

Illustration by Catherine Tai

China's gene giant harvests data from millions of women

A prenatal test used worldwide sends gene data of pregnant women to the company that developed it with China's military. The U.S. sees a security risk.

By [KIRSTY NEEDHAM](#) and [CLARE BALDWIN](#) | Filed July 7, 2021, noon GMT

A Chinese gene company selling prenatal tests around the world developed them in collaboration with the country's military and is using them to collect genetic data from millions of women for sweeping research on the traits of populations, a Reuters review of scientific papers and company statements found.

U.S. government advisors warned in March that a vast bank of genomic data that the company, BGI Group, is amassing and analyzing with artificial intelligence could give China a path to economic and military advantage. As science pinpoints new links between genes and human traits, access to the biggest, most diverse set of human genomes is a strategic edge. The technology could propel China to dominate global pharmaceuticals, and also potentially lead to genetically enhanced soldiers, or engineered pathogens to target the U.S. population or food supply, the advisors said.

Reuters has found that BGI's prenatal test, one of the most popular in the world, is a source of genetic data for the company, which has worked with the Chinese military to improve "population quality" and on genetic research to combat hearing loss and altitude sickness in soldiers.

BGI says it stores and re-analyzes left-over blood samples and genetic data from the prenatal tests, sold in at least 52 countries to detect abnormalities such as Down syndrome in the fetus. The tests – branded NIFTY for "Non-Invasive Fetal Trisomy" – also capture genetic information about the mother, as well as personal details such as her country, height and weight, but not her name, BGI computer code viewed by Reuters shows.

So far, more than 8 million women have taken BGI's prenatal tests globally. BGI has not said how many of the women took the test abroad, and said it only stores location data on women in mainland China.



A BGI Group building in Beijing. REUTERS/Carlos Garcia Rawlins

The tests are a private procedure for the women who take them, a component in their routine prenatal care. But the studies show that they yield increasingly potent information for research.

One BGI study, for instance, used a military supercomputer to re-analyze NIFTY data and map the prevalence of viruses in Chinese women, look for indicators of mental illness in them, and single out Tibetan and Uyghur minorities to find links between their genes and their characteristics.

The scale of BGI's accumulation of prenatal data, and its collaboration with the military in prenatal and neonatal research, have not been previously reported. The company has published at least a dozen joint studies on the tests with the People's Liberation Army (PLA) since 2010, trialling and improving the tests or analyzing the data they provided, the Reuters review found.

DNA data collected from prenatal tests on women outside China has also been stored in China’s government-funded gene database, one of the world’s largest, the company confirmed. BGI, in which the Shenzhen city government and Beijing’s largest state investment vehicle [took stakes](#) in 2014, runs that gene bank.

Reuters found no evidence BGI violated patient privacy agreements or regulations. However, the privacy policy on the NIFTY test’s website says data collected can be shared when it is “directly relevant to national security or national defense security” in China.



Video - NIFTY gene harvest

Beijing made clear in a 2019 regulation that genetic data can be a national security matter, and since 2015 it has restricted foreign researchers from accessing gene data on Chinese people. In contrast, the United States and Britain give foreign researchers access to genetic data, as part of open science policies.

BGI said in a statement it “has never been asked to provide – nor provided – data from its NIFTY tests to Chinese authorities for national security or national defense security purposes.”

Other companies selling such prenatal tests also re-use data for research. But none operate on the scale of BGI, scientists and ethicists say, or have BGI’s links to a government or its track record with a national military.

News BGI developed the prenatal tests with the PLA comes as international scrutiny is increasing over China’s use of civilian technology for military modernization. NATO has warned China’s assertive behavior is a systemic challenge, and Beijing has drawn sanctions for alleged human rights violations in Xinjiang and stepped up a national security crackdown in Hong Kong.

The findings offer new insight into how BGI is using vast computing power to unlock genomic secrets. Previously, Reuters revealed how the company rapidly expanded its gene-sequencing labs globally and gained a role in other nations’ health systems, and how it worked with China’s military on research ranging from mass testing for respiratory pathogens to brain science.

