Words Karen Bartlett **Photography** Jason Millstein

STILL LIFE PHOTOGRAPHY: MATTHEW SHAVE

HARD TO SWALLOW

Can race-based medicine really change lives for the better? African-Americans using the heart drug BiDil (*above*) might say yes. But others, such as the Havasupai, claim pharmaceutical companies are exploiting their genetic legacy for big profits

Carletta Tilousi, a Havasupai council member, who says her tribe's genes have been stolen by medical researchers

THE HELICOPTER HOVERS OVER THE LEDGE AND THEN RUNS FOR SEVERAL MINUTES ACROSS THE RED-ROCK FLOOR OF THE GRAND CANYON.

It ducks down into another, deeper valley with golden trees, fields of Indian corn and horses that sleep in the autumn sun. The "land down below", as it is known, is the world of the Native American tribe the Havasupai ("people of the blue-green water"). It is, in some respects, a natural paradise; though on closer inspection the houses are small and propped up on stilts, with rubbish trampled into the dirt.

The atmosphere over Supai, the town where the helicopter lands, is one of a troubled Utopia. People wear a pinched and unhappy look, strangers are treated with caution. The Havasupai say the blood of their ancestors has been taken and exploited. They blame a local giant for this alleged misappropriation: Arizona State University (ASU). The university's project, both sides agree, was to develop genetic medicine and drugs targeted at diseases prevalent in specific racial groups. Its victims, according to the Havasupai: the very people the university said it wanted to help.

On the other side of the continent, in his two-storey Brooklyn townhouse, Gilbert Charles wakes every morning at six. He eats a small breakfast and takes the first part of his daily course of medication for a serious heart condition. Charles is a lucky man; his allergies and other medical complaints restrict the drugs he can take, but there is a pill that meets his needs – BiDil. BiDil is the only medication licensed in the US solely for use by black people. Charles is originally from the West Indies, and therefore qualifies for the drug. He is fully aware that the colour of his skin has significantly improved his healthcare – and has more than likely lengthened his life.

IN A WORLD OF 'BLACK PILLS', WHAT MINORITIES WILL BE LEFT BEHIND?

The Havasupai and Charles are the early beneficiaries, or casualties, of the revolution that is genome-based medicine. As with all revolutions, there will be winners and losers. Cheaper sequencing of DNA will lead to targeted therapies and fewer adverse drug reactions, but it could also usher in an era of race-based medicine that risks increasing discrimination based solely upon the colour of a person's skin.

For scientists, it is the thorniest of issues. Doctors may agree on the results of unambiguous genetic tests, but the ramifications for identity politics are enormous. Moreover, some worry that the correlation will affect the future development of research and treatment itself. Genomics pioneer Craig Venter recently spoke out against the emergence of race and ethnicity in genomic medicine, calling it a crude tool that can, perhaps, get part of the job done, but should ultimately be used only as a stepping stone to "individualised medicine" based on full genome sequencing.

"One of the major results that has emerged from the rapid development of the sequencing of the human genome is that it's clear we're more than 99.9 per cent the same," says Timothy Caulfield, an expert on the development of race-based medicine at the University of Alberta in Canada. "In that tiny margin, however, lies a whole world of developing and marketing new drugs for people from different races. There's no doubt there is genetic variation, and that is useful info to have. The issue is how scientists understand and use that information – compared to how drugs companies and marketing people might utilise it. In addition, there is the question of how we, the public, interpret data using our own faulty social constructs of what 'race' means."

There are at least nine drugs in development that focus on racial groups, including therapies that target hepatitis B in blacks and Hispanics. As more genomic information is decoded, studies are increasingly linking disease and ethnicity, such as a higher rate of heart disease in South Asians or of breast cancer in Ashkenazi Jews.

