

## Is access to predictive genetic testing for Huntington's disease a problem?



Is access to predictive genetic testing for Huntington's disease a problem? A UBC study says it is.

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*Is access to 'predictive' genetic testing for Huntington's disease a problem? Research from University of British Columbia researchers suggests that it is, at least in Canada. We explore the problem and possible solutions.*

**Predictive testing** for the gene mutation that causes Huntington's disease allows people who know they're at risk to find out if they will develop HD later on. People who want predictive testing usually need to come to a specialist clinic in person, for several counseling appointments. But this and other reasons could be barriers that stop some from pursuing predictive testing altogether. To help understand these barriers and explore ways they could be addressed, researchers at University of British Columbia conducted interviews with 33 people who accessed predictive testing through their Center for Huntington's disease in Vancouver, Canada.

Predictive testing is offered worldwide, typically through a process following international guidelines. These guidelines, for which updated recommendations were recently produced, are designed to make sure that people thinking about getting tested have enough information and time to make whatever decision is right for them - whether they choose to opt for the test or not - and enough support throughout the whole process and beyond. Three to four appointments are recommended before testing, but it's clear that individual needs vary.

The team in Vancouver follows this process, but may adjust it so only one appointment happens in Vancouver. The remainder can involve the individual's local general practitioner, including receiving results.

### Distance and inconvenience

Many of those interviewed said distance was a major barrier for them. Those in rural areas said it was difficult to take a variety of transportation (like an airplane, ferry or bus) to get to Vancouver for appointments.



For people at risk of Huntington's disease, deciding whether or not to have a genetic test is a difficult, and very personal

decision. There is no right or wrong decision.

Some study participants said that the long travel to Vancouver also meant missed work and family opportunities. Some study participants said they couldn't afford long travel for appointments, or couldn't take the time off work. Even though some rural participants were eligible for financial support and assistance in traveling to medical centers, some indicated that this didn't go far enough in covering overall costs.

## **Stressful travel and lack of support**

Some participants, both far from and near to Vancouver, indicated the commute to the testing center was stressful. Sometimes the city rush-hour traffic meant a long commute home, even if the distance was not great. Still others said they felt too far from their family and friends, particularly when making the trip to and from Vancouver to receive their test results.

## **An inflexible and lengthy process?**

Another major barrier study participants identified was the testing process itself. Specifically, many felt it was too rigid and not possible to tailor to an individual's specific circumstances and needs. Others commented they found the process was somewhat 'paternalistic', as if the testing center somehow knew what was best for them.

Some felt there were too many appointments, and could not understand why so many were required. As well, some participants said the testing process took too long. Including a waiting period for the first appointment, the testing process can take several weeks or months to complete (the exact time varies at each testing center). Many described this as difficult.

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## **Receiving results and bringing a support person**

Most interviewed felt the way results are delivered is a very personal preference, and most preferred to receive them in person. Some indicated they would have preferred for their general practitioner to give them their results, while others preferred to hear them from the testing center. Some did not like having to bring a support person to their results appointment. This follows the international guidelines, but some participants thought it was too restrictive and would have preferred to hear their results alone.

## **What are the take-home points of the study?**

- In this Canadian population, there were two major barriers to those accessing predictive testing: distance and inflexibility of the current testing process. Of note, a large geographical distance is not always the cause - sometimes those living in the testing center's city can experience distance barriers.
- Barriers need to be addressed to help those who want to access predictive testing. Otherwise, people who want it may be put off predictive testing - or worse, they could access

testing without proper assessment, genetic counseling and support. Addressing barriers promotes equity in healthcare, particularly in countries with socialized health care delivery. In an ideal world, predictive testing shouldn't be available only to those who can manage travel or taking time off work for their appointments.

- Many people do not understand the predictive testing process. Education about the process, and why it's structured how it is, can help people understand it, which in turn might make it more acceptable.

## Does the study have limitations?

Since they only come from one area and one health system, these results may not apply to all health care regions. Those interviewed may not be representative of the population at-risk for Huntington's disease. Importantly, they had all opted to go through genetic testing. Further studies may be needed to determine why those who decide **not** to test make that decision, and whether these barriers, or others, are part of the reason.



The testing process aims to provide as much information and support as people need to make the decision that's right for them.

## Final thoughts

The recently updated predictive testing guidelines suggested two options to bridge distance if needed: **telehealth** (video-conferencing between two sites) and phone calls. The group in British Columbia is currently undertaking a study to evaluate telehealth for this use.

Those of us who specialize in seeing people for predictive testing for Huntington's disease meet regularly and are constantly evaluating our approach, as our colleagues in other countries do.

We do make adjustments to fit the needs of our population when needed. For example, we use a telephone call in place of some sessions. As well, we have used telehealth in situations where individuals were absolutely unable to travel to us with their support person. So far, this has worked well.

There is no "one size fits all" for every region that offers predictive testing for Huntington's disease, but research studies like this are important to learn about ways the process can be improved, and new approaches to consider.

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