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## Assessing The Impact Of Predictive Testing Protocols On Provider Burden For Huntington's Disease

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**ASSESSING THE IMPACT OF PREDICTIVE TESTING  
PROTOCOLS ON PROVIDER BURDEN  
FOR HUNTINGTON'S DISEASE**

by

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and  
Abigail Patenaude

*Submitted in partial completion of the Master of Science Degree at Sarah Lawrence  
College, May 2019*

## **Abstract**

Predictive testing for HD creates a potentially significant psychological burden on patients and their families, and in turn, the emotional strain of working with at-risk individuals may take a toll on providers. Protocols have been established by the HDSA that emphasize the importance of genetic counseling and support for individuals undergoing testing. Recently, the HDSA's guidelines have switched from recommending a 3-visit protocol to a 2-visit protocol. Little is known about the effect of this change on genetic service providers, their practice, their perception of the patient experience, or the impact of their choice of protocol in terms of the burden on providers. This study examined the impact of such testing from the provider's perspective. Providers involved in the HD predictive testing process at 43 Centers of Excellence across the country were invited to participate in a survey examining protocol use and emotional burden. Of the 54 respondents, 37% reported changing their protocol in light of the HDSA's recommendations while 33% reported always having used the 2-visit protocol. Almost half (48%, n=26/54) of providers reported having feelings of emotional burden related to their work with predictive testing; the most frequent causes being "emotional overextension" and "exhaustion." There was no difference in the emotional burden reported by providers who made the protocol switch and providers who did not. This study provides evidence that a 2-visit protocol for HD predictive testing has been widely adopted by practicing providers, and that many providers switched in response to the HDSA's update to their guidelines. Results also suggest that there is a high emotional burden related to this type of work, regardless of the type of protocol used.

*Key terms: Huntington's disease, predictive testing, provider burden*

## Introduction

Genetic testing for late-onset disorders such as Huntington's disease (HD) has been available for more than two decades (Paneque et al, 2012). Predictive genetic testing, described as a testing option for healthy people at risk of developing HD (Craufurd et al, 2014), has the potential to cause emotional anxiety for these individuals. Because of the psychological sequelae associated with learning that one is likely to develop HD, genetic counseling is regarded as a crucial component of the predictive testing process. Studies have shown that the experience of providing predictive testing itself can be stressful for providers, resulting in, most commonly, compassion stress and fatigue (Bernhardt et al, 2009). While protocols have been established and revised over time by the Huntington's Disease Society of America (HDSA) in order to provide the best outcomes for patients, there have not been any studies to determine which protocol is least taxing for medical providers.

HD is a hereditary neurodegenerative disorder that affects 1/10,000 individuals in the United States. It is caused by a trinucleotide repeat expansion in the *HTT* gene (HDCRG, 1993). This expansion results in a long and unstable fragment with potential for genetic anticipation, especially when paternally inherited. Symptom onset is typically observed in the fourth or fifth decade of life (Chandler et al, 1960), however, onset and progression are variable. In the later stages of the disease, affected individuals experience a decline in cognitive ability, develop difficulty speaking and swallowing, are usually bedridden, and are totally dependent on others for all of their needs. These symptoms can persist for 10 to 25 years until death occurs (Sorensen & Fenger, 1992), typically the result of complications such as malnutrition or aspiration pneumonia. There is no approved cure or treatment for HD at this time, and consequently, there is no medical benefit to undergoing predictive testing.

Many experts have argued that the decision to undergo predictive testing is complex, emotionally challenging, and likely to cause anxiety among participants and their family

members, who may struggle to adapt after receiving their results (Dufresne et al, 2010; Tibben, 2007; Crozier, 2015). Other concerns associated with testing include the potential for genetic discrimination, implications for family members, and potential psychological dysfunction, all of which may create a substantial burden for patients. Conflicting evidence has been presented on these psychological effects and while recent studies have reported that catastrophic reactions to test results are rare (Crozier, 2015; Paulsen et al, 2005; Nance, 2016), other studies have shown higher suicidal tendencies among the at-risk population (Robins Wahlin et al, 2000). For these reasons, although little is known about how genetic counseling impacts preparation for and living with the results of genetic testing (Paneque, 2012), pre-test counseling has typically been a required part of the protocol to allow patients adequate time and information to make what is potentially a significant and irreversible decision (Craufurd et al, 2014).