The implications of such associations are far-reaching. In a world of pills for black people, or tests for Jewish people, which other minorities will be left behind? Social scientists fear that linking diseases to specific ethnic groups also risks dire consequences for employment discrimination, healthcare and immigration. The election of the first "mixed-race" president of the United States illustrates, perhaps, the largest dilemma of all: how to tell who belongs in which group. Barack Obama identifies himself as a black man, but an equal proportion of his genetic make-up is Caucasian (from his mother). If Obama were diagnosed with congestive heart failure, would he qualify for BiDil?

BiDil, the first "race drug", was licensed in the US in June 2005 for the treatment of African-Americans with heart disease. The medication combined the effects of two drugs already in use for patients of all ethnic groups. Hailed by some as the beginning of the end of racial inequality in health, the advent of a "black pill" was greeted with dismay by many others in the medical community. Geneticist Angus Clarke from the University of Cardiff called BiDil "hugely controversial".

US doctors who championed the drug pointed to the stark health disparities faced by the black community. "Look at hypertension in African-Americans. Look at heart disease," said Keith Ferdinand from the American Association of Black Cardiologists. He was influential in persuading the black community to support BiDil. "There's more diabetes. Racial disparities as a means of determining what's wrong with medical care in the US are important."

Black males between 45 and 64 are at a 70 per cent greater risk of heart failure than whites, and are more likely to develop problems earlier in life. In April 2008, a study appeared to find a gene common to African-Americans associated with a bad reaction to the hypertension drugs beta blockers.

The Havasupai, "people of the blue-green water", live on 200 hectares at the bottom of the Grand Canyon

Keen to rectify the disparity, Ferdinand and the Association of Black Cardiologists sponsored the African-American Heart Failure Trial (A-HeFT), which, for the first time, demonstrated the efficacy of a heart-failure therapy for the black participants in the study. A-HeFT was crucial to the development of BiDil, a drug that consisted of a fixed dose of two drugs, isosorbide dinitrate and hydralazine, that were designed to raise low nitric oxide concentrations in the blood. In lay terms, BiDil relaxed blood vessels, making it easier for the heart to pump.

But BiDil was not originally a genetically targeted medicine. Instead, it was a product that had been languishing in the drug-development pipeline after an initial clinical trial in a mixed-race group proved inconclusive, and the US Food and Drug Administration (FDA) declined to grant it a licence. Further analysis of the data, however, demonstrated a significant improvement in black patients (a group usually significantly under-represented in clinical trials). A further sub-group study based on self-identified black Americans demonstrated that, taken in addition to regular treatment for heart disease, BiDil led to a 43 per cent reduction in mortality. The results were so dramatic that the drug was rushed into production by the small pharmaceutical company NitroMed before the clinical trial was even concluded.

The results of the BiDil study were welcomed by those who had encountered racial inequality in the US health system, so it was with some fanfare that BiDil was licensed by the FDA in 2005 as the first-ever drug for black Americans. BiDil was also to

become the first drug for which cost was determined by skin colour. White Americans, who might also benefit from taking BiDil, would be forced to buy the drug off-prescription, and have to pay more.

This difference in treatment disturbs Ferdinand, who believes the development of BiDil as a "black pill" is regrettable: "The fact that BiDil is available to white patients only as a more expensive off-label drug is unfortunate. I hope that [critics] would recognise that scientifically it was a good study. Don't throw out the benefits of BiDil because of the misuse of race as an identifier."

Even its harshest critics have not suggested that BiDil is a bad drug. Potentially it could prolong the lives of as many as 750,000 black Americans suffering from hypertension. Their argument is that it could also alleviate the symptoms of four million other Americans with heart failure who do not self-identify as black. Certainly Gilbert Charles feels positive about BiDil. "It has definitely helped," he says. "I have a short nap in the afternoon, but I do much more."

The evidence for BiDil's scientific merit is clear, but the marketing of the drug and the usefulness of self-identified racial groupings kicked off a debate between academics, led by Jonathan Kahn, a law professor at Hamline University in Minnesota, who worried that promoting drugs on racial lines is little more than a clever advertising ploy. "BiDil has been cast by many as a step towards individualised pharmacogenomic therapy," Kahn wrote. "However, BiDil emerges as a new model of how a pharmaceutical company may exploit race in the marketplace." NitroMed capitalised on health risks faced by black Americans to gain commercial and regulatory advantage, according to Kahn, who highlighted the fact that BiDil was granted a longer patent by the FDA because it was licensed for black patients.

