

# Gene sequencing helps Hong Kong woman know herself better – but not everyone likes how this knowledge is being used

Direct-to-consumer genetic testing is a fast-growing industry, allowing anyone to have their DNA analysed, but there are concerns about accuracy, false marketing and how genetics companies use the data they collect

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COMMENTS: 



Rachel Cheung  
(/author/rachel-cheung)

If you've ever wondered why you often crave certain foods or have a problem losing weight, the mystery could be unravelled by taking a peek into your genetic make-up. It's not difficult to do, with an increasing number of companies offering simple and easy genetic tests.



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Being curious, I took the "health and wellness" genetic test offered by Advanced Genomic Solutions (AGS), which has offices and a lab in Central. You pay HK\$4,300 (I was offered a free media trial), then simply take a swab of your mouth with a cotton bud, and a week later you get a 30-page report on the findings and a consultation.

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Rather than providing raw genetic data – as is the case with many direct-to-consumer genetic testing companies – AGS prepares a short summary beside each genotype to explain the implication of your results. Some findings confirm things we already know about ourselves – in my case, an inability to metabolise alcohol and a fortunate tendency not to crave sweet things. Other findings could help me to keep in better physical shape. For example, although I have a low risk for obesity, I do have a genetic predisposition of reduced ability to utilise the B vitamin, folate.

### How do dogs' genes affect their behaviour? Your pet could help scientists find out

(http://www.scmp.com/lifestyle/article/2056898/how-do-dogs-genes-affect-their-behaviour-your-pet-could-help-scientists) →

The AGS package comes with a free consultation, with either a nutritionist or a fitness trainer, who help clients understand their test results. I chose the nutritionist, who recommended that I consume more foods that are rich in folate, such as asparagus, kale and broccoli.

“The test can help direct people on what exercise plans or what nutritional plans may be right for them based on their own DNA,” says Lance Bennett, a managing partner of AGS. “It’s not a one-size-fits-all plan. We can really help them tailor how they should be exercising and how they should be eating.”

In addition to the health and wellness test, AGS also offers a personalised medicine test that measures the body’s response to various medications.

These are just a few of the growing variety of commercial genetic tests on the market – including ones on parentage, genealogy and ancestry, and predisposition to diseases – with costs ranging from several hundred to thousands of dollars. Some companies even claim they can predict children’s athletic or language abilities.

The fast-growing direct-to-consumer genetic testing industry has made the process widely accessible to the general public, which can help to empower us. However, the tests have also raised concerns among medical professionals and government bodies, over issues such as accuracy, misleading marketing not supported by research, and the potential for misuse of the sensitive information once collected.

For a start, unlike clinical genetic tests, some of those offered commercially have not been standardised, especially predictive ones that companies claim measure genetic susceptibility to certain diseases.

“One thing that needs to be made clearer to consumers is that most companies are not offering full genome sequencing. They are just looking for SNPs,” says Dr Anelka M. Phillips from Trinity College in Dublin, who specialises in information technology and medical law. SNPs, or single nucleotide polymorphisms, indicate common variations in the DNA sequence.

“There have been studies ... that found people can get contradictory results. Someone could be falsely reassured or unnecessarily worried,” she says.

For research purposes, SNPs can be scrutinised as a measure for genetic similarity. The AGS health and wellness test generates results by examining 58 SNPs and 52 genes. (There are about 10 million SNPs and an estimated 24,000 genes in the human genome.)

According to Phillips, there is a lingering debate in the medical field regarding the accuracy and reliability of SNP analysis, and research that measures SMPs’ association

Yeung processing samples at AGS.

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with certain diseases. The most common analytical approach is comparison of the common SNPs among two groups of people – those with and those without a particular disease – and the association of certain SNPs with that disease. This analysis has limitations, Phillips says, because there could be other factors contributing to the disease that are overlooked.

