

BGI Cognitive Genomics Lab: Informed Consent to Participate in GWAS

Please read this document carefully before deciding whether to participate in this study.

What Am I Agreeing To?

By participating in this study, you are agreeing to allow us to use your genetic data, survey responses and any other non-identifying data for research on genetic markers associated with certain perceptual and cognitive abilities. **You are also agreeing to allow us to take reasonable measures to verify that your survey responses are accurate. These measures may include confirming a self-reported test score with the administrator of the test, verifying your self-reported educational credentials with the relevant university department, and determining whether your genetic data is consistent with your self-reported ancestry.** We will remove the Registration Information (information you provided about yourself when registering, such as name, email, address, user ID and password) that can identify you prior to using the data for research, in order to help protect your privacy as much as possible.

This document describes an ongoing research study conducted by the BGI Cognitive Genomics Lab (BGI-CGL). A person's level of intelligence is determined by a complex interaction of genetic, environmental, and stochastic factors. Our study aims to extract the genetic contribution to population variability in intelligence. Toward this end we seek your voluntary participation in this study.

The research consists of using your genetic data and/or survey responses and other non-identifying personal information to discover genetic markers that vary in frequency across levels of intelligence. In order for this research to receive approval by an ethical review board, people must give informed consent before joining. This document provides the following information, which is necessary for an informed consent:

- the nature of the research,
- what you are being asked to do,
- any risks and benefits of participation,
- and who to contact if you have questions.

How Do I Provide My Genetic Data?

After creating an account and filling out a survey, a DNA collection kit will be sent to the physical address that you have provided. You will have to spit saliva into the kit and then mix the saliva with a preservative according to the accompanying written instructions. This procedure poses absolutely no threat of injury. Finally you will mail the kit to a return address that will be provided to you.

In some rare cases, an individual's saliva does not yield usable DNA. If this happens in your case, we may recontact you in an attempt to obtain your DNA using a different protocol. In this event you will provide a separate Informed Consent.

How Will My Data Be Used in Research?

Your data will be used to discover links between genetic markers and cognitive abilities. Your genetic data and responses to surveys on these topics can help to find these links.

If you participate, BGI-CGL will use your genetic data, information you enter into surveys, forms, or features labeled with the BGI-CGL research logo, and your age and ancestral background. Together, these data are referred to in this document and the BGI-CGL website as "Genetic and Self-Reported Information". The Genetic and Self-Reported Information does not include identifying information (such as name, address, or email).

What Will You Do With My Data?

Your Genetic and Self-Reported Information will be stripped of personally identifying Registration Information and made available to a separate research environment. BGI-CGL investigators will then compare all participants' Genetic and Self-Reported Information to identify associations between specific genetic and non-genetic markers and traits, behaviors, or conditions.

BGI-CGL may collaborate with external parties. Under this informed consent, external parties will only have access to pooled data stripped of identifying information. BGI-CGL will never release your individual-level data to any third party without asking for and receiving your explicit authorization to do so.

Are There Any Risks to Participating?

There are some potential risks to participating in the BGI-CGL research study, as described below.

BGI-CGL uses a range of reasonable physical, technical, and administrative measures to safeguard your data, in accordance with current technological and industry standards. In particular, all connections to and from our website are encrypted using Secure Socket Layer (SSL) technology. However, you acknowledge that security safeguards, by their nature, are capable of circumvention and BGI-CGL does not and cannot guarantee that personally identifying information will not be accessed by unauthorized persons capable of overcoming such safeguards (such as hackers) who may use viruses, worms, trojan horses, and other undesirable data and software to obtain access to or damage our site. Your genetic data, survey responses, and/or personally identifying information may be stolen in the event of a security breach by unauthorized persons. If your data are associated with your identity they may be made public or released to insurance companies, which could have a negative effect on your ability to obtain insurance coverage. [Note, however, that the Genetic Information Nondiscrimination Act (GINA) protects Americans against discrimination based on their genetic information. Because of GINA, it is illegal to deny individuals health insurance on the basis of their genes.]

In summary, BGI-CGL has strong security procedures in place to minimize the possibility of a breach. Although BGI-CGL cannot provide a 100% guarantee that your data will be safe, BGI-CGL policies and procedures minimize the chance that a breach could take place.

Your genetic data may contain information that you find distressing or uncomfortable. For example, you may discover that you are not of a particular ethnic group, casting doubt on who your biological parents really are. Such surprising disclosures are rare in genetic research, but they are known to happen.

If BGI-CGL investigators publish results of this research study, your Genetic and Self-Reported Information may be made public, but only after being pooled so that identifica-

tion of your individual-level data is extremely difficult. However, it is possible that a third party that has obtained partial genetic data from you could compare the partial data to the published results and determine your survey responses.

As with any online service, if you disclose your account password to others, they may be able to access your account and your Genetic and Self-Reported Information.

There may also be additional risks to participation that are currently unforeseeable.

None of the surveys or other procedures used by the investigators in this research study are invasive or experimental. The procedures involved do not involve more than the minimal risks described above, and no compensation or treatment is available if injury occurs as a result of participation.

Are There Any Benefits to Participating?

At an advanced stage of the study, BGI-CGL may provide you access to your genetic data and interpretations thereof with respect to ancestry, disease risk, and predicted trait levels (including level of cognitive ability). However, you will not receive any financial compensation or other direct benefits from BGI-CGL for participating in research.

If BGI develops intellectual property and/or commercializes products or services, directly or indirectly, based on the results of this study, you will not receive any compensation.

How Will You Protect My Data?

BGI-CGL uses a range of physical, technical, and administrative procedures to protect the privacy of your personal information, your genetic data, and your survey responses. These measures are described in more detail in the BGI-CGL Privacy Statement to Research Participants.

How Do I Withdraw From This Study?

Receiving a sample collection kit, or any step up to that point (e.g. creating a login), does not commit you to participating in the study. You are free to discontinue your participation up till that point. After you have mailed your sample to us, however, your participation

will be considered complete. Any research on your data following the receipt of your DNA sample cannot be reversed, undone, or withdrawn.

Who Do I Contact If I Have Questions?

Send an email to contact@cog-genomics.org.