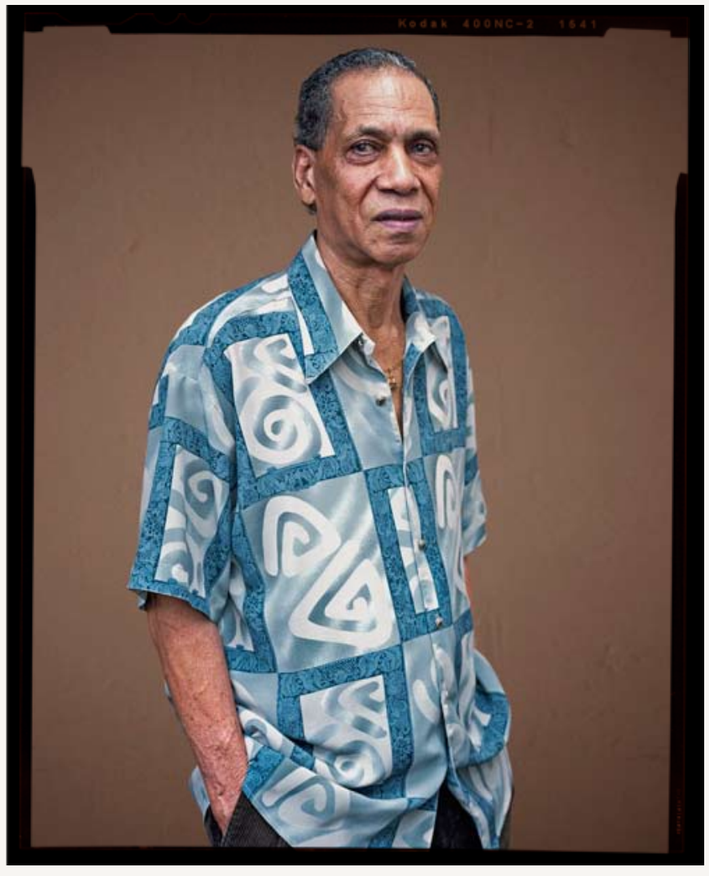
Further research by Pauline Ng at the J Craig Venter Institute revealed a huge genetic variation in how Ethiopians, Tanzanians and Zimbabweans metabolise drugs for psychosis and heart disease. In other words, there is no "African" gene, let alone an African-American gene. Regardless of the science, NitroMed's commercial approach tapped into a growing market for self-identified "African-American" products.

Yet BiDil has not been a commercial success. Sales proved lacklustre and in January 2008 NitroMed said it would discontinue promotion of the product. Later in 2008, it unveiled plans to sell the rights to BiDil and it has since merged with another small biotech company. So what went wrong?

Industry experts believe that BiDil's failure lies in overpricing and a weak patent that relied on a set dosage of two drugs already on the market. Of more concern to drug makers and social scientists alike is the question of whether racial branding had a positive or negative effect on the drug's performance in the marketplace.

When big pharma found its traditional business model cracking, and profits decreasing, BiDil allowed drug manufacturers to consider a different model – a way for pharmaceutical companies to use genetic tools to salvage drugs stuck in development following inconclusive clinical trials. Whereas most large companies would find salvaging drugs too time-consuming, they might profit by turning to partnerships with smaller biotech companies and selling on development rights. (NitroMed had only one drug – BiDil – on its books.) Wayne Rosenkrans of the Personalized Medicine Coalition says: "The old pharma model is under pressure. Personalised healthcare is one of the potential solutions." Markets for genetically tailored drugs are smaller, but could be more profitable because patients are likely to stick with a tailored product.