The HDSA has endorsed guidelines for predictive genetic testing that HD centers are encouraged to follow. These guidelines specifically emphasize recommendations for counseling. The initial guidelines, introduced by the HDSA in 1989 and revised again in 2003, required that the HD predictive testing process be spread out over three visits (HDSA, 2003). The first two visits were to consist of a neurological evaluation, genetic counseling session, and a psychological assessment. Only after the neurologist, genetic counselor, and psychologist agreed that the patient was equipped to handle information about their gene status would the patient be recommended to move forward with testing. Results would be disclosed on the third visit. Updated guidelines produced in 2016 reduce the recommended number of visits from three to two, only requiring one visit before test results would be disclosed (HDSA, 2016).

Genetic and psychological support services have become standard of care in the management of HD families. There are currently 43 HD Centers of Excellence across the nation that follow guidelines written by the HDSA to provide care programs for families choosing to undergo testing. Eligibility and classification criteria for HD Centers of Excellence include the clinic's ability to "provide comprehensive diagnostic and therapeutic services" with onsite

personnel responsible for services in neurology, psychiatry, psychology, genetic counseling and testing, social services, physical therapy, occupational therapy, speech-language services, nutritional/dietary services, and direct participation in HD clinical trials (HDSA, 2018). Guidelines strongly encourage physicians to refer appropriate applicants to one of these designated predictive testing centers (HDSA, 2016).

Because of the range of services required by an HD Center of Excellence, a variety of different providers are often involved in the predictive testing process: neurologists, psychiatrists, genetic counselors, social workers, and nurse practitioners. HDSA guidelines emphasize the importance of extensive genetic counseling for individuals considering testing. While many studies exist that examine the effects of predictive genetic testing on patients (Almqvist et al, 1999; Crozier 2015; Erwin et al, 2010; Nance, 2016; Paneque, 2012; Paulsen et al, 2005; Robins Wahlin et al, 2000; Paulsen et al, 2013), little is known about the degree of burden placed on genetics professionals as a result of working with patients involved in predictive testing, particularly for HD.

Literature exploring burnout among physicians shows that burnout is a common serious condition with devastating personal and professional consequences (Romani & Ashkar, 2014; Everall & Paulson, 2004). Shanafelt et al, 2012 reported 45.8% of physicians in the United States having at least one symptom of burnout. Another study by the European General Practice Research Network Burnout Study Group, which included 1,400 family physicians in 12 European countries, revealed that 43% of respondents scored high for emotional exhaustion, 35% for depersonalization, and 32% for low personal accomplishment, while 12% of participants suffered from burnout in all three dimensions (Soler et al, 2008).

There is currently one study examining distress and burnout among genetics professionals, which found that genetic service providers experience various types of distress that may be risk factors for burnout and professional dissatisfaction, citing the most prevalent examples as compassion stress, the burden of professional responsibility, negative patient

regard, inauthenticity, and concerns about informational bias (Bernhardt et al, 2009). Pletcher et al, 2002 identified several external factors potentially contributing to burnout: reimbursement issues, lack of institutional support, low-earning potential, and uncertainty about the future of clinical genetics. The aim of our study was to determine internal factors that may impact the burden, as measured by the Maslach Burnout Inventory (Maslach & Jackson, 1981), experienced by genetic service providers involved in HD predictive testing using the 2- or 3-visit testing protocol. No studies currently exist that examine the experiences of genetic counselors and other medical personnel working in HD centers, particularly in light of the recently revised protocol which reduces the number of required visits from three to two.