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The Reuters examination also sheds new light on concerns expressed by a U.S. expert panel, the U.S. National Security Commission on Artificial Intelligence (NSCAI), led by former Google chief executive Eric Schmidt. The panel said in March that the United States should recognize China’s strides towards global leadership in biotechnology and AI as a new kind of national security threat, and boost funding for its own research to counter China’s state-driven effort.

China’s Ministry of Foreign Affairs said the reporting in this article reflected “groundless accusations and smears” of U.S. agencies. The PLA did not respond. China has released new privacy and data security laws that offer greater protection of personal data, but also allow Chinese national security authorities to access that data.

BGI did not respond to questions on its military collaboration or the national security threats that the United States says its research poses. “At no stage throughout the testing or research process does BGI have access to any identifiable personal data or the ability to match that data with personal records,” the company said. Signed consent is obtained in advance, BGI said, and its data privacy protocols meet strict international standards.

A 2016 Chinese regulation requires samples and genetic sequences from the tests on Chinese women to be kept for at least three years, after which the women can request that the data is deleted. For women overseas, BGI told Reuters it destroys samples and deletes paper records and electronic data after a maximum of five years.

Some of BGI’s research has medical benefits, and BGI has cut the cost of gene sequencing so more universities, companies and hospitals worldwide can access sequencing technology, a key driver in the growing field of genomics. Genetics is the study of individual genes; genomics looks at all of a person's genes, including how they interact with each other and the environment.

“Whilst BGI is a Chinese-based company, we consider ourselves part of the global race towards ending the COVID-19 pandemic and a key international contributor to the advancement of public health outcomes around the world,” the company said, adding it collaborates with a large number of academic and research organizations not just in China, but also the United States, United Kingdom and Europe.

“When you can combine large amounts of genomic data – including mothers and their unborn children – with their medical data and history, it is really powerful.”

Anna Puglisi, former U.S. counterintelligence officer



BGI is one of about half a dozen major providers of the tests, more generally known as non-invasive prenatal tests (NIPT), which women take about 10 weeks into a pregnancy to capture DNA from the placenta in the woman’s bloodstream. Its tests are marketed in at least 13 European Union countries, including Germany, Spain and Denmark, as well as in Britain, Canada, Australia, Thailand, India and Pakistan. They are not sold in the United States.

However, the company is a pivotal player in a genomics race between China and the United States. In its latest annual report, it said it “has been working hard to promote Chinese technology, Chinese experience and Chinese standards to ‘go global.’”

BGI grew as a result of Chinese government policies, said Anna Puglisi, a senior fellow at Georgetown’s Center for Security and Emerging Technology, who worked until 2020 as the U.S. government’s National Counterintelligence Officer for East Asia. “The Chinese state can really compel, in their national security law, companies to work with them,” she said, referring to a 2017 law requiring all Chinese organizations to assist national intelligence efforts.

8.4 million

Number of women who have taken the test

Being able to understand how physical characteristics relate to a gene – and thus figuring out what genes actually do – “really is the cutting edge of genomics,” said Puglisi, who worked on biosecurity issues in the U.S. government.

“When you can combine large amounts of genomic data – including mothers and their unborn children – with their medical data and history, it is really powerful.”

The data offer insight into foreign populations as well as China’s own. Computer instructions that BGI uses to process the NIFTY data show it collects a wide range of information about customers besides their genetic code. This includes the women’s country, medical history and the sex of the fetus, according to the instructions, reviewed by Reuters on a programmers’ forum online.

Reuters reviewed more than 100 documents, from research papers to marketing materials, to determine the scope of data being captured by BGI through its prenatal tests, how it is using this in its research and its military collaboration. Reuters also interviewed more than two dozen scientists and experts in genetic law, including researchers who worked with the company, as well as four women, in Poland, Spain and Thailand, who took the tests.

The women, who signed consent forms stating that their genetic data would be stored and used for research, said they did not realize their genetic information could end up in China. For example, one of them, a 32-year-old office administrator in Poland, signed a BGI form agreeing to have her sample sent to Hong Kong and her genetic data retained, but the form did not say where it would be held, or make clear that BGI’s headquarters and research base are in Shenzhen.

The woman, Emilia, spoke on the condition that only her first name be used. She said that if she had known that, and understood the extent of BGI's secondary research, she would have chosen a different test.

