THIS WEEK

EDITORIALS

ENIGMA The puzzling case of the latest weird dinosaur fossil **p.586**

WORLD VIEW Public data restrictions hamper research in China **p.587**

MAMMOTH Genome clues show likely path to extinction **p.589**

Thank you for sharing

Initiatives to make genetic and medical data publicly available could improve diagnostics — but they lose value if they do not share with other projects.

The modern world is all about sharing, driven by the borderless flow of information through the Internet. Pictures, articles, jokes, links, ideas, criticism — information has never been so free to move. And from open access to giant web-based data repositories, science in 2015 is increasingly based on shared knowledge and expertise.

Sharing should be equal, but some is more equal than others. The principals behind one genetic data-sharing project unveiled last week have described their initiative as a model of "scientific openness" that offers "broader access" to genetic data. Indeed, the name of the project — BRCA Share — trades on the idea of data freedom. The initiative focuses on clinical data concerning mutations in the genes *BRCA1* and *BRCA2*, which increase risk of breast and ovarian cancer.

In truth, it creates more of a walled garden of genetic data than an open field. That runs contrary to crucial ongoing efforts to amass large amounts of linked genetic and medical data to help scientists and doctors to improve interpretation of genetic test results.

The commercial market for genetic testing for breast cancer is growing. On 21 April, for instance, a firm called Color Genomics in Burlingame, California, promised to offer women *BRCA* gene testing — which normally costs thousands of dollars — for as little as US$249. If the companies that offer such testing share their data, stripped of identifying information, with researchers, it could aid efforts to understand how all of the thousands of possible *BRCA* mutations affect cancer risk. The more data researchers can gather, the more they can determine whether 'variants of unknown significance' — genetic differences whose health effects are unknown — are benign or pose risks.

BRCA Share is a partnership between Quest Diagnostics of Madison, New Jersey, and INSERM, the French National Institute of Health and Medical Research. Testing labs that sign up will get access to each other's *BRCA* data and an INSERM repository of information about the genes. The project will run functional studies on the effects of mutations.

But it will not share data with similar efforts such as ClinVar, a US National Institutes of Health-funded initiative that is making linked genetic and medical data publicly available for all. Quest says that BRCA Share cannot contribute to ClinVar because its data are structured differently. But this seems a weak excuse. Researchers say that increasingly, where there is a will to share, a technological way can be found. Because of the restrictions, several labs have declined to join BRCA Share.

Quest says that participants in BRCA Share will be allowed to share their own data with ClinVar. But the first to join the initiative — diagnostics company LabCorp of Burlington, North Carolina — has so far chosen not to; it has not deposited any *BRCA* data in ClinVar. Quest says that it will share BRCA and other genetic data with the Human Variome Project and the Leiden Open Variation Database, based in the Netherlands, which has an agreement to share data with ClinVar, but the agreement between Quest and Leiden has not yet been signed.

The episode showcases an uncomfortable truth about personalized medicine: everyone agrees that large data sets are crucial, and everyone is racing to collect them. The larger the data set, the more useful. The most useful of all would be one huge database containing all available data. But even though all parties recognize the value of it, many are choosing not to share, and this holds back medical progress.

BRCA Share is only one example; there are many others. The company 23andMe in Mountain View, California, for instance, has collected genetic data on 900,000 people. It shares aggregate statistics with outside researchers and has published or contributed to 32 papers in the past 5 years. But to protect users' privacy, it does not routinely share linked genetic and medical data.

"Even though all parties recognize the value of it, many are choosing not to share."

The field is young and will take time to settle. Already, dissatisfaction with limits on sharing is driving new initiatives, such as Genes for Good at the University of Michigan in Ann Arbor, which is enlisting Facebook users for a genetic study (see page 597), and the online community Open Humans, which is helping participants in genetic studies to share their data with other researchers.

Awareness of the issue among consumers is also driving companies to share more widely. Color Genomics, for instance, promises to share its *BRCA* data with ClinVar, as do many other companies.

The imperative to share data remains an esoteric issue for much of the public, and one that is easily obscured. Companies or researchers who talk the talk of sharing but do not actually walk the walk should be challenged. Data sharing is too important to be turned into meaningless marketing speak. ■

A hard sell

Scientists must stand up for marine parks if the value of the seas is to be recognized globally.

Studland Bay is an unlikely battleground. The sandy shore, part of England's southern coastline, is both a beauty spot and the site of "the most popular naturist beach in Britain". More importantly for *Nature*-ists, the seagrass that thrives in the bay's shallow waters is home to rare sea-horse populations. But keeping it that way is a growing challenge, because Studland is also a playground for the wealthy and powerful, including some yacht-club members who like to anchor their boats there, to the possible detriment of the natural habitat.

Scientists can make the case for conservation, but the value of marine sites such as Studland is hard to sell. It is not the Great Barrier Reef with its miles of coral, or the Galapagos Islands and their sharks, turtles and marine iguanas. It is not even Lundy — the island at the