Critics claim that by supporting the A-HeFT trials, and subsequently approving BiDil, the FDA allowed manufacturers to avoid the costs of developing drugs for the entire population and focus their attention on a "niche group" that is easier to study. The larger concern is that developing drugs for a niche population could lead to companies focusing only on those groups that can afford the most expensive treatments.



Gilbert Charles, one of BiDil's success stories

PHOTOGRAPHY: ROB HANN

COLOUR-CODED HEALTHCARE

A-HeFT
The first African-American Heart Failure Trial (A-HeFT) ran from 2000 to 2004, and was designed to study BiDil's effect on more than 1,000 black patients with heart failure. Using patient questionnaires it analysed the risk of mortality, as well as the date of first hospitalisation, for heart failure. The trial demonstrated the effectiveness of BiDil on patients compared to a placebo.

BiDiL
Thanks to A-HeFT, BiDil, the first prescription drug specifically for black people, went on sale in the US in July 2005. It treated heart disease, heart failure and diabetes. It combined two generic drugs: isosorbide dinitrate, which widens blood vessels; and hydralazine hydrochloride, an arterial dilator. Yet despite huge publicity and proven efficacy, sales soon dropped.

ENTECAVIR & TELBIVUDINE
The effectiveness of BiDil opened the door for more race-based drug trials. In June 2009, drug company Nortavis launched a trial to test the efficacy of Telbivudine – which treats chronic hepaptitis B (HBV) – on African-Americans and Hispanics. A trial for Entecavir – another HBV drug, made by Bristol-Myers Squibb – on black and Hispanic Americans started a month later.

That scenario is not just scaremongering, according to the Havasupai. They believe their blood was stolen and exploited by the white medical establishment. The tribe is currently engaged in a $50 million lawsuit with ASU over the case. "They treated us like human guinea pigs," says Vivian Wescogame, a Havasupai resident. "I asked for my blood back, but never got it."

Rob Rosette's law firm sits on an uninspiring stretch of dusty strip malls outside Phoenix, Arizona. Deep leather chairs, dark wood and polished adobe walls indicate that modern Native Americans can be professional, wealthy and successful, but Rosette's most famous client, the Havasupai tribe, is none of those things. ASU is seeking to become a leader in the field of medical research, and is a powerful force in Arizona politics. By contrast, the Havasupai have only one valuable possession – their genes. "There are two different worlds," says Rosette. "There's the world at the top – that's ordinary America. Then there's the one at the bottom. That's the Havasupai."

Visitors to Supai, 70 miles north-west of Flagstaff, find a health clinic, a café, a general store, tribal-council buildings, a village school and – tucked out of sight – a police station and jail. There are no roads, only sandy trails that the police navigate in little golf buggies, while locals trek along pulling their goods, and their elderly relatives, on trolleys. In Supai, life is traditional but tough. There is a small tourist trade in the summer months, but most of the population lives on government subsidies.

The Havasupai have lived in the Grand Canyon for hundreds of years. They were originally nomadic, spending half the year hunting on nearby plateaux. When the US government passed the Reservation Act in 1882, the Havasupai were stripped of 90 per cent of their hunting grounds and were restricted to 500 acres at the bottom of the canyon. But that loss was not to be the greatest threat to their survival. Within a century, they faced a battery of health problems, including diabetes.

One white man who won the trust of the Havasupai was John Martin, an anthropologist who had been studying the tribe since the 60s. On a summer's day in 1989, Martin was visiting the Havasupai when members of the tribe described how diabetes affected their community. "Many people had this sickness," said the then vice-chairman of the Havasupai, Rex Tilousi. It ranged across all ages, leaving many dependent on insulin and others with amputated limbs. Martin promised to look into this, and returned to ASU to seek advice. The university agreed to help by investigating genetic research and nutritional education.

'THEY TREATED US LIKE GUINEA PIGS. I ASKED FOR MY BLOOD BACK'

Environment clearly played a part in the Havasupai's medical problems. Many members of the tribe suffer from obesity, with airlifted food making healthy eating difficult. Linda Vaughan from ASU agreed to help with nutrition, saying she understood the project to be about "diabetes only".