“I want to know what is happening with such sensitive data about me, such as my genome and that of my child,” she said. “This could be a very important matter when choosing a test. For me it would be.”

It was also unclear to the other women where their data was stored.



Office building administrator Emilia, who took the NIFTY test before she had her child, holds a copy of the consent form in Warsaw, Poland. REUTERS/Kuba Stezycki

The U.S. National Counterintelligence and Security Center (NCSC) told Reuters in response to this report that it had “serious concerns” over how genetic data is “collected, transmitted, stored and used” by China’s government and companies.

The NCSC, which issues public warnings on intelligence threats to the United States, [has said](#) China’s collection of healthcare data from America poses serious risks, not only to privacy, but also to U.S. economic and national security.

It urged health institutions to carefully assess risks associated with sharing such data with Chinese companies, and for patients to be told about the “value and sensitivity” of their genetic information – and the risks associated with turning it over. Women taking the NIFTY test

outside China should be concerned about the privacy terms that allow data to be shared with Chinese national security agencies, the center said.

“Non-invasive prenatal testing kits marketed by Chinese biotech firms serve an important medical function, but they can also provide another mechanism for the People’s Republic of China and Chinese biotech companies to collect genetic and genomic data from around the globe,” the center said.



The “Millionome Database”

Shenzhen-based BGI shot to global prominence last year after selling or donating millions of COVID-19 test kits and gene-sequencing labs outside China. U.S. security agencies warned this was part of an effort to collect large amounts of foreign genetic material. BGI said this year it has built 80 COVID-19 labs in 30 countries, which it plans to repurpose for reproductive health screening.

It says its COVID-19 tests do not collect patient DNA.

But its prenatal tests do.

Inside BGI’s offices in mainland China, huge screens update in real time as samples harvested from the tests of pregnant Chinese women are uploaded to the China National GeneBank, according to a scientist who has been inside the Shenzhen facility and photographs published in Chinese state media. The screens also show the location of the women.

BGI told Reuters the project – known as the “Chinese Millionome Database” – does not contain data of women outside mainland China.

However, online records reviewed by Reuters show that the genetic data of at least 500 women who have taken the NIFTY test, including some outside China, are stored in the government-funded China National GeneBank.

This example of a consent form was used in Denmark in 2017. REUTERS/Sarah Slobin

The GeneBank website acknowledges the “NIFTY database” as among its “rich sources of biological data.”

BGI patented its tests in 2011 and began marketing them abroad in 2013. Within three years, more than 2,000 healthcare providers globally were selling them, according to BGI marketing materials. In 2019, the last full year before the COVID-19 pandemic, BGI reported that 42% of its sales of 2.8 billion yuan (\$433 million) came from its reproductive health division. Prenatal tests are the major contributor.

As gene sequencing technology has expanded worldwide, so has the scope of NIPT tests on offer. BGI’s now reveal 84 genetic conditions that affect the pregnancy of women under 40, and sex chromosome disorders that can cause learning delays.

The tests sequence about a tenth of the mother’s genome, said Dennis Lo, the Hong Kong scientist who pioneered the technique independently in 1997.