## **Methods**

### ***Study Design***

We created a survey through SurveyMonkey, composed of demographic, multiple choice, and open-ended questions. Healthcare providers were asked about the protocol for HD predictive testing currently in place at their institution, and changes that occurred in response to the change in HDSA guidelines in 2016. One set of multiple-choice questions consisted of “agree” or “disagree” options and others employed a 3-point Likert scale with the options of “increase,” “decrease,” or “no change.” These questions were intended to measure provider burden related to the HD protocol used by each provider at their respective institution subsequent to the 2016 protocol change. Study participants were able to provide more detailed opinions of each protocol in open ended questions. Provider burden was measured by a modified form of the Maslach Burnout Inventory-Human Services Survey for Medical Personnel (MBI-HSS (MP)), which addresses three issues: emotional exhaustion, depersonalization, and personal accomplishment. Each participant was asked to identify whether or not they felt an emotional burden, defined as “the feeling of being emotionally stressed, sometimes in the form of feeling the pain of others or feeling inner guilt,” as a result of their work by indicating if they experienced

any of the following: emotional overextension, exhaustion, impersonal feelings, depersonalization of work, incompetence at work, and feelings of lack of achievement. A complete copy of the participant questionnaire is provided in Appendix A.

### ***Study Participants***

A sample of 66 participants were recruited from the 43 Centers of Excellence and six HDSA partner centers in the United States that offer predictive testing for HD. All participants in this study were volunteers. This study was approved by the Sarah Lawrence College Institutional Review Board on October 11<sup>th</sup>, 2019 and was endorsed by the HDSA. Service providers were eligible to participate if they currently provide predictive testing for HD as part of their practice. Potential study participants were recruited through the HD Centers of Excellence and partner centers by an email invitation detailing study information and providing a link to the questionnaire distributed through SurveyMonkey. An informed consent form was presented prior to the start of the questionnaire which contained information about the purpose of the study, benefits and risks of participating, the voluntary nature of participation, and contact information for the researchers. Participants were free to skip questions and could withdraw from the survey at any point.

### ***Inclusion and Exclusion Criteria***

We received 66 survey responses. In order for a survey participant to be included in the study, they must be directly involved in HD predictive testing and have completed the questionnaire. Of the 66 responses, 54 were included in the data analysis. Data from one survey participant who reported no direct involvement in predictive testing for HD was excluded. Data from 11 survey participants who did not complete the survey were also excluded.

## ***Data Analysis Procedures***

The responses to each open-ended question (questions 39-40) were reviewed and organized into themes agreed upon by both investigators. Common themes were recognized in responses and investigators tallied each time a theme recurred. Responses from questions 39 and 40 were each coded as “comments of support” or “comments of concern” or, in some cases, both. Comments of support were further divided and coded into seven themes for question 39 and five themes for question 40. Comments of concern were further divided and coded into six themes for question 39 and four themes for question 40.

## **Results**

### ***Demographics***

Study participants were predominantly female (87%, n=47/54). Approximately half of participants were genetic counselors (48%, n=26/54) and the rest was comprised principally of social workers (22%, n=12/54) and neurologists (17%, n=9/54). Most of these providers (87%, n=47/54) reported seeing 1-5 patients per month for predictive testing for HD. Geographically, 37% (n=20/54) of participants are currently practicing on the East Coast, 31% (n=17/54) in the Midwest, 17% (n=9/54) in the South, and 15% (n=8) on the West Coast. Participants were an experienced group: 57% (n=31/54) were age 41 or older, and most have been practicing as a healthcare provider for greater than 10 years (61%, n=33/54). A majority (54%, n=29/54) have been involved with HD predictive testing for 5 years or more. Complete study demographics can be found in Table 1.

