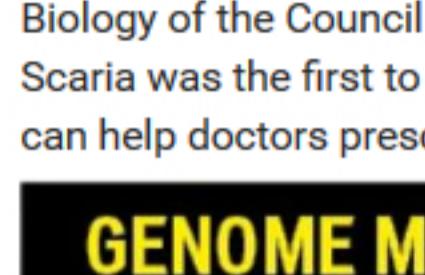


## Can your genes predict your future?

Kanika Sharma, Hindustan Times | Updated: Aug 07, 2016 09:51 IST



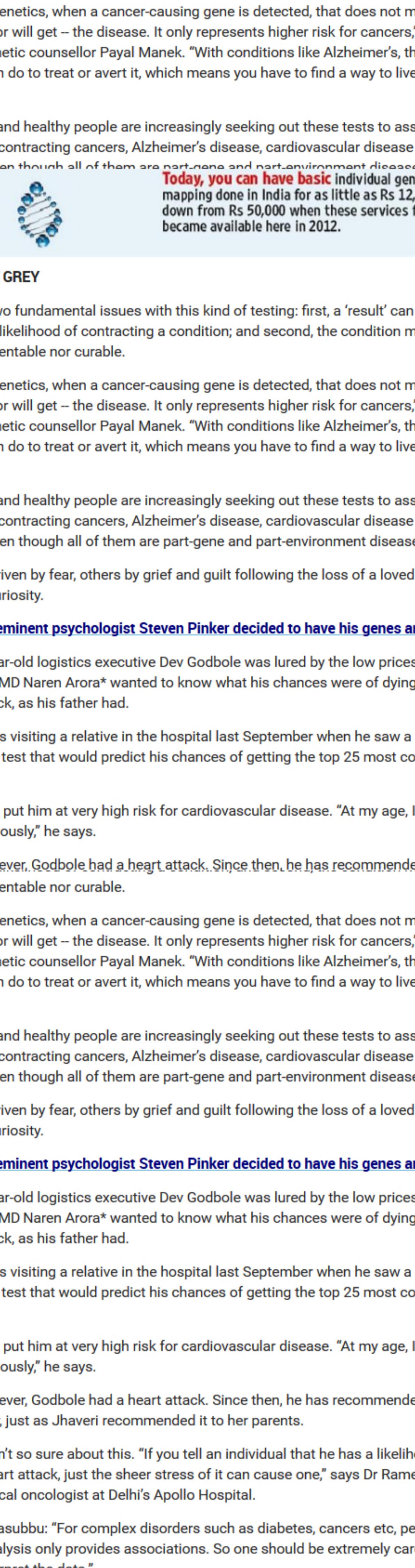
As more Indians get their genes screened, the tests are raising questions. Would you want to know your chances of contracting Alzheimer's? What would you do with the information? (Shutterstock)



How far would you go to cheat death?

That question haunted 25-year-old Pooja Jhaveri. Her relatives on both sides had lived to an average age of 90. Jhaveri was in rude health herself. But what if there was a disease silently lurking inside her?

Thirteen years ago, a 13-year-long project to map the human genome was completed. The data has just begun to be interpreted, but scientists have found credible links between certain genes – like BRCA 1 and 2 – and diseases such as breast cancer.



Mumbai-born finance professional Pooja Jhaveri, at the age of 23, felt driven to get her genes mapped and discover which diseases she is mostly likely to get. (Positive Bioscience)

Jhaveri decided to use that information and, two years ago, the Hong Kong-based finance executive had her genes analysed. The Mumbai girl came home to submit samples of saliva to Positive Bioscience.

A month later, her report said she was at high risk for lung cancer, hypothyroidism and arthritis. Clinical tests for each also revealed she had goitre. "I had my thyroid gland removed, and I was so glad I'd done the test," says Jhaveri.

### Read: Why the Harvard Medical School is sharing personal genome data on the internet

Positive Bioscience is one of four Indian firms (the others are Strand Life Sciences, Mapmyogenome and Medgenome) offering gene-mapping services. Since they started in 2012, the starting price of a mapping test has fallen from Rs 50,000 to as little as Rs 12,500, and these companies have tripled their client base. They now also liaise with hospitals like Apollo, Medanta, Kokilaben Dhirubhai Ambani, Breach Candy and Saifee, to offer their services to patients. While Positive Bioscience and Mapmyogenome can be directly approached, Strand and MedGenome ask for a prescription first.