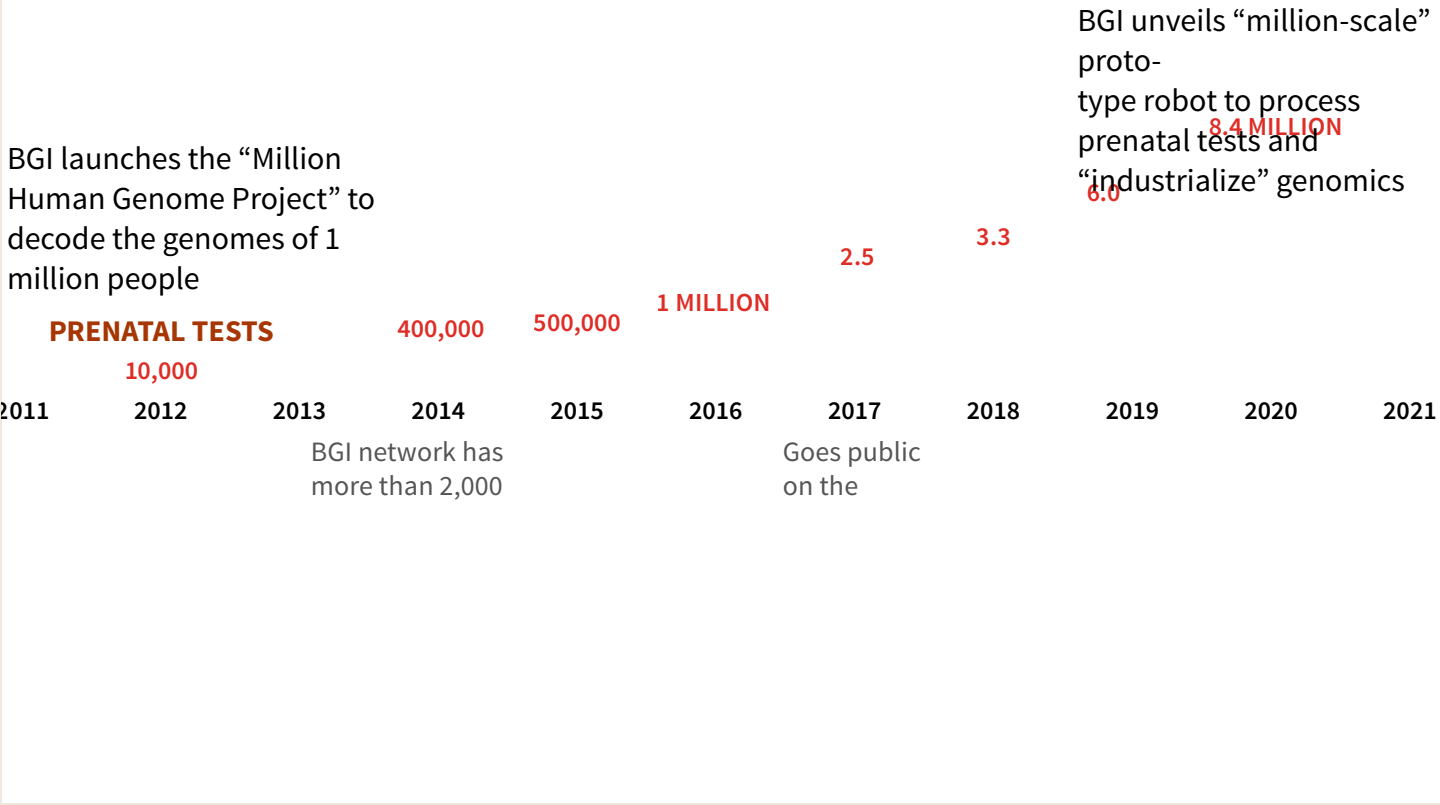
“And so you can imagine if you got a tenth of the genome sequence and you pull it from millions of people – let’s say 10 million every year – I think that would be quite powerful.”

Lo said the technology would unlock patterns of genetic variations in populations around the world. NIPT tests can also show if the mother has any chromosome anomalies, cancer, an autoimmune disease, a recent organ transplant or blood transfusion, Lo said.

In the future, he said, it may be possible to reconstruct what a person looks like from an NIPT test.

Large genomic datasets can be used to design disease therapies, yet they also expose genetic vulnerabilities in a population; an adversary could exploit a susceptibility to disease in a targeted genetic attack, a report to the U.S. Director of National Intelligence by science and medical experts warned last year.

The report also raised privacy concerns, saying it had “been demonstrated that individuals can be identified from even a portion of their DNA.”



As BGI’s testing has grown, so has its secondary research. Two years ago, BGI researchers wrote in a scientific paper that they had re-analyzed 1.93 million NIPT tests processed in BGI labs between 2016 and 2017. They found 542 women with anomalies that could indicate cancer.

Those women, including customers in mainland China, Hong Kong, Slovenia, Spain and Taiwan, were then contacted for research purposes. Reuters found the women’s genetic data in the China National GeneBank, recorded under seven-digit sample identifiers.

The study said 41 of the women were diagnosed with cancer by their physicians, separately from the BGI research, which was [published](#) in Genetics in Medicine.