**Table 1. Demographics**

	<b>n</b>	<b>%</b>
<b>Gender</b>		
Female	47	87%
Male	6	11%
<b>Age</b>		
21-25	1	2%
26-30	3	6%
31-35	11	20%
36-40	8	15%
41+	31	57%
<b>Region</b>		
East Coast	20	37%
Midwest	17	31%
South	9	17%
West Coast	8	15%
<b>Role</b>		
Genetic Counselor	26	48%
Neurologist	9	17%
Nurse Practitioner	2	4%
Psychiatrist	2	4%
Other	3	6%
<b>Years of Practice</b>		
< 5 years	7	13%
5-10 years	14	26%
> 10 years	33	61%
<b>Years of Experience with HD Predictive Testing</b>		
< 5 years	25	46%
5-10 years	8	15%
> 10 years	21	39%

***Are Providers Making the Switch?***

Asked about practice at their institution prior to 2016, 54% (n=29/54) of respondents reported that they had been following the HDSA-recommended 3-visit protocol whereas 33% (n=18/54) of respondents reported following a 2-visit protocol. The remainder of respondents (13%, n=7/54) were unsure of the protocol used by their respective testing center or followed alternative protocols, including one 4-visit and one 5-visit protocol. After the guidelines changed in 2016 to a recommended 2-visit protocol, 37% (n=20/54) of respondents reported making the switch. No respondents who were using a 2-visit protocol prior to 2016 reported any change in practice.

A majority of respondents (63%, n=34/54) reported that their center's protocol remained unchanged in light of the HDSA's updated recommendations. A significant portion of providers who reported no change in practice were already following their own 2-visit protocol (44%, n=15/34). The remaining 29% (n=10/34) continued to follow the 3-visit protocol, and 24% (n=8/34) are not following either of the two recommended protocols.

### ***Workload***

Of the 20 respondents who reported that their center changed their protocol in light of the HDSA's updated recommendations (37%, n=20/54), more than half (65%, n=13/20) reported that since the change in protocol, the number of individuals choosing to undergo predictive testing for HD has not changed, while 35% (n=7/20) of this group reported that this number has increased. Of participants who switched, 60% (n=12/20) reported that the amount of interaction they have with patients did not change, whereas 20% (n=4/20) reported an increase and 20% (n=4/20) reported a decrease. Additionally, the change in protocol did not change the amount of time providers spent interacting with other providers according to 80% (n=16/20) of respondents who switched. Most participants who reported switching to the 2-visit protocol after 2016 indicated that their institution continued to use the new 2-visit protocol at the time of this study (85%, n=17/20).

### ***Emotional Burden***

A significant portion of providers reported an emotional burden related to their work with predictive testing for HD (48%, n=26/54). The most frequent types of emotional burden cited by participants were "emotional overextension" (62%, n=16/26) and "exhaustion" (27%, n=7/26). A complete list of the types of emotional burden examined is listed in Table 2.

There was no difference in the emotional burden reported by providers who made the protocol switch and providers who did not. Furthermore, there was no difference in the type of emotional burden cited between those who have continuously followed the 2-visit protocol or the 3-visit protocol. However, those who switched to a 2-visit protocol were more likely to cite “feelings of lack of achievement” (12%, n=3/26) than those who did not. Of those who reported making the protocol switch after 2016, most (83%, n=10/12) reported that there was no change in their feelings of emotional burden. One provider (8%, n=1/12) reported increased emotional burden after the switch in protocols. None of the respondents reported that the switch in protocols decreased their feelings of emotional burden.

**Table 2. Measure of emotional burden in HD predictive testing providers.**

<b>Feeling of Emotional Burden</b>	<b># of Respondents</b>
Emotional overextension	62% (n=16/26)
Exhaustion	27% (n=7/26)
Feelings of lack of achievement	12% (n=3/26)
Impersonal feelings	8% (n=2/26)
Depersonalization of work	8% (n=2/26)
Incompetence at work	0% (n=0/26)

### ***Provider Opinions on Protocols***

When asked whether or not they feel it is important to follow a protocol, 96% of respondents (n=52/54) said yes, and when asked whether or not it should be the same protocol for each patient, 41% (n=22/54) said no. Participants were also asked to comment on which protocol they believed patients prefer and 72% of respondents (n=39/54) reported that patients prefer the 2-visit protocol. Overall, 54% of respondents (n=29/54) reported a personal preference for the 2-visit protocol.

