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Genetic privacy

The ability to identify an individual from their anonymous genome sequence, using a clever algorithm and data from public databases, threatens the principle of subject confidentiality.

How private is private? A study published on 17 January reveals vulnerabilities in the security of public databases that contain genetic data, the latest in a series of similar revelations. So far, research funders that host the databases have responded to such problems on a case-by-case basis, but it is now clear that the research community as a whole must devise a more comprehensive approach.

In the latest study, led by Yaniv Erlich at the Whitehead Institute for Biomedical Research in Cambridge, Massachusetts (M. Gymrek *et al. Science* **339,** 321–324; 2013), researchers showed that they could discover the identity of some men whose genomes had been sequenced as part of a genomics project (see *Nature* http://dx.doi.org/10.1038/nature.2013.12237; 2013). Erlich's team wrote an algorithm that infers an individual's pattern (a haplotype) of genetic markers called short tandem repeats from the nucleotide sequence of his Y chromosome. The team then searched genealogical databases for the names of men with corresponding Y-chromosome haplotypes. The team confirmed the correct names by cross-referencing the possible last names with public records of people of similar ages and locations.

Using this strategy, the team was able to confirm the identity of known individuals whose genomes have been sequenced, such as genomics entrepreneur Craig Venter, and to discover the identities of anonymous research subjects, including five men who participated in both the 1000 Genomes Project and a study of Utah Mormons initiated by the Centre for the Study of Human Polymorphism (CEPH) in Paris. Erlich's team was also able to discern the identity of some of the study subjects' family members, because family pedigrees were collected as part of the CEPH study.

It is important to note that the CEPH cohort is particularly suitable for this method of identification, because of the volume of informative data that has been collected and published about CEPH participants. Their family pedigrees, the places where they lived and their ages at the time of the data collection are all public information. Or at least they were until the US National Institute of General Medical Sciences, part of the National Institutes of Health (NIH), responded to Erlich's study by removing participants' ages from public view on the Human Genetic Cell Repository website that it funds.

It would probably be more difficult to use Erlich's method to identify participants in studies lacking extensive demographic information. And Erlich responded in an exemplary way to his team's findings by contacting the NIH and other genetics researchers with his findings before publishing them. This sets an important precedent for constructively dealing with newly discovered privacy loopholes, and other researchers should take note. Erlich's team is also not publishing the names of the anonymous study participants whose identities they uncovered.

How the genetics community addresses these issues is crucial to how large-scale genetic studies will proceed. Although research participants are already sometimes told that their data might not remain private — as the CEPH study participants were — the fact that their identities could be revealed would seem a remote risk to them, as that has only recently become possible. It is now imperative that participants fully understand that it is unlikely that their identities can be kept hidden if their genetic data are revealed. Some participants might welcome this, such as those with an interest in genealogy. Others — perhaps those with stigmatized diseases, for instance — might not.

Moving data behind a controlled-access barrier lessens their utility to science and to society at large. But researchers need to show the public that they are acting as careful stewards of the data entrusted to them. Erlich argues that the solution is to make sure that participants understand what they're signing up for, and to adopt laws that adequately protect people against the misuse of their genetic information.

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Geneticists are brainstorming other proposals for balancing data sharing with the need to protect the privacy of research subjects. One is to move more data behind a controlled-access barrier, but to authorize trusted users to access the data from many studies, rather than having to obtain it piecemeal from different studies, as researchers must do today. There are logistical barriers to this — for instance, ensuring compatibility across databases. And it is debatable whether such restrictions might do more harm than good.

But if controlled access is not the right solution, it is up to the research community, in consultation with the public, to devise a better one. A solution should come sooner, rather than later, because this latest revelation of a privacy loophole will be far from the last. ■

Vigilance needed

Experiments that make deadly pathogens more dangerous demand the utmost scrutiny.

The year-long voluntary moratorium on research to engineer strains of the H5N1 avian influenza virus that can transmit between mammals has already borne fruit. Claims of public-health benefits have received thorough scrutiny, and the researchers involved have better explained the biosafety and biosecurity precautions that they take. The debate has drawn attention to, and exposed gaps in, the rules that govern 'dual-use' research — work that can bring public benefit but might also be used for harmful purposes. The row has also, for example, prompted long-overdue national guidelines in the United States and made funders everywhere more aware of the need to assess

risky research proposals proactively. In short, the moratorium — the lifting of which is announced this week (see page 460) — has seen serious thought on the complex issues involved.

In the past year, the debate's focus has somewhat shifted from bioterrorism concerns — which, being classified, are difficult for outsiders to evaluate — towards biosafety issues. And it has concentrated attention more broadly on how best to regulate 'gain-of-function' research: work intended to increase the transmissibility, host range or virulence of pathogens. The United States is the main funder of such research, and what it decides is key to international thought. The proposed framework for assessing H5N1 gain-of-function research, outlined by the US National Institutes of Health at an international meeting in Bethesda, Maryland, in December, spells out several criteria that such research would need to meet before being funded.

