

DNA Land Consent



INTRODUCTION

You have your genetic data and you want to be part of DNA.Land? Great! Before you can be part of our community, we want to tell you a few things about DNA.Land, make sure you know what research is being done, what it will entail, and the risks and benefits. Remember: If you do decide to participate, you are free to withdraw your consent and to discontinue participation at any time, no questions asked. Your participation is entirely voluntary. We thank you for considering joining our community.



PURPOSE

DNA.Land is a place where you can learn more about your genome while enabling scientists like us to make new discoveries for the benefit of humanity. The website is not-for-profit and run by academics affiliated with [Columbia University](#) and the [New York Genome Center](#). The purpose of DNA.Land is to enable you to learn more about your DNA and allow you the autonomy to share your data to facilitate important scientific research at the forefront of genome sciences and medicine. Our goal is to help members interpret their data and connect potential participants with research studies.



PROCEDURES

After you provide consent, your participation would consist of creating your personal profile and securely uploading your genetic data to DNA.Land. We will use the most cutting edge genetic tools to analyze your data and return your results regarding ancestry, relatives, and different traits. As we want to learn about the genetic basis of different traits, we will ask you to fill out surveys relating to your (or your family's) ancestry and health. You will also have the option to automatically contribute data from your social media profiles for new types of analysis, allowing us to learn about traits that are dynamic and more difficult to measure such as social preferences. Your profile will also display a badge that summarizes your various contributions to DNA.Land. You can tweet this badge, share it on Facebook, or sew it on your old scout uniform.

There are no costs associated with taking part DNA.Land and you will not be compensated for participating.



CONFIDENTIALITY

We value your contribution scientific research through DNA.Land and respect your privacy. We are quite familiar with this matter. Our research on genetic privacy was featured in the mass media, including the [New York Times](#) and the [Wall Street Journal](#) and leading scientific journals, including [Science](#), [Nature Reviews Genetics](#), and [PLoS Biology](#). Therefore, we pledge the following guidelines that in our perspective will mitigate most of the risks while maximizing your impact on scientific studies:

- As a default, we will not share with third parties before obtaining your explicit permission: the personal identifiers in your profile, your contact information, your individual-level survey results, or your individual level-genomic data.
- If you do decide to connect your social media profiles with DNA.Land, we will never share your genomic data or survey data with any of the social media websites.

- To facilitate cutting edge research, as a default, we will only share with other researchers or publish aggregated data. For example, we will mix your genomic information with tens of thousands of other genomes before sharing the average allele frequencies with other researchers. We will follow the [best practices](#) and [tools](#) developed according to the “Framework for Responsible Sharing of Genomic and Health-Related Data” of the [Global Alliance for Genomics and Health](#) of the [National Institutes of Health](#).
- We may release your information if required to do so by law, or if such action is necessary to comply with state or federal laws or respond to a court order, subpoena, law enforcement or regulatory request, or search warrant.

We also have a skin-in-the-game philosophy. Both Principal Investigators of this website have made their individual genomes publicly available ([Dr. Pickrell's genome](#), [Dr. Erlich's genome](#)). We are in this together.



CODE OF CONDUCT

We also have some expectations of you. You agree not to use DNA.Land to promote hate, discrimination, or violence towards groups or individuals based on race, ethnicity, religion, sexual preference, gender, age, health data, income, or family heritage or to use DNA.Land for any illegal activity. We reserve the right to delete user profiles, data, and prevent user access at our discretion.



RISKS

There are no physical risks from participating in this study but there may be information risks.

We are going to provide you with information about your ancestry, traits, and relatedness with other individuals. You might learn unexpected findings about you or your family. These can include finding a certain [ethnic heritage](#), predisposition for a [trait](#), or a [non-paternity event in your family](#) (all examples are

from people we know and have worked with). For some, such information is empowering; for others, these findings create anxiety and discomfort.

As stated above, we will do our best to protect the information you provide to us. Despite our efforts, we cannot guarantee that your identity and/or data will never become known, which could have significant implications in some scenarios. We estimate that the risk for such a breach is low but not zero.



POTENTIAL BENEFITS

By being part of DNA.Land, you will be able to connect with the scientific community and learn more about your genome for free. Genetic research is transformative for understanding human heritage, health, and well-being. Thanks to people like you, our labs were able to solve the genetic basis of three devastating pediatric diseases ([1,2,3](#)), reveal the shared genetic origin of [multiple diseases](#) such as Parkinson's disease and schizophrenia, and understand how [humans evolved](#). We expect great outcomes from this project and thank you for being part of this scientific endeavor.

NEW INFORMATION

If any new information is learned about this study that might affect your willingness to stay in this study, you will be told promptly.



CONTACT

Dr. Yaniv Erlich is the investigator in charge of the study at the New York Genome Center. If you have any questions or requests for information relating to this research study or your participation in it, or if you want to voice a complaint or concern about this research, please email us (consent@dna.land).

If you have any questions about your rights as a research subject or complaints regarding this research study, or you are unable to reach the research staff, you may contact a person independent of the research team at the Biomedical Research Alliance of New York Institutional Review Board at 516-318-6877.

Questions, concerns or complaints about research can also be registered with the Biomedical Research Alliance of New York Institutional Review Board at www.branyirb.com/concerns-about-research.



CONSENT

I have read about this research study. All my questions about the study and my part in it have been answered. I understand that my participation is voluntary and I freely consent to be in this research study.

I expressly authorize the collection, processing, use and disclosure of my data for use in research.

I permit DNA.Land to contact me as part of the study.

I confirm that the data submitted to DNA.Land belongs to me or that I was explicitly authorized by the data owner to submit it on his or her behalf.

I understand that the research in this study may lead to new products, research tools, or inventions that have financial value. By signing this consent, I understand that I will not be able to share in the profits from future commercialization of products developed from this study.

I understand that the information served by DNA.Land is for only for educational and research purposes and it is experimental by nature. It is not intended to diagnose, treat, cure, or prevent any disease.

I understand that DNA.Land has the right to change the terms of this consent in the future.

By signing this consent form I have not given up any of my legal rights. I am free to withdraw my consent at any time and free of charge without providing a reason. I understand that results may be published and so cannot be destroyed.

Your electronic signature indicates that you have read and that you understand the above information and that you have decided to participate based on the information provided.