When asked to share any additional thoughts or concerns about the 2-visit protocol, comments were coded by investigators as “comments of support” or “comments of concern” or, in some cases, both. Of the 42 total comments regarding this protocol, 48% (n=20/42) were comments of support and 74% (n=31/42) were comments of concern. The most frequently noted comments of support were coded as “flexibility to add sessions as needed” (25%, n=5/20), “improves patient autonomy” (20%, n=4/20), and “accommodates long-distance patients” (20%, n=4/20). Of the comments of concern, 39% (n=12/31) were coded as “insufficient time to reconsider decision,” 19% (n=6/31) were coded as “lack of provider reimbursement for required telephone counseling,” and another 19% (n=6/31) were coded as “additional workload.” A complete list of coded comments regarding the 2-visit protocol can be found in Tables 3A and 3B.

**Table 3A. Comments of support for the 2-visit protocol.**

<b>Comments of Support</b>	<b>Number of Respondents</b>
Flexibility to add sessions as needed	25% (n=5/20)
Improves patient autonomy	20% (n=4/20)
Accommodates long distance patients	20% (n=4/20)
Less “push back” from patients	10% (n=2/20)
Saves patients time and money	10% (n=2/20)
Allows for collaboration with other providers	5% (n=1/20)
Stops patients from seeking testing through “faster” source	5% (n=1/20)

**Table 3B. Comments of concern for the 2-visit protocol.**

<b>Comments of Concern</b>	<b>Number of Respondents</b>
Insufficient time to reconsider decision	39% (n=12/31)
Lack of provider reimbursement for required telephone counseling	19% (n=6/31)
Additional workload	19% (n=6/31)
Insufficient time to make insurance considerations	10% (n=3/31)
Less face-to-face counseling	3% (n=1/31)
Lack of autonomy	3% (n=1/31)

When asked to share any additional thoughts or concerns about the 3-visit protocol, comments were again coded by investigators as “comments of support” or “comments of concern” or, in some cases, both. Of the 36 total comments regarding this protocol, 28% (n=10/36) were comments of support and 75% (n=27/36) were comments of concern. Of the reported comments of support, 50% (n=5/10) were coded as “sufficient time to establish rapport.” Of the reported comments of concern, 52% (n=14/27) were coded as “too burdensome for everyone involved” and 37% (n=10/27) were coded as “unnecessary number of visits.” A complete list of coded comments regarding the 3-visit protocol can be found in Tables 4A and 4B.

**Table 4A. Comments of support for the 3-visit protocol.**

<b>Comments of Support</b>	<b>Number of Respondents</b>
Sufficient time to establish rapport	50% (n=5/10)
Patients appreciate thorough process	20% (n=2/10)
Sufficient time to make insurance considerations	10% (n=1/10)
Less telephone counseling required	10% (n=1/10)
Decades of experience prove protocol's success	10% (n=1/10)

**Table 4B. Comments of concern for the 3-visit protocol.**

<b>Comments of Concern</b>	<b>Number of Respondents</b>
Too burdensome for everyone involved	52% (n=14/27)
Unnecessary number of visits	37% (n=10/27)
Patients may seek “faster” sources of testing	7% (n=2/27)
Lack of patient autonomy	4% (n=1/27)

## **Discussion**

Our study provides considerable evidence that the 2-visit protocol for HD predictive testing has been widely adopted by practicing providers. One third of the participants in this study had already been following a 2-visit protocol prior to 2016 despite the fact that HDSA at that time recommended three visits, and more than half of those who were not previously using a 2-visit protocol made the switch after 2016 when the HDSA guidelines were amended. This means that 70% of participating providers are currently using the 2-visit protocol.

