

# Getting personal

The commercialization of personal genomics is moving with dizzying speed and scientists need to find innovative ways of discussing the implications with consumers.

As the first conference on personal genomes opened earlier this month at Cold Spring Harbor Laboratory in New York, some present were wondering whether the event was a little premature. After all, only four people's genomes have so far been fully sequenced and assembled, and it's still quite difficult to interpret the genetic variation found in them (see page 1014). But the participants soon began to realize that, in one sense, the meeting was overdue. Increasingly, private companies are offering personal genome scans and genetic tests for sale — and consumers are buying them. Meanwhile, some scientists earlier this week made public parts of their genetic and medical data through the Personal Genome Project, spearheaded by George Church, a geneticist at Harvard University. In this context, the ethical, legal and social issues usually sidelined at such gatherings kept intruding with uncommon urgency.

The day before the meeting began, for instance, deCODE Genetics of Reykjavik, Iceland, began selling a US\$1,625 risk-assessment test for breast cancer, which surveys seven of the single-point genetic variations known as single nucleotide polymorphisms (SNPs). The company says that the test will help identify women with a significantly elevated risk of the disease.

But the test is worrying some oncologists and geneticists. Mary-Claire King of the University of Washington in Seattle told the meeting that the SNPs included in the test are present at slightly different background frequencies in different populations across Europe. She raised the possibility that rather than predicting breast-cancer risk, the test might instead be detecting population differences between the control and test groups included in the studies that linked the SNPs to disease.

Regulation of such tests is patchy at best, so women have little official

guidance when it comes to balancing the potentially confusing scientific and medical facts about a product against their fear of breast cancer. But, as *New York Times* reporter Amy Harmon told the meeting, the public desperately wants help in making such decisions.

Part of the problem is the information overload provided by the Internet. Consumers can point their browsers to a slew of content, which can come from both trusted sources and charlatans. And in the age of e-mail whisper campaigns, lies can proliferate, opinions can replace facts, and experts are no longer trusted to know the truth.

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Scientists can and should help the public sift through this information, interacting through blogs, newspaper articles or science cafes, for example. And if researchers are surprised at how quickly genome-wide association studies have become consumer products, they need to realize that things will only move faster in the future, with findings moving from the lab to Internet chat rooms and people's lives with astonishing rapidity.

The issue was articulated at the meeting by Robert Cook-Deegan, an ethicist at Duke University in Durham, North Carolina, who pointed out that scientists cannot put the genie back in the bottle. Anyone can now access his or her genome information through a personal genomics scan. And if people can get that information, they will — with or without the advice of genetic counsellors, doctors or expert scientists. It is impossible to guess what issues this will raise as the science matures, although new discoveries will no doubt trigger a fresh and more complicated set of societal discussions. Scientists need to get creative about how they participate in these discussions, because they won't have the luxury of opting out. ■

## A look within

A series of Essays examines what science has to say about being human.

Some 2,500 years ago, legend has it, visitors to the Oracle at Delphi in Ancient Greece had to pass by an inscription bearing the words *gnothi seauton* — know thyself.

That advice is as wise today as it was then — and as hard to follow. Modern science can help, but using it to uncover truths about ourselves can also be fraught with difficulty. Consider, for example, that an important first step towards understanding contemporary human behaviour — establishing the evolutionary context in which it emerged — means piecing together odd scraps of evidence left by our hunter-gatherer ancestors tens of thousands of years ago. The paucity of data makes it all too easy to come up with untested,

and even untestable, Darwinian versions of Rudyard Kipling's *Just So Stories*.

Another major challenge for researchers is being objective about a topic as philosophically, politically and ethically charged as human nature. Take the sociobiology wars of the 1970s and 1980s. Left-wing scholars rejected biological explanations for phenomena such as gender roles, religion, homosexuality and xenophobia, largely because they feared such explanations would be used to justify a continuation of existing inequalities on genetic grounds. The resulting debates became hugely political.

The combustibility of the interface between science and society is one major reason for the extraordinary fragmentation of research that tackles human behaviour. In part because of the sociobiology battle, most social scientists still steer clear of using evolutionary hypotheses. And even researchers who do work under the unifying framework of evolution tend to fall into distinct camps such as gene-culture co-evolution or human behavioural ecology — their practitioners