

Keeping DNA 'all in the family'

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Scientists look for clues about therapies and cures for life-threatening childhood illnesses in children's DNA -- it seems only logical to do so. But the decision as to who should have access to DNA samples from children provides a unique ethical conundrum, says a Tel Aviv University researcher in a recent publication for the esteemed journal *Science*, co-authored by colleagues from The Netherlands and Canada. The recommendations, which call for new policies on access to biobanked children's DNA, could shape America's legislation on the issue in the coming years.

With his co-authors, Dr. David Gurwitz, director of the National Laboratory for the Genetics of Israeli Populations (NLGIP) in the Department of Human Molecular Genetics and Biochemistry at TAU, explains that we cannot be aware today of future implications of widely distributing personal [genetic information](#). In the wrong hands it could lead to unforeseen privacy risks. And since children cannot give consent to research on their DNA, they argue, population biobanks (including the National Children's Study planned at the U.S. National Institutes of Health) should not distribute DNA samples from children to outside researchers -- not before certain fail-safe checks are in place.

In-house research can be performed at the biobanks, they suggest, and the data published with sufficient protections, so that pediatric research is not seriously impaired or delayed. This approach gives maximal protections against the misuse of individual [genetic data](#) from non-consenting children, they write in *Science*. Additional measures could include encoding the critical data -- sets of polymorphic genetic

sequences -- an argument presented recently and one which Dr. Gurwitz agrees could be among the measures for protecting the privacy of DNA donors.

Weighing society against privacy

The recommendations are not written-in-stone, Dr. Gurwitz warns, but it's important that decision makers weigh in a number of factors. "When the societal benefits appear to outweigh the privacy risks, such as with DNA samples from disease-specific biobanks -- or tissues from children with paediatric diseases -- we suggest that the non-consented children's DNA could be distributed in the same manner as before to outside researchers, while taking appropriate safeguards," says Dr. Gurwitz.

"There are many new initiatives for children's biobanks taking place all around the world now, from the U.S. to China, yet we feel that not enough attention is being paid to addressing what could be serious concerns for the future privacy of participating children," he adds.

Avoiding future genetic discrimination

"We can expect that the today's younger generation will live a long and healthy life as active members of society, and we need to protect their future privacy," Dr. Gurwitz reasons. "What if a child whose parents donate her DNA today to a population biobank becomes a future candidate of a future national election campaign, and an opponent comes up with tell-tale hints to health risks carried in her DNA sequence?" Fifty years from now such data could be used to discriminate against people who want to take a mortgage, attend a private school, or immigrate to a new country, Dr. Gurwitz adds.

Dr. Gurwitz spoke at an European Science Foundation Biobanks meeting

last year, where he first suggested new guidelines for access by researchers to DNA collected from children. While research on children's DNA pushes full-steam ahead, Dr. Dr. Gurwitz and his colleagues want researchers to start openly discussing the ethics concerning biobanked children's DNA.

Through his work at TAU's unique NLGIP biobank, Dr. Gurwitz has seen firsthand how complex the issues of protecting the genetic details of individuals can be. The biobank he safeguards contains several thousand DNA samples, taken from consenting adult and healthy Israeli individuals. Representing diverse and unique ethnic populations of Israeli Jews and Arabs, the biobank includes people whose ancestral communities were isolated from each other in the Jewish Diaspora -- from India and Yemen to Iran, Georgia, Ethiopia, and Poland. The DNA samples of these donors have been constructive for scores of research projects on genetic contributions to cancer and other diseases, as well as on the history of the Jewish people. For example, studies have shown genetic relatedness of Jews from all over the Diaspora.

Studying these unique populations, and some of the unusual genetic diseases and traits carried through them, can be like a glimpse back in time, says Dr. Gurwitz. Such research also helps him visualize the future of medicine -- one where diseases will be managed with personalized medicine allowing individually-tailored, safer and more effective therapies, based on personal genetic information, but without compromising the privacy of the individual.

Source: Tel Aviv University ([news](#) : [web](#))

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