On the genetic side, Martin recruited biology professor Therese Markow, who told Martin that she would like to broaden the scope of the project to include a study of schizophrenia. According to a report conducted by attorney Stephen Hart into the case in 2003, John Martin told Markow that he believed the Havasupai would be very unlikely to agree to a study on schizophrenia, but would be interested in help with diabetes. Martin claimed he believed Markow pulled back on her plan to study schizophrenia in the Havasupai; but, in fact, by September 1989 she had already applied for a grant of almost $100,000 from the National Alliance for Research on Schizophrenia and Depression. In July 1990, ASU graduate student Kevin Zuerlein was sent to Supai to begin drawing blood. He told Hart that at night, when everyone had left, he searched through the medical records at the clinic looking for signs of schizophrenia. Zuerlein said Markow had told him to search the records, and he believed she had permission.

Evangeline Kissoon, 31, is a member of the tribal council. Her grandmother was one of those who gave blood: "She spoke about it now and then. It was sad. She even went to ASU to see how much fat was in a cheeseburger. Then she found out something degrading. To find out they think we all have schizophrenia is upsetting."

David Morgan, who worked for the Indian Health Service, confirmed that the tribe was "very sensitive" about mental-health matters and that searching the records for evidence of schizophrenia would have required the consent of the tribal council and the individuals involved. No such consent on this matter was ever sought.

Now based at the University of California in San Diego, Markow maintains that she had consent forms to test for diabetes and schizophrenia – although forms could be found only for blood drawn in 1990, and refer to testing "behavioural and medical problems". She told Hart that the diabetes project fell under the broader umbrella of a medical genetics project that covered other diseases. In 2003, when Martin uncovered the scale of the research using the Havasupai blood, he told Hart that he thought "bullets would fly".

Gathering together on a bench outside the store on a quiet Sunday morning, those villagers who gave blood say they feel depressed and devastated, and that their trust has been betrayed. Perhaps worst of all, most of them are now unwilling to visit the local clinic to see the doctors dispatched to serve the community on fortnightly rotations. Without being reunited with their blood, the Havasupai say, their spirits cannot ascend to the next life. The big problem now is that no one knows which blood sample belongs to whom.

One man, known as Regina Star, says: "I had my blood drawn for diabetes. If they had asked us about testing for other things we might have said yes. But they made friends with us and then they used us to get their degrees. We wanted to be equal, but they treated us just like a bunch of dumb Indians who would never find out what was happening. We were violated."

In total, the Havasupai discovered that their blood had been used for studies into schizophrenia, inbreeding and migration. In addition to the ASU research, blood samples were sent to at least five other private scientists. Eight graduate students earned advanced degrees and two dozen research papers were published, 15 of them into schizophrenia. The Havasupai seem to have gained little from the research and, controversially, samples had been used to support the theory that Indians had crossed the Bering Strait into North America, which goes against Havasupai beliefs.

"I knew we wouldn't have given anyone permission to do that study," Carletta Tilousi, a Havasupai council member, told *The Phoenix News*. "I started to think, 'How dare this guy challenge our identity with our own blood, DNA.'" Tilousi has since become the lead plaintiff in the Havasupai's case against ASU.

Would you want to be tested for a gene mutation that radically increases your cancer risk? Aviva Schulman chose not to be. She asked, "What is the point of knowing?" After growing up in Brazil, Schulman moved to north London. Her family is of Eastern European Ashkenazi Jewish descent, putting her within the group most commonly found to carry the defective BRCA1 or BRCA2 genes linked to hereditary breast cancer. She has since been treated for breast cancer.

"I was unaware of any history of cancer in my family. A cousin had colon cancer, but I didn't give it much thought. Then in 2004, I was diagnosed with tumours in my breasts. I had a double mastectomy." When Schulman phoned her family in Israel to tell them about her diagnosis, she discovered that another cousin had been diagnosed with breast cancer a year earlier – and also had the BRCA2 gene mutation.