One can quibble with some ambiguities in the wording of those proposals, but overall the framework should serve as an important checklist. The criteria include sensible questions, such as whether safer, alternative approaches exist that could address the same scientific points. Researchers already accept the need for regulations in areas such as animal welfare, and an extra layer of review for gain-of-function H5N1 research — which will affect only a few projects — is a small price to pay for improved public confidence in safety and oversight.

Flu researchers have been generous with their time over the past year. They have engaged in public debates and expressed their often-conflicting views in commentaries in scientific journals. The polarization of views between proponents and opponents of such research has, however, too often resulted in reiterations of entrenched viewpoints, rather than substantive discussions. Whether justified or not, there remains a perception among many critics that the debate has taken place largely behind closed doors, and has been dominated by flu scientists and research funders who have vested interests in the outcome.

As several critics point out, the assessments of the relative risks and benefits of such research remain restricted to largely qualitative arguments. The formal, quantitative risk assessment common in the nuclear power and other industries could have helped to nail down and quantify risks, and would have informed the debate better. One year on, an irreproachable, independent risk–benefit analysis of such research, perhaps convened by a body such as the World Health Organization (WHO), is still lacking.

"The lifting of the moratorium by researchers must not be seen as closure of the debate."

When it comes to mitigating risks, it is gratifying that the WHO guidelines on mammalian-transmissible H5N1 research, released last July, go beyond simply discussing the required level of biocontainment facility. They also recommend that labs doing such work should conform to international risk-management standards, thus encouraging a culture of safety in all procedures and practices.

The guidelines go on to state [original emphasis]: "Given the potential of these newly developed laboratory-modified H5N1 strains to start a pandemic, it is important that facilities that are NOT able to identify and appropriately control the risks associated with these agents REFRAIN from working with them." Those are sensible words, but unfortunately lack any means of enforcement.

The lifting of the moratorium by researchers must not be seen as closure of the debate. The potential risks of the work demand exceptional precautions in any future research. It is clear that the immediate practical applications of gain-of-function flu research remain largely hypothetical, and that its true value lies in long-term fundamental research to improve understanding of the transmissibility and pathogenicity of the virus. That makes it even more incumbent on researchers and authorities to exercise the greatest responsibility and prudence. ■

Science stakes

With the Royal Institution in trouble, Britain's crowded public–science scene must evolve.

Since 1799, the Royal Institution of Great Britain has occupied a grand building in London's Mayfair, surrounded today by luxury shops and private art galleries. For many years, the building was a central part of British science. Michael Faraday dazzled crowds there in the nineteenth century with pyrotechnic displays of chemistry.

In many respects, its address, 21 Albemarle Street, is the Royal Institution (RI) — hence the consternation in the United Kingdom and abroad when *The Times* newspaper last week reported that the RI building was up for sale. The news was no surprise. The RI has been on the financial ropes for years, lumbered with the costs of a misguided £22-million (US$35-million) refurbishment.

Richard Sykes, the RI's current chairman, said last week that the charity was likely to be restructured. But the RI, whose property includes a remarkable collection of historic scientific equipment and documents, insists that it will continue its mission to educate and inform the public about science and will not fold.

In many ways, the RI is a victim of the trend it pioneered. When the charity started out in 1799, science itself was a novelty. What would now be deemed 'science outreach' was even more so. Albemarle Street became London's first one-way street, to deal with the crowds that headed there. Now, nearly every university encourages its academics to push their research to the public, and science communication itself has become a career.

Perhaps more importantly, people who wish to be informed about a topic no longer need to sit in an uncomfortable seat and listen to a lecture by an *éminence grise*. While the RI resolutely championed this formal mode of engagement, the rest of the world has moved on. The vectors of knowledge are the Internet and mass media, not refined public meeting rooms. In its defence, the RI has made some attempt to modernize, but it is still known to most people as the place with the famous old (and very steep) lecture theatre.

Happily, there remains a market for science events. People flock to informal venues and to the type of flamboyant entertainment pioneered by Faraday. Cafés Scientifiques have taken off in many countries, and thousands of people attend science festivals in the United Kingdom, elsewhere in Europe and in the United States.

With the future of the RI in severe doubt, those who care about science communication in Britain should take this opportunity to discuss publicly how the landscape should change. And if such efforts fail to be self-sustaining, the RI's trustees should consider whom to favour with the charity's collection of historic equipment and other resources.

Here is *Nature*'s brief guide to the runners and riders, should the RI withdraw from the race. The Royal Society does not have the corporate stomach or skills to take on a substantial increase in science communication and engagement activities. The British Science Association has appointed an ambitious new chief executive, and faces a tough challenge just to develop its annual public meeting into an event with national impact. The Wellcome Trust is strong in the crowded science-outreach field, at least in London, but is focused on biomedicine.

Alongside these, and with a lively pack of mass media, bloggers and tweeters snapping at its heels, the RI seems likely to emerge redundant, whatever happens to its lovely buildings. The institution best positioned to inherit its legacy is the Science Museum, which has invested well in showmanship and online facilities. It has yet to make its mark as a forum of national discussion, but has ambitions to do so. And its headquarters are always crowded with children and adults, and fun to visit, too. ■

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