1996; Meijers-Heijboer et al, 2000; Baer et al, 2010). The second of these studies (Meijers-Heijboer et al, 2000) explicitly separates individuals at 25% risk from those at 50% risk and shows higher testing rates among the 50% risk group.

Cancer screening (mammography in particular) shows similar patterns. In a meta-analysis focusing on perceived risk and screening behavior, Katapodi et al (2004) demonstrates that perceived risk is associated with increased screening behavior.

In the case of HIV testing in the US, testing also seems to be increasing in risk (Wortley et al, 1995; Stein and Nyamathi, 2000; Samet et al, 1997). The African context is perhaps more interesting, given extremely low testing rates and high prevalence in many countries in the region, and shows more mixed evidence. A number of studies find self-perceived risk increases testing (Wringe et al, 2008; Adeneye et al, 2006; Fylkesnes and Siziya, 2004), although some have found the opposite (Sambisa et al, 2010; Thierman et al, 2006).

It is worth noting that this evidence is weaker than the HD evidence in the sense that to a large extent these behaviors are directly linked to disease risk, disease avoidance or disease transmission and, given that, it seems inherently more likely that those with positive test results would respond more. This underscores the advantage of the HD setting and data.

Appendix C: Alternative Non-Neoclassical Models

In this section we describe two alternative, non-neoclassical, models which have been suggested to explain these behaviors.

Wishful Thinking (Mayraz, 2011)[15]

The key assumptoin of this model is that individuals engage in "wishful thinking": when faced with a bad state of the world, they are overly optimistic. More concretely, individuals hold subjective beliefs which depend on the payoff function. We describe the setup and results below.

Setup

As before, there is a binary state $s \in \{0, 1\}$ and individuals are endowed with $p = E(s)$. The starting point in this model is bias in subjective beliefs: the assumption that individuals engage in wishful thinking causes their beliefs to be (potentially) biased toward the healthy state. As in the basic setup, we assume that individuals prefer to be healthy than to be sick. We denote the utility from health as $f(s)$. As in the body of the paper, we assume that $f(s = 1) = 0$ and $f(s = 0) = 1$, implying that the maximum possible utility in the healthy state is 1 and in the sick state is 0.

In general, Mayraz (2011) describes the formulation of subjective beliefs $\pi(s)$ from objective probabilities $p(s)$ as: $\pi(s) = p(s)e^{\psi f(s)}$ where ψ represents the level of optimism. Someone with a value of $\psi = 0$ is a realist; high values of ψ indicate high optimism. This model can also accommodate pessimism (with a negative ψ). In the HD case, the subjective probability can be computed

$$\pi = \frac{pe^{\psi(f(s=1))}}{pe^{\psi(f(s=1))} + (1-p)e^{\psi f(s=0)}} = \frac{p}{p + (1-p)e^{\psi}}$$

As in the baseline model, individuals choose a binary action $a \in \{0, 1\}$. Utility in this model is delivered in the same way as in the optimal expectations model:

$$U((a, s)|p) = \delta E(u(\hat{a}, s)|\pi) + E(u(\hat{a}, s)|p)$$

where $\hat{a} = argmax_a E[u(a, s)|\pi]$. However, in this model individuals consider *only* the anticipatory utility period when making choices about testing. In the optimal expectations model individuals make a choice of action based only on the beliefs in the anticipation period, but make choices about testing based on both periods. In this case, both action and testing choices are made based only on the anticipatory period, so we can write the object that individuals actually maximize as $U((a, s)|p) = E[u(\hat{a}, s)|\pi]$. For simplicity, we assume symmetric values for utility losses, so we have:

$$\begin{aligned} u(0, 1) &= -\Phi \\ u(1, 1) &= 0 \\ u(1, 0) &= 1 - \Phi \\ u(0, 0) &= 1 \end{aligned}$$

We assume that testing carries a real financial cost C.

Results

Results on beliefs and actions are shown in Appendix Proposition 3.

Appendix Proposition 1. Beliefs and Actions

[15] We are extremely grateful to Guy Mayraz for very helpful conversation about this model, and for developing the version of the model we present here.

1. *If $\psi > 0$ individuals hold beliefs $\pi < p$.*

2. *Action $a = 0$ will be taken for values of $p^* \leq \frac{e^{\psi}}{1+e^{\psi}}$*

Proof. 1. As noted above, in this model $\pi = \frac{p}{p+(1-p)e^{\psi}}$. As long as $\psi > 0$ this is less than p.

2. Lemma 1 in the paper describes the choice of action based on π. The model here corresponds to the symmetric case, so the cutoff value to switch from $a = 0$ to $a = 1$ is $\pi = .5$. This statement follows directly from solving for p when $\pi = .5$

□

The intuition for this result is similar to the optimal expectations case, although the result is delivered with one fewer step. By assuming biased beliefs, we deliver that result immediately, and the actions follow.

We next turn to testing behavior. The proposition below describes the relationship between testing and risk, the condition for individuals to test at all, and the condition for confirmatory testing. As in the optimal expectations case, we assume that testing for confirmation carries a value Ψ.