"Personal genome analysis not only details an individual's genetic makeup but is also a time capsule for their genetic history and provides a window to future generations," says Dr Sridhar Sivasubbu, senior scientist at the CSIR-Institute of Genomics and Integrative Biology of the Council of Scientific and Industrial Research. He, along with Dr Vinod Scarpa was the first to sequence the human genome in India in 2009. "This knowledge can help doctors prescribe preventive measures and precise treatments."

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**SHADES OF GREY**  
There are two fundamental issues with this kind of testing: first, a 'result' can only represent a likelihood of contracting a condition; and second, the condition may be neither preventable nor curable.

"In cancer genetics, when a cancer-causing gene is detected, that does not mean that you have – or will get – the disease. It only represents higher risk for cancers," says Strand's genetic counsellor Payal Manek. "With conditions like Alzheimer's, there is also little you can do to treat or avert it, which means you have to find a way to live with your results."

Still, young and healthy people are increasingly seeking out these tests to assess their chances of contracting cancers, Alzheimer's disease, cardiovascular disease and diabetes, even though all of them are part-gene and part-environment diseases.

**Today, you can have basic** individual gene mapping done in India for as little as Rs 12,500, down from Rs 50,000 when these services first became available here in 2012.

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Some are driven by fear, others by grief and guilt following the loss of a loved one; still others by curiosity.

### Read: Why eminent psychologist Steven Pinker decided to have his genes analysed

While 43-year-old logistics executive Dev Godbole was lured by the low prices, 51-year-old MD Naren Arora\* wanted to know what his chances were of dying young of a heart attack, as his father had.

Godbole was visiting a relative in the hospital last September when he saw a poster for a Rs 12,500 test that would predict his chances of getting the top 25 most common diseases.

"The results put him at very high risk for cardiovascular disease. "At my age, I didn't take that too seriously," he says.

In May, however, Godbole had a heart attack. Since then, he has recommended the test to his father, just as Jhaveri recommended it to her parents.

Doctors aren't so sure about this. "If you tell an individual that he has a likelihood of having a heart attack, just the sheer stress of it can cause one," says Dr Ramesh Sarin, senior surgical oncologist at Delhi's Apollo Hospital.

Adds Dr Sivasubbu: "For complex disorders such as diabetes, cancers etc, personal genome analysis only provides associations. So one should be extremely careful and not overinterpret the data."

**THE RISKS: PUTTING TESTS TO THE TEST**  
Individual gene mapping is the result of a 13-year project to map the human genome, which was completed in 2003. The results of data gathered are still being analysed and understood, so the mapping available today represents only about 1% of the total body of data.

**As such, some doctors** argue that even the likelihood of someone contracting, say, breast cancer, cannot be realistically assessed, since we still don't have all the tools to connect.

**Add to that the fact** that environment plays a key role in your health, and you can see why some medical professionals like Dr Ashwin Dalal, diagnostics head at the centre for DNA fingerprinting and diagnostics of the Indian Statistical Institute, are sceptical of the entire undertaking.

**Genomic analysis**, in isolation, cannot be used to rule out the possibility of a particular condition. When conducted without consulting a doctor and/or genetic counsellor, it can additionally leave the individual and family confused and anxious.

**Since there is no exact formula** for calculating any likelihood of conditions, these results can also vary from company to company, leading to further confusion. Dr Sridhar Sivasubbu, senior scientist at the CSIR-Institute of Genomics and Integrative Biology of the Council of Scientific and Industrial Research.

**An additional issue** in the digital age is loss of privacy. Leaving personal data logged with a private company makes it vulnerable to theft.

**Some medical professionals** say it could also be misused by insurance companies, even employment agencies, and/or traded without donor's knowledge to be biomedical companies in the future.

**Genetic tests** are themselves still evolving and have not been adjusted for the Indian setting, points out Dr Vinod Raina, former head of medical oncology department at the All India Institute of Medical Sciences, Delhi.

As the famed Dr Siddhartha Mukherjee, author of *The Gene: An Intimate History*, put it: "I thought about it quite deeply and I decided that I would not get my genome sequenced, partly because I would not know what to do with the information... it would only kind of give a set of probabilities."

### Read: Dr Siddhartha Mukherjee's opinion on what all gene mapping could do

Where they can pay off, in some cases, is in prodding you to test for certain conditions regularly – something we're supposed to do but usually don't. Arora, for instance, has been having regular tests for testicular cancer, which popped up as a high-risk condition on his test results.

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