Although a majority of providers use the 2-visit protocol, some concerns about this protocol were reported in the open-ended responses to our survey. A majority of participants believed the 2-visit was most preferred by patients and over half reported a preference for the 2-visit protocol overall. Still, when asked to make any additional comments about the 2-visit protocol, a majority of these comments were concerns. Of all the comments for this protocol, one of the concerns expressed most frequently (39%) was that patients would not have enough time to reconsider their decision to undergo testing before receiving results. Another frequently cited concern (19%) was related to lack of provider reimbursement for the extra telephone counseling that would be required due to the omission of a third visit. Some commenters (19%) also expressed concern about additional burden that would be placed on providers related to the 2-visit protocol. Notably, these concerns came primarily from commenters who have not

made the switch to the 2-visit protocol. Commenters who reported having not made the switch to the 2-visit protocol (33%, n=12/36) were three times as likely to report comments of concern than commenters who report currently using the 2-visit protocol (11%, n=4/36). Data from our study shows that the majority of providers who made the switch in protocols are not experiencing a change in workload, as suggested by the following statistics: 65% of providers who changed protocols reported no change in or decreased number of individuals choosing to undergo predictive testing, 60% report no change in or decreased interaction with patients undergoing testing, and 80% report no change in or decreased amount of time spent interacting with other providers. These numbers suggest that hypothetical concerns about increased provider workload may not be the experience of those who have made the switch.

Respondents also offered several reasons to support the 2-visit protocol. The majority of these comments were centered around improving the overall testing experience for the patient. Commenters reported that the 2-visit protocol allows for greater patient autonomy by allowing an individual to proceed with predictive testing after the initial in-person visit if they choose to do so. Many commenters also expressed support for the flexibility of this protocol, citing the ability to add additional counseling sessions if necessary. One commenter stated, "I look at the protocol as a minimal standard, not a limit as to what can be done." Additionally, commenters reported support for this protocol for its increased accessibility to patients traveling long distances for this testing. This makes sense given there are relatively few HD Centers of Excellence in comparison with the at-risk population and traveling to one of these centers for several visits may not be feasible for some individuals. Notably, these supportive comments came primarily from providers who are currently using the 2-visit protocol. Commenters who reported use of the 2-visit protocol (56%, n=20/36) were about seven times as likely to report comments of support than commenters who reported not having made the switch to the 2-visit protocol (8%, n=3/36). This further supports our observation that providers overall are

embracing the 2-visit protocol and that the concerns for this protocol are coming from providers who have not had firsthand experience with the switch.

In regard to the 3-visit protocol, commenters noted much more concern (75%) than support (28%). While one provider argued that decades of experience prove the success of the 3-visit protocol, over half of commenters remarked that the 3-visit protocol is too burdensome for everyone involved, and 37% of commenters agreed that three visits is simply unnecessary.

The ratio of negative to positive comments was higher for the 3-visit protocol (2.7:1) but both protocols drew more negative than positive comments, highlighting the difficulty in a one-size-fits-all solution. While 96% of providers agree that following a protocol is important, a significant portion (41%) do not feel the same protocol should be followed for each patient. Several providers remarked in the free response section that protocols should be patient-specific and done on a case by case basis. It was suggested by one provider that rather than implementing a mandatory pre-test protocol, providers should instead implement a mandatory post-test assessment of need for follow-up care. This post-test protocol was theorized by the provider as being more beneficial to the well-being of the individual. A few providers also said that “the protocols are good guidelines but each clinic should be able to make variations at their own discretion.” Overall, the responses suggest that while the protocols are good starting points, providers should have the flexibility to adapt to each patient’s specific needs in the predictive testing process.

Prior to this study, we hypothesized that the change in protocol would have a negative impact on provider burden by increasing workload and psychological distress. However, no evidence was gathered to suggest that the 2-visit protocol has caused an increase in provider workload. In regard to emotional burden, our data shows that there is no difference in the emotional burden reported by providers who made the protocol switch and providers who did not. Results from this study do however suggest high emotional burden for this type of work, regardless of the protocol. 48% of providers reported feeling emotionally burdened by their

involvement in the predictive testing process. Of those who reported emotional burden, the most commonly cited evidence of burnout was emotional overextension (62%) and exhaustion (27%). Further studies are needed to assess emotional burden in more detail.

