gene, *EFTUD2*. The finding allowed the Ottawa doctors to diagnose their patient with a disease called mandibulofacial dysostosis with microcephaly, and to begin to understand why mutations in *EFTUD2* cause the disease's symptoms.

That's the upside of the new era of data sharing. But there is a possible downside too: invasion of privacy. Massive genetic studies in countries such as the United States, Qatar, Saudi Arabia and Brazil are collecting genetic data on millions of people, so there is a chance that a person's identity could be dragged from those data — especially if they are linked to clinical information, such as medical history. The risk is that someone who volunteers their DNA could see their medical problems opened to public scrutiny.

This is a legitimate concern for many researchers, and is one reason why data sharing is easier said than done. Others include the lingering sense of ownership, and the career benefits offered to those who have privileged access. Those concerns relate to the standard model of data sharing, in which different groups of scientists deposit their results into centralized databases. This model has had some success, but researchers have already encountered problems, such as how to grant and control access to the pooled information.

Pooling it in the first place becomes more difficult as the data sets get larger and the underlying techniques more varied. Imagine the difficulty of finding a specific book by gathering all the contents of a dozen different national libraries and then devising a way to integrate the numerous ways in which they are filed, tracked, recorded and made available. It would be much easier to ask each library whether it holds that book. What if data sharing in science could go the same way?

The diagnosis of the Ottawa child shows that it can. The doctors tapped into a system that is part of the Matchmaker Exchange, which allows researchers to query multiple databases of information on patients with undiagnosed rare diseases. A doctor can feed the system information about a patient's symptoms and genetic make-up, and then ask it whether other people have them too. (Normally, it's hard for doctors to find other patients with similar rare diseases; often they learn about such cases by word of mouth.)

The Matchmaker Exchange exemplifies a subtle shift in how researchers think about data sharing — and one that more scientists should engage with. It was created by the Global Alliance for Genomics and Health, a 3-year-old organization with more than 700 members from 70 countries that aims to help researchers, doctors and patients to make scientific progress by sharing data (see Global Alliance for Genomics and Health *Science* **352,** 1278–1280; 2016).

"As technology to permit targeted data access improves, so will smart sharing."

The alliance is creating technological tools that allow researchers to find out where data that are relevant to their patients are held around the world. It aims to make data not just shareable but discoverable, too. Doing this allows those who produce the data to keep more control of the information. It also streamlines searches. For example, researchers looking for a diagnosis want to know the symptoms that other doctors have seen in people with particular genetic traits. Thus they just want to know who might have seen these mutations and what symptoms might have been observed in patients who have them; they don't want to comb through all the existing databases of genetic information themselves.

Of course, there are still many instances in which accumulating and sharing large amounts of data — on particular genetic traits, for example — is essential and valuable. The gene-testing company Myriad Genetics is locked in a tussle with doctors and patients who want it to open up its massive database of information on variations in the *BRCA1* and *BRCA2* genes, which are linked to a higher risk of breast and ovarian cancer. (Another alliance project, the BRCA Exchange, seeks to provide easily searchable interpretations of BRCA variants that have been shared by groups outside Myriad.)

But in other cases, data access works best, for both sides, when the requests for information are targeted at specific traits. And as the technology to permit that improves, so will smart sharing. ■

At gunpoint

The problem of gun violence in the United States must finally be addressed.

It has been a bloody year in the United States. So far, the country has lost around 6,000 lives to gun violence — dozens of them in mass shootings in public spaces. The attack that left 49 men and women dead in Orlando, Florida, this month is, by some counts, the 136th mass shooting in the United States just this year.

Mourning — and then moving on — in the wake of a mass shooting has become a sombre tradition. But after Orlando, a new development emerged. On 14 June, the American Medical Association (AMA) declared gun violence a public-health crisis, and announced that it will apply its considerable lobbying power to pressure Congress to fund research into this violence. It is cause for optimism that a lengthy freeze on federal funding for such research — particularly at the Centers for Disease Control and Prevention (CDC) — may soon thaw.

It makes sense that this push would come from the medical community: it has a front-row seat on the violence. "Here we are again," physicians wrote in a *New England Journal of Medicine* editorial in January, following a shooting in San Bernardino, California, that killed 14 and injured 22. Six months later, at a press conference following the Orlando tragedy, one surgeon choked back tears as he described the chaos in an emergency room filled not only with the injured, but also with hundreds of their panicked friends and families. Another coolly described the reality that surgeons at his Orlando trauma centre face daily: people wounded by high-calibre assault rifles, once considered to be the exclusive domain of the military, now flooding into civilian emergency rooms.

Yet while doctors struggle to treat the wounded, the CDC has been hamstrung in tackling fundamental public-health questions about the causes of gun violence and its possible solutions. An amendment placed on appropriations bills since 1996 has prohibited federally funded research from advocating gun control — a provision that some have interpreted as making gun-violence research broadly off limits.

In 2013, US President Barack Obama explicitly stated that such research should take place and need not be interpreted as advocacy, but Congress failed to allocate funds in the CDC budget to support it. (The US National Institutes of Health, which has more discretion in how it applies its funding, has sponsored some gun-violence research following Obama's announcement.)

The AMA is a lobbying powerhouse: in 2015, it was the fourth-largest lobbyist in the country. If it chooses to make gun-violence research a high priority, it has the resources to make headway. But it will take a tremendous push — and coordination with other stakeholder organizations — to do so.

In the wake of the Orlando shooting, lawmakers followed what has become a legislative post-mass-shooting tradition: the rapid-fire proposal — and equally rapid rejection — of bills intended to address the country's gun-violence crisis. Earlier this week, the US Senate defeated five such measures. Similar proposals, including one intended to explicitly allow research into gun violence, met the same fate last December. But with concerted effort from the AMA and others, perhaps the United States will break with these traditions. ■

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