Tight genes: appetite for high-fat foods may be precoded in obese people's DNA

(<http://www.scmp.com/news/world/article/2025216/tight-genes-appetite-high-fat-foods-may-be-precoded-obese-peoples-dna>) →

"The cost of sequencing technology has dropped rapidly, and the amount of time [needed] to process genetic data has dropped exponentially. But the time it takes to interpret and analyse that data has not dropped anywhere near as much," Phillips says.

"We're generating a lot of data much more cheaply and much more quickly. But we don't necessarily have all the answers in terms of analysis at the moment. Overall, a lot of these services just need to be treated with some level of scepticism."

Scientists study the DNA of thousands of people with depression  
(<http://www.scmp.com/tech/science-research/article/1997939/scientists-study-dna-thousands-people-depression>) →

Another concern is the lack of genetics professionals involved in the process, says Yoyo Chu Wing-yiu, a genetic counsellor at Queen Mary Hospital, and the only such professional in Hong Kong's public welfare system. The industry is largely based in the United States, therefore many companies simply mail the kits to buyers, test the samples sent back in their labs, and then return the results to customers in the form of raw genetic data. Some companies provide genetic counselling, but at an extra cost. This is essential to help customers comprehend their test results and the possible implications for their health.

However, rather than pay extra to undergo counselling – if it is indeed an option – many clients turn to online databases to fish for explanations.

"The worst-case scenario is when clients interpret the results themselves by searching online. For example, if they find that their genetic risk of a certain disease is higher than the general population, they may panic and even take extreme actions, such as undergoing radical treatments to eliminate the risk," says Chu.

Counsellors would be able to explain the genetic mechanisms to clients, assist them in weighing different options during the medical decision making process, adds Chu, stressing the need for pre- and post-test genetic counselling.

The controversy surrounding direct-to-consumer genetic tests doesn't end there. Another aspect of the industry that ought to be raising more eyebrows is what companies are doing with the information they collect.

A kit from AGS.

“Genetic companies are required to notify the individuals concerned upon collection of genetic data from them regarding the purpose for which the data is to be used, and the classes of persons to whom the data may be transferred,” says Hong Kong’s Privacy Commissioner for Personal Data, Stephen Wong Kai-yi.

However, according to Phillips, the companies are usually vague in the stated terms and conditions concerning how they handle physical samples or the genetic information derived from them.

Often the terms and conditions contain a clause that allows the company to unilaterally alter the terms at a later date, normally without notifying the consumer. That could allow companies to significantly alter their privacy policies regarding how they store the data, how they share it, whether they can sell it, how long they store it for,” she says. “They are selling you the services. But the value for them is the data they collected from you.”

This US start-up is selling US\$1 million plates of custom-built DNA to companies like Microsoft (<http://www.scmp.com/tech/start-ups/article/2019636/us-start-selling-us1-million-plates-custom-built-dna-companies>) →

Bennett says such a practice is not in line with AGS’ business model. “We are a personalised medicine company. Our information is not available on the cloud. We don’t have any deals to sell any of our information. We only collect the information, which is provided back to the customers,” he says.

Many companies in the industry, however, are monetising the genetic databases they have compiled from customers’ tests. One industry likely to be interested in the data is insurance. The problem here is that insurance companies could raise premiums if customers are found to have a genetic predisposition to certain diseases.

Rachel Cheung’s results can help her with exercise and diet.

Other corporations eyeing the genetic databases are in the biotech and pharmaceuticals industries, which could become a major source of profit for personal genetics companies.

Leading gene-testing company 23andMe, for example, has signed lucrative deals with biotech company Genetech and drug giant Pfizer. Although 23andMe says the genetic data it has accumulated is used in research to discover new drugs to treat diseases, Phillips remains sceptical.

University of Hong Kong virologist receives HK\$2m research award to study flu virus mutations (<http://www.scmp.com/news/hong-kong/health-environment/article/2054227/university-hong-kong-virologist-receives-hk2m>) →

“When you are a for-profit company that sells tests and uses the samples for ongoing research, and then enters lucrative partnerships and buys up other companies ... I don’t think the argument for altruism is that strong,” Phillips says.

“Some of these [genetic tests] can be really beneficial, but it needs to be done in a responsible way and there needs to be more transparency.”

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