Interestingly, a large portion (61%) of the providers who completed the survey reported having been practicing for over 10 years, but 46% have less than 5 years of experience with the predictive testing for HD process. We theorize two possible explanations for the lack of experienced providers. First, the amount of emotional burden endured by genetic service providers during this process is so great that there is a high rate of burnout. This may lead to a high level of employee turnover. Secondly, the lack of experience may be due to an increase in demand of individuals looking to pursue predictive testing. In this case, providers are becoming involved to help mitigate the surge in demand. Another possibility is that this line of work is demanding and does not tend to be done by inexperienced counselors. Further studies would be necessary to explore this topic.

Our study had several limitations. First, our sample size was small (n=54), as it was tied to the limited number of HDSA approved HD Centers of Excellence. All 43 designated centers as well as six recognized partner centers received invitations to participate, but in order to preserve as much anonymity as possible, providers did not report which center they were from. Although we have a fairly even distribution across regions, we are unable to determine how many centers are represented. In addition, not all of the participants responded to the entire survey. These responses were eliminated from the final data set, reducing the total number of responses. Second, although we asked providers who did not make the switch in protocols questions about how the switch would have affected their overall burden, these responses were speculative and have limited value. Similarly, we were not able to directly assess patients' experience with decisional regret and responses from providers may not accurately reflect the opinions of patients.

Ideal future research into the patient experience should involve a prospective longitudinal study with two groups of study participants: patients who go through testing using a 3-visit protocol and patients who go through predictive testing using the 2-visit protocol. This would allow researchers to assess directly the impact on the individual, both positive and negative, of each protocol.

## Conclusion

This study demonstrates that a 2-visit protocol for HD predictive testing has been widely adopted following the HDSA's 2016 update to their guidelines. While respondents had concerns about this protocol, our study did not show that making the switch had any impact, positive or negative, on the burden of participating providers related to workload or emotional burden. However, our results do suggest a high emotional burden related to this type of work, regardless of the type of protocol, a topic that has not been investigated previously. We propose that future research include longitudinal studies of the patient's experience of this process.

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## APPENDIX

### Appendix A. Complete copy of the participant questionnaire.

Q1. *What best describes your gender?*

*Male*

*Female*

*Choose not to say*

Q2. *What is your age?*

*21-25*

*26-30*

*31-35*

*36-40*

*41+*

Q3. *Which geographical region best describes your primary work location?*

*East Coast*

*West Coast*

*Midwest*

*South*

Q4. *What best describes your role as a healthcare provider?*

*Genetic Counselor*

*Neurologist*

*Psychiatrist*

*Social Worker*

*Nurse Practitioner*

*Other (please specify)*

Q5. *How many years have you practiced as a healthcare provider?*

*Less than 5 years*

*5-10 years*

*Greater than 10 years*

Q6. *Do you currently work, or have you in the past worked, with patients participating in predictive genetic testing for HD?*

*Yes*

*No*

Q7. *How many years of experience do you have working with predictive genetic testing for HD?*

*Less than 5 years*

*5-10 years*

*Greater than 10 years*

Q8. *On average, how many patients does your clinic currently see for predictive genetic testing for HD in one month?*

Q9. *Select all of the following healthcare providers that you work with during the predictive testing protocol for HD (include your own role).*

*Genetic counselor*

*Neurologist*

*Nurse practitioner*

*Psychiatrist*

*Social worker*

*Other (please specify)*

Q10. Do you feel your clinic has enough providers available to meet the demand of patients choosing to undergo predictive testing?

- Yes
- No

Q11. Prior to 2016, which model of testing did your clinic follow?

- 2-visit
- 3-visit
- Other (please specify)

Q12. Since 2016, has your clinic changed the protocol for predictive testing in HD?

- Yes
- No

**For those who answered yes:**

Q13. Currently, which model of testing does your clinic follow?

- 2-visit
- 3-visit
- Other (please specify)

Q14. Since your clinic's change in predictive testing protocol, how has the number of individuals choosing to undergo testing been affected?

