News in focus

JAMIE KIDSTON/ANU

Ross Mandi Wunungmurra helped to negotiate the return of blood samples to his community.

AUSTRALIAN BIOBANK REPATRIATES HUNDREDS OF INDIGENOUS BLOOD SAMPLES

The return is part of a groundbreaking approach that could inspire other institutions grappling with how to use historical samples ethically in research.

By Dyani Lewis

Late last year, the Galiwin'ku community of Elcho Island off the coast of northern Australia celebrated the return of more than 200 vials of blood that were collected from their ancestors half a century ago, before modern research principles on informed consent existed. Unbeknownst to the Galiwin'ku community, the blood vials had been in freezers at the Australian National University in Canberra ever since.

Many Indigenous Australian communities believe that the remains of their people, including blood and hair, must return to their ancestral home, or Country, to be at peace. Having the vials returned "meant a lot to us", says Ross Mandi Wunungmurra, chair of the Yalu Aboriginal Corporation, the community organization that helped negotiate the return. Mandi is one of several hundred living members of the community whose blood was also collected after a typhoid outbreak in 1968.

Before the samples from deceased people were repatriated, their relatives gave permission for DNA to be extracted from the blood. People who are still alive offered fresh samples. The genetic information will be stored in the biobank of the National Centre for Indigenous Genomics (NCIG), which the Australian National University (ANU) established specifically to manage its historical samples.

The return was part of a groundbreaking attempt by the NCIG to right the research wrongs of the past. It comes against a backdrop of global uncertainty about what institutions should do with such historical samples, which might contain genetic or other information that is valuable to science, but which were gathered before the establishment of modern research principles governing the ethical collection and storage of such samples. When the Galiwin'ku samples were collected, Australia's government had only recently recognized Indigenous people as citizens, and racist

attitudes that denied them the same rights as white Australians were rife.

Scientists say that the approach is laudable, and could be adopted by other institutions with similar legacy collections. But some researchers warn that it may be challenging to find a data-access policy that satisfies both Indigenous communities and the researchers who want use the data.

Governed by a majority-Indigenous board, the NCIG has a mandate to approach communities whose historical samples are in the ANU's store and ask whether the samples should be kept for future research, returned or destroyed. So far, the team has contacted four out of several dozen communities.

"The basic principle here is we just do what the community wants us to do," says NCIG director Simon Easteal.

Innovative approach

Researchers say the scale of the NCIG's endeavour is impressive. Visiting communities, many remote, to ask them what to do about historical samples is resource-intensive and beyond the budget of many institutions, so many just leave such samples in their freezers, says Easteal.

Sometimes researchers will ask communities for permission to collect specimens for an individual research project, but that doesn't solve the problem of what to do with the specimens once that project is over, he adds.

Negotiations between the Galiwin'ku community and the NCIG took two years, and involved people from both groups travelling between Canberra and Elcho Island many times, says Azure Hermes, a Gimuy Walubara Yidinji woman from far north Queensland who runs community engagement for the centre.

The centre will attempt to follow the wishes of every Indigenous person whose samples are in its collection, which includes specimens and records from 7,000 Indigenous people. If the person from whom a sample was collected has died, the centre will consult their relatives.

Of the roughly 2,000 people from 4 communities whom the NCIG has contacted, about 90% have given permission for their DNA or the DNA of their deceased relatives to be extracted and data added to the NCIG biobank, says Hermes.

"Australia is definitely leading the way with legacy samples or orphan samples, and figuring out how to deal with them," says Ripan Malhi, an anthropologist at the University of Illinois at Urbana–Champaign, who has worked with Native American communities.

The NCIG is giving communities control over their genomic data, as well as their samples.

Data in the centre's biobank will eventually be available for other researchers, but participants are able to withdraw consent for their DNA to be used in specific projects — or the biobank as a whole — at any time using an online portal, an approach known as dynamic consent. Annual visits to communities provide further opportunities for people to make decisions about how their data are used, and learn about research outcomes, says Hermes.

Dealing with the genomic data appropriately is just as important as handling the samples themselves sensitively, says Māui Hudson, a Maori man who is a research ethicist at the University of Waikato in New Zealand.

But he says that the dynamic-consent model is at odds with the move towards open data in research. Communities "need to be involved in the process of decisions about what appropriate uses look like, and that's not possible in a truly open-data environment", he says.

UNITED STATES TO FUND GUN-VIOLENCE RESEARCH AFTER 20-YEAR FREEZE

Government spending deal includes $25 million for studies of firearms safety.

By Nidhi Subbaraman

Lawmakers in the United States have reached an agreement that would fund gun-violence research for the first time in more than 20 years.

A wide-ranging spending bill introduced on 16 December includes US$25 million for studies on the issue, split evenly between the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH). President Donald Trump signed the bill into law on 20 December, after it was approved by the House of Representatives and the Senate.

"It's a good start," says Garen Wintemute, director of the Violence Prevention Research Program at the University of California, Davis, who has been studying gun violence for decades. "Violence-prevention policy should be guided by solid scientific evidence."

"We've lost several generations of researchers in this field."

"Is it adequate? Absolutely not. But is it meaningful and is it important? Absolutely yes," says Mark Rosenberg, president emeritus of the non-profit Task Force for Global Health in Atlanta, Georgia, and the founding director of the CDC's National Center for Injury Prevention and Control (NCIPC), also in Atlanta.

The CDC says that 39,773 people died of gun-related injuries in 2017, the last year for which it has released a full analysis.

The federal government stopped funding gun-violence research after Congress passed a rule called the "Dickey Amendment" in 1996. It barred the CDC from using funds "to advocate or promote gun control". That was widely interpreted as prohibiting the funding of research into gun violence.

Jay Dickey, the Republican congressman from Arkansas who wrote the amendment, reversed his position on gun-violence research in the years before his death. "Both of us now believe strongly that federal funding for research into gun-violence prevention should be dramatically increased," Dickey wrote in *The Washington Post* in 2015, along with former NCIPC chief Rosenberg.

Slow thaw

Last year, Congress clarified that the ban on federal dollars for "advocacy" or the promotion of gun control did not extend to a ban on research. But lawmakers did not immediately set aside money for such research. The new law will require that the CDC and NIH directors report back to Congress to ensure that any grants they award "support ideologically and politically unbiased research projects".

David Studdert, who studies health law at Stanford Law School in California, says that the push to fund gun-violence work at the NIH and CDC is encouraging, but that meaningful research would require sustained support.

"We've lost several generations of researchers in this field, and it's going to take a while to build that back up," Studdert says.

The federal government is best positioned to undertake such an immense financial commitment, says Andrew Morral, a senior behavioural scientist at the RAND Corporation in Arlington, Virginia, and director of the National Collaborative on Gun Violence Research, a philanthropic organization that funds research on the topic. "Where are illegal guns coming from? Are different state laws effective? Are the programmes that are being developed to counter firearm suicide effective? There are so many questions that we don't have answers for."