Appendix Proposition 2. Testing Behavior

1. *Value of testing is increasing in p for values of $p < p^*$ where $p^* = \frac{e^{\psi}}{1+e^{\psi}}$. Value of testing is decreasing in p for values of $p \geq p^*$.*

2. *Individuals will test if either:*

   (a) $p < p^*$ and $\pi(p)\Phi > C$ or

   (b) $p \geq p^*$ and $(1 - \pi(p))\Phi > C$

3. *Confirmatory testing will occur without predictive testing if and only if $\Psi > \Phi$.*

Proof. 1. Both points (1) and (2) follow from the value of testing. If $\pi(p) \leq .5$ and individuals are taking action $a = 0$ then value of testing is $V_{test} = \pi(p)\Phi$. If $\pi(p) > .5$ and individuals are therefore taking action $a = 1$ then $V_{test} = (1 - \pi(p))\Phi$. Note that p^* is the value such that $\pi(p^*) = .5$. Testing value is therefore increasing up to this $p^*$and decreasing for higher values. Moreover, in either case individuals will test if the value to testing exceeds the real cost.

2. To have confirmatory testing without predictive testing requires that individuals want to test for confirmation but not for predictive reasons. Testing for confirmation requires that $\Psi > C$. *Not* testing predicatively requires that the value to testing for confirmation only be higher than

the value to testing predictively, where the latter is evaluated at the highest testing value point (p^*, or $\pi = .5$), at which point individuals are still taking action $a = 0$. These values are given:

$$V_{test,predictive} = .5u(1,1) + .5u(0,0) - C + \pi\Psi$$
$$V_{test,confirmation} = .5u(0,1) + .5u(0,0) + .5(\Psi - C)$$

Testing for confirmation and not predictively will therefore occur if $C > \Phi$. Together with the condition for testing for confirmation rather than not testing at all, we have $\Psi > \Phi$.

□

This model delivers the implication that testing is increasing in p directly through the wishful thinking. As an a neoclassical model, individuals want to test when they are most uncertain (when they believe the probability of the disease is 50%). Because of the wishful thinking, this occurs at an objective probability of higher than 50%, namely at p^*.

The other parts of Appendix Proposition 4 are more similar to the rational model. Individuals are prevented from testing here only by the real cost of testing, and therefore this cost must be high in order to prevent testing. In particular, for the same parameter values preventing testing requires a higher cost of testing than in the optimal expectations model. The required cost is not as large as in the neoclassical model, however, since there the value of testing was $p\Phi$, and here it is $\pi\Phi$ and, as shown in Appendix Proposition 3, $\pi < p$.

With regards to confirmatory testing, this model has an issue similar to the rational model. Generating confirmatory testing requires that the gain to confirmatory testing be larger than the gain to taking the correct actions up to that point. We have argued this is not the case, so effectively this model cannot rationalize confirmatory testing behavior.

Summary

In many ways this model is observationally similar to the optimal expectation case, given what we can see in our data. Both models predict biased beliefs, skewed actions and testing increasing in risk. In terms of the predictions on beliefs, this model may actually be a better fit than the optimal expectations, since it accommodates the fact that reported beliefs are increasing in actual risk, even if slowly, rather than suggesting all biased beliefs are $\pi = 0$.

The two models have different psychological micro-foundations, but testing between these is beyond the scope of our data. More specifically, the underpinnings of the optimal expectations model suggest that individuals "know" their true p – it's effectively a two-self model in which, if pushed, individuals could in principle access their true risk, even if they are adopting biased beliefs. The wishful thinking model has only the biased beliefs. Through wishful thinking individuals literally forget their true risk. Although this does differentiate the models, it's not something we can test in our data.

The most significant difference between this and the optimal expectations model comes in the testing. Like the neoclassical model, there is nothing limiting testing here other than real testing costs. This means that both (a) higher real testing costs would be required to rationalize low testing rates and (b) this model struggles to explain confirmatory testing. For this reason, we favor the optimal expectations setting, although the similarities between the models make this a plausible

alternative. Richer data, with more information on psychological processing of these decisions, might help differentiate the two.

Information-Averse Preferences

Setup

We retain the basic setup from Section 4.1. The state is binary ($s \in \{0,1\}$) and individuals have some exogenously given $p = E(s)$. Consumption utility at time 2 is given by: $U_2 = E[u(a,s)|p] = pu(a,1) + (1-p)u(a,0)$.

