



Open Genomes

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Sample Collection and Sequencing Consent Form



Introduction

Before reading this 'Sample Collection and Sequencing Consent Form', please first review and sign our Consent Form for collecting, storing and displaying genetic sequence data, and making it publicly available for research.

Donating a genetic sample and having it sequenced is another simple and effective way to contribute to the advancement of genetic science. Your sample could be valuable for genetic research. Genomic sequencing technology is constantly changing and getting better, more complete and accurate, and less expensive. You or a relative may have already done genetic testing, but this is an opportunity to get the best sequences possible using different kinds of testing.

If you decide to participate, you may withdraw your consent at any time, no questions asked. Your participation is entirely voluntary.



Purpose

Before you contribute your genetic sample, we want to tell you a few things about Open Genomes and how donating your sample is different from having your sample sequenced commercially. Open Genomes is a worldwide research institution and international public charity. Open Genomes can collect your genetic sample, extract the DNA/RNA, store it, sequence it and make the results available non-commercially. We can do this through other non-profit research institutions, which can lower the costs. For-profit companies use your genetic sample, and can then sell it to other companies for their commercial research, while restricting access to everyone else. We can protect your sample and data from commercial exploitation and make sure it's available for not-for-profit scientific research. Donating your genetic sample this way can help make sure that it provides the greatest benefit to everyone and that it is being used solely for the public good.

As a not-for-profit charitable research organization, Open Genomes can also accept contributions to cover the cost of collecting and storing your genetic sample, and having it sequenced. Tax-deductible charitable donations can be used to pay for the sequencing, because your anonymous genetic sample and sequences will be made available to everyone for free, for non-commercial research. Also, more than one person or organization can get together to donate funds for the sequencing. Part of Open Genomes' mission is to stop commercial exploitation of genetic samples and sequences, to make sure that honest science is being done without unscientific agendas, and to refute false myths that divide people. You can help make a difference.



Procedures

If you decide to take part and send in a genetic sample, a sample collection kit will be sent to you. This sample can be saliva that you spit into a tube, or collected by a swab rubbed against the inside of your cheek or from a different area, or it could also be another external bodily fluid. Please follow the specific instructions on your kit. Any sample collected will just be from the surface of your skin or mucous membranes, and swabbing or spitting in a tube is entirely painless and should not cause any discomfort at all.

The extracted genetic material and possibly any remaining sample may be stored at a secure laboratory together with similar samples from other projects.

Because genetic samples may spoil or get used up, we may request that you provide additional samples.

Once your genetic sample has been sequenced, you will have access to your genetic sequences at the same time and in the same way as everyone else, as soon it's publicly released in the International Nucleotide Sequence Database (INSD), which includes the European Nucleotide Archive, NCBI Genbank, and the DNA Databank of Japan.

Because genetic sequencing is evolving and improving, we may further sequence your genetic sample in the future.

If you choose, you can request at any time that your genetic sample be removed and destroyed.



Confidentiality

Open Genomes values your contribution to the scientific community and your privacy. We pledge to adhere to the following guidelines which in our perspective will reduce the risks, while maximizing the scientific impact.

- We will not share any explicitly identifying or contact information connected to your genetic sample. Your anonymous sample will be identified by a code.
- We may share your genetic sample anonymously with other non-profit researchers for further genetic sequencing. Any researchers who sequence your sample will also make your sequences freely available to the public for non-commercial use in the International Nucleotide Sequence Database.
- Once your genetic sequence data has become publicly available, you may request that your anonymous sequence data be removed from the International Nucleotide Sequence Database. However, anyone could have already copied and stored your anonymous public data, so your data may still be publicly available.



Risks

There is virtually no risk from collecting a genetic sample from your body using swabs or from collecting your external bodily fluids, such as saliva.

While your genetic sample will be identified by an anonymous code, it might be possible for other researchers or sample storage and sequencing facilities who have access to your sample to identify you as the source. We will try to minimize this risk to the best of our ability. We will also try to ensure that everyone with access to your anonymous sample behaves ethically and respects your privacy.



Potential Benefits

- Donating your genetic sample will allow it to be sequenced in the future using new and better technologies.
- It may be possible for more than one person or organization to help pay for the cost of sequencing your genetic sample using tax-deductible charitable donations.
- Not-for-profit organizations may be able to do genetic sequencing more cheaply, with less overhead, so there can be opportunities to fund more research.
- Your genetic sample can be shared with other researchers who have access to new technologies that may not be available to anyone else.
- Your genetic sample may be stored indefinitely and sequenced repeatedly using different sequencing technologies, until it is used up.



Contact

Dr. Nathan Bowen PhD is the principal investigator and Dr. Brian Hamman PhD and Dr. Asa'ah Nkohkwo PhD FRSPH are the sub-investigators who are in charge at Open Genomes.

If you have questions, please email us at: info@open-genomes.org

If you have any concerns, complaints, reports of violations, questions about your rights as a research subject, or you are unable to reach the research team, you may contact a person who is independent of the research team at Fox Commercial Institutional Review Board, Ltd. at +1-217- 492-1369 www.foxirb.com.



Consent

I have read this consent, my participation is voluntary, and I freely contribute my genetic sample to Open Genomes.

- I expressly authorize the collection, processing, use, and sequencing of my genetic sample for use in research as indicated in the Confidentiality section.
- I have read and I also agree to the Open Genomes Consent Form for the contribution and sharing of genetic sequences derived from the sequencing of my sample.
- I permit Open Genomes to recontact me as part of the study.
- I permit Open Genomes to conduct further sequencing of my genetic sample.
- I permit Open Genomes to anonymously share my genetic sample with other researchers.
- I confirm that the genetic sample submitted to Open Genomes belongs to me personally and that I am over 18 years of age.

The sample collection, DNA storage, and genetic sequencing by Open Genomes is only for educational and research purposes and it is experimental by nature. It is not intended for us to diagnose, treat, cure, or prevent any disease. We encourage you to share your sequence results with licensed healthcare professionals.

Open Genomes has the right to change the terms of this consent in the future.

By accepting the terms of this consent form I have not given up any of my legal rights. I am free to withdraw my consent at any time without having to provide a reason. At any time, I can request that my DNA sample be removed from storage, and destroyed. Also, at any time after the sequence data is made public, I can request that my genetic sequence results be removed from the International Nucleotide Sequence Database and the Open Genomes site.

Signature

Date

Print Name

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For more information, see <http://www.open-genomes.org/imprint.html>