The study marked a massive mobilization of the genetic information in BGI’s possession. BGI marketing statements show the firm had processed 2.5 million NIPT tests in total by the end of 2017. That meant that during the period of the study, which encompassed nearly 2 million tests, it had re-used most of the NIPT tests it processed.

Last year, BGI announced that it would “industrialize” genomics, and in April, it said a “million-scale” prototype robot, capable of sequencing a million whole genomes a year for population genomics, was now being used to process NIFTY tests.



“Military Medicine Innovation Project”

BGI has worked with Chinese military researchers to study the genomes of fetuses and newborns since at least 2010, when it signed a research cooperation agreement with the People’s Liberation Army General Hospital in Beijing, a hospital document shows.

The hospital is at the forefront of Chinese genetic research on deafness, and its head of obstetrics, Lu Yanping, was developing a prenatal test for deafness and Down syndrome. In April 2011, Lu began a clinical trial of NIFTY with BGI on 3,000 women in the hospital clinic, a published study shows. Neither Lu nor the hospital responded to requests for comment.

In August 2010 BGI started work with another military institution, the Third Military Medical University in Chongqing. Liang Zhiqing, vice chairman of the PLA’s Institute of Obstetrics and Gynecology, and BGI researchers have published at least five joint studies based on data from women who took the test at the university’s prenatal clinic.

Liang’s work was funded by the Chinese government as a “Military Medicine Innovation Project,” and the samples were sequenced in a BGI “joint laboratory” at the university, according to a paper in the European Journal of Medical Genetics. Liang did not respond to a request for comment.

The university and BGI ran conferences on preventing birth defects and “improving population quality,” conference promotion shows. The PLA was closely involved in a foundation to prevent birth defects, led by a key figure in the implementation of China's One Child Policy, from 2011.

A BGI executive was among the experts at its first meeting, which heard that “birth defects not only affect the health and quality of life of children, but also the quality of the country’s population and manpower.” A plan to promote screening for 48 genetic and metabolic diseases was approved.

Military Medicine

Five of the documents that Reuters found that show BGI and Chinese military hospitals conducted joint studies on non-invasive prenatal tests (NIPT) and genetic research:

- [Study in Prenatal Diagnosis, July 2018](#)
- [Research letter in Prenatal Diagnosis, 2012](#)
- [Study in Science China, 2018](#)
- [Chinese Obstetrics Gynecology Online, 2019](#)
- [Study in PLOS Digital Health, 2015](#)

Kirsty Needham

The People's Liberation Army General Hospital in Beijing. REUTERS/Thomas Peter

Soldiers of the PLA Marine Corps training in Bayingol, Xinjiang, in 2016. REUTERS/Stringer/File Photo

BGI’s research with the PLA on the NIFTY test has continued. In 2019, Lu was [credited](#) by Chinese medical journals with detecting a single-gene disease – fetal achondroplasia, which causes dwarfism – through NIPT, in a clinical trial with BGI at the PLA General Hospital. BGI later released a new NIFTY single-gene test that detects the condition.

BGI researchers also conducted studies on novel NIPT methods in 2019 and 2020 with the military hospitals.

As well as prenatal research, BGI has collaborated with the military hospitals on genetic research programs designed to enhance soldiers’ performance.

It worked with the PLA General Hospital to identify genes linked to hearing loss: The hospital uses stem cells and gene therapy in research on combating deafness in soldiers caused by weapons training, papers in military medical journals show.

And BGI published studies with the Third Military Medical University in Chongqing exploring whether drugs interacting with genes could protect Han Chinese, the country's majority ethnic group, from brain injury at high altitudes. Those studies refer to soldiers stationed in Tibet and Xinjiang, high plateau regions which border India's Ladakh, where fighting broke out last June.



“An untapped resource”

For more than a decade, scientists worldwide have searched for a cost-effective way to study the genetic profiles of a whole population of people. A handful of efforts reached tens of thousands of participants, but anything larger stalled on cost and logistics, BGI researchers wrote in a 2018 scientific paper [published](#) in Cell.

Left-over samples and test data from prenatal tests meant BGI could run studies on an unprecedented scale.