Individuals also experience some anticipatory utility at time 1. Individuals have information-averse preferences over anticipatory utility (Kreps and Porteus, 1978). We adopt an extremely simple formation for time 1 utility (or "anxiety"), drawn from Caplin and Leahy (2004): $U_1 = c(1-p) - b\left(p - \frac{1}{2}\right)^2$, with $c, b > 0$. The $c(1-p)$ term indicates an individual with these preferences would prefer a low p, since it indicates they are unlikely to be sick. However, this individual also (all else equal) has a preference for uncertainty: as p moves away from $\frac{1}{2}$ in either direction, utility falls. We can interpret c as a general disutility of being sick. We interpret b as the degree to which the individual dislikes uncertainty.[16]

Since action choices *do not* enter time 1 utility, a^* is determined based only on consumption utility at time 2, so $a^*(p) = argmax_a[pu(a,1) + (1-p)u(a,0)]$. Total two period utility is given by the equation below.

$$U(a,s,p) = c(1-p) - b\left(p - \frac{1}{2}\right)^2 + pu(a^*(p),1) + (1-p)u(a^*(p),0)$$

We define the parameter values as in Section 4.

$$\begin{aligned} u(0,1) &= -\Omega \\ u(1,1) &= 0 \\ u(1,0) &= 1 - \Phi \\ u(0,0) &= 1 \end{aligned}$$

Results

We summarize the results in two propositions. The first describes beliefs and actions. The second describes the relationship between testing and risk. We discuss confirmatory testing at the end.

Appendix Proposition 3. Beliefs and Actions

1. *Self-reported beliefs are accurate* ($\pi = p$)

2. *Action* $a = 0$ *is taken as long as* $p < p^*$ *where* $p^* = \frac{\Phi}{\Phi+\Omega}$. *Note* $p^* > .5$ *iff* $\Phi > \Omega$.

[16] In principle, this taste for uncertainty could imply people actually prefer $p = .5$ to $p = 0$, which seems unlikely; however, with high enough c this will not be the case.

Proof. 1. This follows directly from the fact that the model does not accommodate the possibility of beliefs other than p.

2. Note that the action utility enters only at time 2. The individual will choose $a = 0$ if $(1-p)\Phi \geq p\Omega$. Rearranging, we find that the individual will choose $a = 0$ up to a value of $p^* = \frac{\Phi}{\Phi+\Omega.}$. Note this is the same as the neoclassical case.

□

This proposition notes first that this model cannot accommodate biased beliefs. Second, it demonstrates that generating skewed actions in this model requires the same type of asymmetry as in the neoclassical case, summarized in Section 5 in the paper.

Appendix Proposition 4. Testing and Risk *Define* $p^* = \frac{\Phi}{\Phi+\Omega}$*, as above. Individuals will choose to test if one of the following conditions holds:*

1. $p \leq p^*$ *and* $p > \frac{b-\Omega}{b}$

2. $p > p^*$ *and* $p < \frac{\Phi}{b}$

Proof. 1. When $p \leq p^*$ the individual is taking action $a = 0$. Given this, $V_{test} = p\Omega + b(p^2 - p)$. This is positive for values of $p > \frac{b-\Omega}{b}$.

2. When $p > p^*$ the individual is taking action $a = 1$. Given this, $V_{test} = (1-p)(\Phi - bp)$. This is positive when $\Phi - bp > 0$

□

For values of p below p^*, the utility from testing has two components. First, over this range of p, individuals take the action $a = 0$. As p increases, it becomes more and more likely this is wrong and the value to learning the true state and taking the correct action increases. This component of the testing utility is always positive. Pushing against this is the anxiety associated with testing which is the difference in anticipation utility if tested versus untested: $-\frac{b}{4} + b\left(p - \frac{1}{2}\right)^2$. This difference is the greatest (most negative) when $p = .5$. If b is large enough, this anxiety may be large enough to outweigh the positive benefits of testing and individuals may prefer not to test.

For small values of b, individuals with $p < p^*$ will always want to test. The model requires values of $b > \Omega$in order to generate any testing avoidance over this range. Given that $b > \Omega$, testing value will be increasing with p up to p^*, which could produce the result that testing is increasing in risk; to have testing value be highest somewhere above 0.5 it must be the case that $b > 2\Omega$.

For value of $p > p^*$, the value of testing is decreasing in p. If $\Phi > b$ then the actor will want to test for any value of $p > p^*$. If $b > \Phi$ they may test only for values of p closer to p^*.

It is worth noting that, while this model does include the assumption that people prefer to have a lower p (in the form of the $c(1-p)$ term), this does not enter the decision-making about testing. Because this is linear in p, from the standpoint of someone deciding whether or not to test, individuals experience the same value for this (in expectation) whether or not they choose testing.

Confirmatory testing fits easily in this model. Individuals avoid testing here not due to testing costs but due to preferences for information avoidance. Once those concerns are removed (as they would be once the individual was sure of their status) they would be willing to test if Ψ(the value of confirmation) is greater than the cost of testing. This relationship has no bearing on the desire to avoid testing in the anticipation period.

Summary

Under some conditions, this model can fit the data. However, it shares two problems with the neoclassical model. First, it does not allow for overly-optimistic beliefs. To the extent this is a fact we would like to fit, the model fails there. In addition, explaining the skewed actions and testing increasing in risk requires some asymmetry in the loss to the wrong action in the two states (just as in the neoclassical model). As we discuss in Section 5, there is not a lot of empirical support for that claim. The latter result on testing and risk also requires a particular set of parameter values for b relative to Ω, an assumption which is plausible but difficult to test. Where this model clearly preforms better than the neoclassical model is on the testing costs and testing confirmation: it is able to explain limited testing without resorting to the extremely high testing costs and it can accommodate the confirmatory testing easily.