"In Israel they automatically do the test and tell you to notify your family. But my cousin said nothing. I could have been tested a year earlier."

Since they were discovered in the 90s, the BRCAs have become among of the most heavily researched genetic mutations. BRCA1 and BRCA2 are responsible for creating proteins that fix broken DNA strands, but when the genes mutate the cells produce bad proteins that are unable to repair the DNA, which can lead to cancer. Hereditary cancers account for five per cent of the UK's 41,000 annual breast-cancer cases. In the general population, one in 1,000 carry the mutated BRCA1 gene, and one in 700 carry the faulty BRCA2 gene. In the Ashkenazi community, one in 40 women carry one or both faulty genes. After the discovery of the BRCA gene mutations, many women were tested and chose to have a double mastectomy, even though a proportion would probably never develop the disease.

In this US, this research sparked fierce debate in the Jewish community about the project's potential for discrimination, with some comparing the focus of the medical establishment to Nazi-era eugenics programmes. In 2005 the European Patent Office considered the ethics and legality of the first case of racial-gene patenting, when Myriad Genetics reapplied for worldwide monopoly rights for "diagnosing a predisposition to breast cancer in Ashkenazi Jewish women". Geneticist Gert Matthijs, speaking against Myriad, said that if the patent were allowed it would mean he could test free of charge for the mutation only if "the woman doesn't say she is an Ashkenazi Jew".

Aviva Schulman chose not to take a genetic test

PHOTOGRAPHY: MICHAEL CLEMENT

After three appeals, the European Patent Office decided in November 2008 to reinstate one of three Myriad patents held on the BRCA1 gene (Myriad's patents on the BRCA genes are now owned by the University of Utah), which specifically relates to frame-shift mutations most commonly found in Ashkenazi women. A second patent relating to the Ashkenazi mutation on BRCA1 was also upheld. Matthijs said: "No other group finds itself in this position. Other populations have greater genetic differences, but the gene mutations in the Ashkenazi Jewish population have been identified and can be tested with a simple kit. Producing that test kit for that community has commercial advantages. But, obviously, that group will have to pay royalties to take the test."

Schulman said that the requirement to enter the results of the BRCA test on subsequent medical insurance forms had influenced her decision not to be tested: "I asked myself, 'What have I got to gain?' I assume I have the gene because my cousin told me that my aunt also had a malignant lump. The only thing is my daughter, but what will she gain by knowing? I'm happier for her to have her a yearly check-up instead."

The Ashkenazi Jewish community continues to find itself under the medical spotlight. In January, specialists at University College Hospital in London announced the birth of a baby who'd been screened as an embryo to ensure that she was free of BRCA abnormalities. A pilot programme at the hospital is now investigating how screening for the genes might be offered to a wider population, and is currently offering free screening to all members of the Ashkenazi Jewish community in London.

Further research has indicated, however, that other minority groups also exhibit high rates of BRAC1 abnormalities, including Hispanics. A very high 16.7 per cent of African-American women with breast cancer under the age of 35 also had the abnormal gene.

To illustrate the argument that race-based medicine reveals a crude and incomplete picture, Craig Venter points to a Columbia University study published in the *American Journal of Public Health*. It concluded that there was no point in seeking specific racial genes for breast cancer within Ashkenazi Jewry, because the group had been so diluted by breeding with other racial groups.

Venter is the man perhaps most responsible for recent discoveries that paved the way for the development of race-based medicine, but he is also its most vehement critic. "It's bad science," he says. "Race-based medicine is my pet peeve. You can't tell a book by its cover. Race is a social construct; it is very unlikely that your skin colour will be the basis of your genetic group."

As the first person on the planet to have had his entire genome sequenced, Venter claims to have had "more time to think about this issue than most". Venter's approach to mapping the human genome was described as "quick and dirty" by US government scientists when his revolutionary technique outpaced them. Back then, he was the maverick who changed our understanding of DNA; but now "quick and dirty" is how Venter describes the efforts of scientists and pharmaceutical companies currently trying to develop genetic race-based medicine. "I just think that it is not defensible at all. And the faster we get genetic information, the faster people will realise it is a meaningless criterion."

