

# Scientists share secrets of their own DNA – warts and all – with the world

## Genetic experts hope to accelerate discoveries

**Mark Henderson** Science Editor

A group of 12 genetics experts will expose their DNA to public view today to challenge the common view that such information is so private and sensitive that it should not be widely shared.

The “DNA dozen” will publish full results of their own genetic tests, including implications for their health, in a controversial initiative to explain the significance of the human genome for medicine and society.

The Genomes Unzipped project aims to demystify the genetic code, showing what it can and cannot reveal about individuals’ health and allaying fears about discrimination and privacy.

The participants — 10 British-based scientists, one American scientist and an American genetics lawyer — hope to encourage many more people to share details of their genomes with researchers. This would allow the creation of open-access DNA databases that any scientist could use, enabling a “wisdom of crowds” approach to research that will accelerate discoveries about genetics and health.

“We hope that by sharing our experiences and publishing our data, people will see the genome in a clearer light,” said Daniel MacArthur, a geneticist who is leading the project.

“We want to show that genetic infor-

mation need not be frightening and that the risks of publishing data can be managed.”

At present, DNA databases used in research are bound by confidentiality agreements that can limit their usefulness to scientists. “We want to encourage a radical new approach, where people opt into genetic research on an open basis so that anyone interested in the data can access it and use it,” Dr MacArthur said. “It’s a really powerful model for research, but the challenge is that people are frightened of sharing their genetic information.”

The initiative will reopen debate about access to genetic data, as the Nuffield Council on Bioethics publishes a major report on genetic medicine tomorrow.

Critics say that Genomes Unzipped underplays the hazards of releasing DNA data. While there is a moratorium on the use of DNA by insurers, they said that this could change in future to allow genetic discrimination, while identity theft could be another danger.

Helen Wallace, of GeneWatch UK, who campaigns on the risks of genetic technologies said: “Your DNA contains very personal information about you, and in the longer term we can’t be certain this won’t be used by insurance companies. I don’t think scientists should be encouraging this.” Dr MacArthur said that, as professionals in the field, the group was well-placed to road-test any risks on society’s behalf. “If there are risks we are in a good position to manage them,” he said. “We think the risks are theoretical and small, but an open approach could have major benefits.”

The project was hatched in the Eagle pub, in Cambridge, where Francis Crick and James Watson announced in 1953 that they had “found the secret of life” by identifying the double-helix structure of DNA.

All the participants consulted their close relatives before agreeing to take part, because one person’s DNA can reveal information about siblings,

parents and children. Each then had their DNA tested by a company called 23andMe; the results and reports will be posted today on the website: [genomesunzipped.org](http://genomesunzipped.org).

The results highlight both the usefulness and the limitations of genetic testing. Luke Jostins, another geneticist involved in the project, discovered from his DNA that he has a high risk of age-related macular degeneration — a leading cause of blindness. “It was a surprise as I had no family history, but it is information I can act on,” he said.

Dr MacArthur learnt little of relevance to his health from his 23andMe scan, but he will publish the tests that he took with his wife, Ilana, to determine if they were carriers of inherited diseases such as cystic fibrosis before starting a family. The results were negative and their son, Tobias, was born in August.

Linda Avey, the co-founder of 23andMe, said: “At this juncture, I don’t know that individuals will have all that much to gain from publishing their data, but I think that Genomes Unzipped will help to prove that there’s not all that much to lose, either.”

“The benefit will come when large numbers of people demonstrate the utility of huge datasets that have been made available for research. The sooner we can get to this sort of model, the better for everyone.”