- Increased
- Decreased
- No change

Q15. Since your clinic's change in predictive testing protocol, how has the amount of interaction you have with other predictive testing providers been affected?

- Increased
- Decreased
- No change

Q16. Since your clinic's change in predictive testing protocol, how has the quality of interaction you have with other predictive testing providers been affected?

- Better
- Worse
- About the same

Q17. Since your clinic's change in predictive testing protocol, how has the amount of interaction you have with individual predictive testing patients been affected?

- Increased
- Decreased
- No change

Q18. Since your clinic's change in predictive testing protocol, how has the quality of interaction you have with individual predictive testing patients been affected?

- Better
- Worse
- About the same

Q19. What changes have you observed in terms of the number of individuals experiencing decisional regret? (Decisional regret is defined as feelings of regret or remorse felt after a health care decision is made)

- Increased
- Decreased
- No change

Q20. Does your role in the predictive genetic testing protocol for HD affect your personal emotional burden?

- Yes
- No

Q21. Select all of the following that you have experienced as a result of working with the predictive testing protocol for HD:

- Emotional overextension
- Exhaustion
- Impersonal feelings
- Depersonalization of work
- Incompetence at work
- Feelings of lack of achievement

Q22. How has the level of your personal emotional burden been affected? (Emotional burden is defined as the feeling of being emotionally stressed, sometimes in the form of feeling the pain of others or feeling inner guilt)

- Increased
- Decreased
- No change

**For those who answered no:**

Q23. Currently, which model of testing does your clinic follow?

- 2-visit
- 3-visit
- Other (please specify)

Q24. In your opinion, how would a change in your clinic's predictive testing protocol affect the number of individuals choosing to undergo testing?

- Increase
- Decrease
- No change

Q25. In your opinion, how would a change in your clinic's predictive testing protocol affect your workload as a provider?

- Increase
- Decrease
- No change

Q26. In your opinion, how would a change in your clinic's predictive testing protocol affect the amount of interaction you have with other predictive testing providers?

- Increase
- Decrease
- No change

Q27. In your opinion, how would a change in your clinic's predictive testing protocol affect the quality of interaction you have with other predictive testing providers?

- Better
- Worse
- About the same

Q28. In your opinion, how would a change in your clinic's predictive testing protocol affect the amount of interaction you have with individual predictive testing patients?

- Increase
- Decrease
- No change

Q29. In your opinion, how would a change in your clinic's predictive testing protocol affect the quality of interaction you have with individual predictive testing patients?

- Better
- Worse
- About the same

Q30. In your opinion, how would a change in your clinic's predictive testing protocol affect the number of individuals who experience decisional regret? (Decisional regret is defined as feelings of regret or remorse felt after a health care decision is made)

Increase

Decrease

No change

Q31. Does your role in the predictive genetic testing protocol for HD affect your personal emotional burden?

Yes

No

Q32. Select all of the following that you have experienced as a result of working with the predictive testing protocol for HD:

Emotional overextension

Exhaustion

Impersonal feelings

Depersonalization of work

Incompetence at work

Feelings of lack of achievement

Q33. In your opinion, how would a change in your clinic's predictive testing protocol affect these feelings for you personally?

Increase

Decrease

No change

Q34. Do you feel it is important to follow a protocol for predictive genetic testing in HD?

Yes

No

Q35. Do you feel it is important to follow the same protocol for predictive genetic testing in HD for each patient?

Yes

No

Q36. In your opinion, which protocol do you believe provides the best patient care?

2-visit

3-visit

Other (please specify)

Q37. In your opinion, which protocol do you believe patients prefer?

2-visit

3-visit

Other (please specify)

Q38. Which protocol do you prefer overall?

2-visit

3-visit

Other (please specify)

Q39. What additional comments/concerns do you have regarding the 2-visit protocol? [Eg. anything you particularly like or disagree with]

Q40. What additional comments/concerns do you have regarding the 3-visit protocol? [Eg. anything you particularly like or disagree with]

Q41. Please use this space for any further comment on predictive genetic testing protocols for HD.