Venter now occupies an office at the J Craig Venter Institute in Rockville, Maryland. Sitting at his desk in jeans and an open-necked shirt, he says his thoughts about race-based medicine crystallised after his genome was compared to that of fellow scientist James Watson. Venter says that both he and Watson are "bald middle-aged Caucasians, but genetically we are totally different". The study showed that Watson had traits usually found in Chinese populations. "We have different types of drug metabolism," Venter says. "James has a rare genetic combination – if we took the same dose of an antidepressant drug, he would overdose and I would be underdosed. There is more genetic difference between all the people with dark skin than there is between people with light skin and dark skin."

He argues that race-based medicine should be nothing more than a stop gap en route to the true goal: personalised medicine, made affordable by the $1,000 genome. (This is the figure at which it would be affordable to map everybody's DNA and tailor treatment accordingly, he says.)

Decoding his genome revealed that Venter has a slightly higher statistical probability for developing heart disease and Alzheimer's. "That would be the worst disease for me, so I take a statin as a preventative measure. But my genome didn't tell me I would develop the disease; I might never get it. On top of genetic factors, people have to be educated to understand that there are environmental factors. My father died of a heart attack at a young age; my mother is in her eighties and still plays golf."

Personalised medicine, which allows everyone access to their genetic data, could be a reality within five years. Venter fears, however, that it is race-based medicine that drug companies see as the potential gold mine. As the pharmaceutical sector struggles to reinvent itself, Venter believes the industry could exert pressure to slow down research and prevent the development of affordable personalised medicine by giving precedence to race-based treatments that are more lucrative, but scientifically second-rate – or, to some, not scientific at all.

The controversy surrounding BiDil and the BRCA tests has raised questions about how such medication and diagnostic testing should be licensed. Doctors and legislators are now considering whether any new targeted drug should be tested on the population as a whole, or only on the sub-group at which it is aimed. Some scientists argue that whole-population testing will always be required to account for adverse drug reaction and off-prescription use (despite the fact that, prior to BiDil, more than 80 per cent of the subjects of clinical trials were white, middle-aged males).

Once such a drug is licensed for a specific racial group, what criteria will be used to determine who falls into that remit? Skin colour and self-identification have proved poor markers for determining a genetic response. For many years, black Americans believed racism held back research into diseases that predominantly affected their community. Now some believe the results can be exploitative, and have stopped taking part in clinical trials. Genetic sequencing will raise different issues in the UK. "I could see that we could have a genetic equivalent of the postcode lottery, with certain groups receiving treatment and others being denied," says Richard Tutton of Lancaster University.

Tutton believes the reaction of the medical community to genetic technology will be key: "In Britain, most people would have to utilise this information through the NHS. A big question will be how GPs respond. For some conditions, like hypertension, they prefer family history. There is a lot of resistance to genetically targeted medicine from doctors; it takes matters out of their hands."

The potential of genomic medicine is beyond doubt. "Genomic sequencing will dramatically improve the quality of medicine," Venter says, adding that cutting adverse drug reactions, a leading cause of death in the US and the UK, would be a major benefit. While defending the advances made by scientists, he is in no doubt about the hazards – misunderstanding and exploitation of data could lead to far greater inequality. "People will overinterpret data and act out sci-fi scenarios in their lives. To me that is frightening. We will go through a disturbing period."

But while Venter agonises over the misinterpretation of data, others suggest he is naive. Reanne Frank, a sociologist at Harvard, argues that "science is always a product of culture" and scientists who believe otherwise are dangerously deluded in believing their work can exist in a vacuum. As genome sequencing becomes more widely available, personalised medicine will be the arena where scientific advances and race-based identity politics meet.

'YOU CAN'T TELL A BOOK BY ITS COVER. RACE IS A SOCIAL CONSTRUCT'

Karen Bartlett is a London-based journalist specialising in the ethical and political issues within genomics and science