In the Cell paper, BGI researchers said they had performed the largest study of Chinese population genetics ever – which they undertook with 141,000 re-used prenatal tests. The tests, they said, “provide an untapped resource” to understand how people's genes relate to their characteristics, and to their susceptibility to viruses.

This, they said, could offer “considerable mapping power.”

The researchers were able to see genes associated with bipolar disease, schizophrenia, immune response and resistance to malaria. They were able to link genes to height and percentage of body fat as well as to a diet high in animal fat.

And they were able to track viruses including hepatitis B – which they found to be relatively common among the Chinese population – and two types of herpes virus, which they said were more prevalent among Europeans. “We ... reveal a different viral sequencing distribution spectrum compared to Europeans,” the researchers wrote.

A biology professor at the University of California, Berkeley, Rasmus Nielsen, advised BGI researchers on how to extract information from the prenatal test data for the study.

“It's amazing that this is even possible,” he told a Berkeley newsletter in 2018. “You can take these massive samples and do association-mapping to see what the genetic variants are that explain human traits.”



A technician in a genetic testing laboratory of BGI in Kunming, Yunnan province, in 2018. REUTERS/Stringer/File Photo


The researchers were also able to trace genetic distinctions between the country's dominant Han Chinese ethnic group and minorities including Uyghurs and Tibetans, and look at population movements and intermarriage caused by Chinese government policy since 1949. This data was later released to other Chinese researchers studying how “significantly different” genetic variations in Uyghurs affected their response to drugs, a 2019 scientific paper shows.

China's collection and analysis of the DNA of its Uyghur Muslim population – including systematic collections of samples from residents in Xinjiang – has drawn sharp criticism. The United States sanctioned two BGI subsidiaries last year for what it called China's “abusive DNA collection and analysis schemes to repress its citizens.” BGI denied it was involved in any human rights abuses in Xinjiang. China's foreign ministry said health check-ups of Uyghurs there did not collect biological information such as DNA.


UC Berkeley’s Nielsen told Reuters he no longer worked with BGI. He chose to end a decade-long collaboration soon after the 2018 study was published in Cell, because changes to Chinese law restricted foreign researchers working with Chinese genomic data, he said.

“Things are really changing in China,” Nielsen told Reuters. “Science used to be free.”

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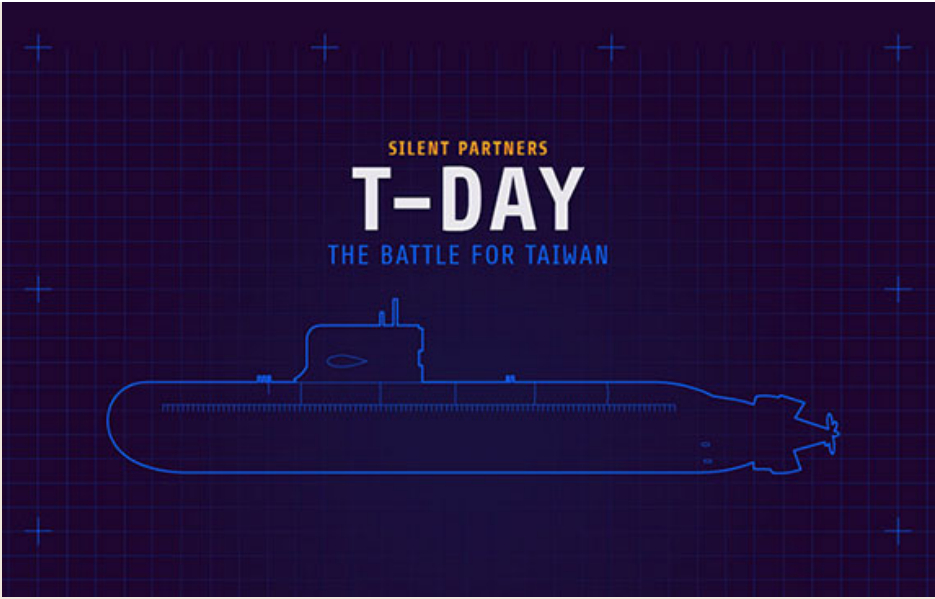


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