

Participating in the Personal Genome Project Memory Challenge

Before signing-up for the Personal Genome Project (PGP), participants are encouraged to read about the PGP on our [website \(https://pgp.med.harvard.edu/participate/\)](https://pgp.med.harvard.edu/participate/).

Step 1: Sign-up for the Personal Genome Project

If the participant feels comfortable being a PGP participant, they can sign the consent form to sign-up at the bottom of [this page \(https://my.pgp-hms.org/signup\)](https://my.pgp-hms.org/signup).

Failure to accurately represent your full name on this informed consent will invalidate your eligibility for enrollment. You may not submit or sign this consent form on behalf of any other person, even if you are the parent, guardian or hold a power of attorney or comparable authority with respect to such person.

Once you submit this consent form, you will not be able to change the name associated with your account. Please enter your name as it appears on government issued identification, such as a valid driver's license.

First name MI Last name

(optional)

Email

Step 2 ->

Continue to “Step 2” to create your account, then a confirmation email will be sent to you. Follow the link in the email to continue with registration.

It will take approximately 40-60 minutes to complete all of the registration modules. If you need to log out and come back later, your progress will be saved. Brief descriptions of each step are provided below.

5 minutes	Consent for Eligibility Screening Completed 3 minutes ago	✓
10 minutes	Eligibility Questionnaire Completed less than a minute ago	✓
instant instant	Eligibility Questionnaire Results Completed less than a minute ago	✓
30-90 minutes	<u>Entrance Exam</u> Current step	←
30 minutes	Review of PGP Consent Form Not started	🔒
30-60 minutes	Consent to Participate Not started	🔒
5 minutes	Name Designated Proxies Not started	🔒
1 minute	Trait Data Not started	🔒
1 minute	Identity Verification Not started	🔒
1 minute	Submit Enrollment Application Not started	🔒
instant instant	Enrollment Application Results Not started	🔒

Consent for Eligibility Screening: Participants determine whether they give permission for the PGP research team to administer the eligibility questionnaire. That is, to determine if the participant is eligible to participate in the PGP.

Eligibility Questionnaire: Participants answer a series of questions to determine if they are eligible to participate in the PGP. The requirements for enrollment are as follows:

- Willingness to share genetic, health and trait data in a public and non-anonymous manner.
- United States citizen or permanent resident.
- At least 18 years of age.
- Capable of giving autonomous consent. We do not permit enrollment through legal guardianship, for example.
- Current employees and students of the Principal Investigator (Dr. George Church) are not eligible.
- Identical (monozygotic) twins are welcome, but both twins must complete the enrollment process to be eligible.

Eligibility Questionnaire Results: Participants find out if they are eligible to enroll in the PGP.

Entrance Exam: Provides participants with information about the risks and benefits of participating in the PGP. Participants have to answer all questions correctly but they can repeat the individual modules as many times as needed. *There are a total of 6 modules.*

- Module 1: Human Subjects Research and Informed Consent (4 questions)
- Module 2: Genetic Concepts (6 questions)
- Module 3: PGP Enrollment Procedures (5 questions)
- Module 4: PGP Participation, Sample Collection & Data Release Procedures (4 questions)
- Module 5: Potential Consequences of Receiving Personal Genome Data (4 questions)
- Module 6: Risks Associated with Making Your Data Public (4 questions)

Review of PGP consent form: Participants are given a link to download the consent form for review. Once the participant has reviewed the form, they confirm by checking the box.

Review of PGP Consent Form

You must review the PGP consent form before continuing. [Download PDF now.](#)

I have reviewed the PGP consent form.

Save Consent review

Consent to Participate: Participants fill out certain fields on the consent form to ensure eligibility and confirm their name and email address to give informed consent.

Name Designated Proxies: Participants can name two people (next of kin or other trusted individual) to be their proxy only for purposes of this study. Participants are strongly encouraged to discuss their wishes with their family and “Designated Proxy” as part of their enrollment in the PGP.

Trait Data: This step informs participants that they can provide trait data on their PGP profile. This does not have to be done at this stage.

Identity Verification: This step informs participants that the PGP can, at a later date, require them to verify their identity. They do not have to do so at this stage.

Submit Enrollment Application: Participants click on “Apply to enroll” to submit their application to be a PGP participant.

Submit Enrollment Application

By clicking the submit button below, your application materials will be made available to researchers at the PGP for review. Your enrollment application will be reviewed as soon as possible, although the process may take time, possibly three to four business days or more. Once a determination has been made you will be notified by email that you are either (1) selected to continue, (2) waitlisted, or (3) rejected.

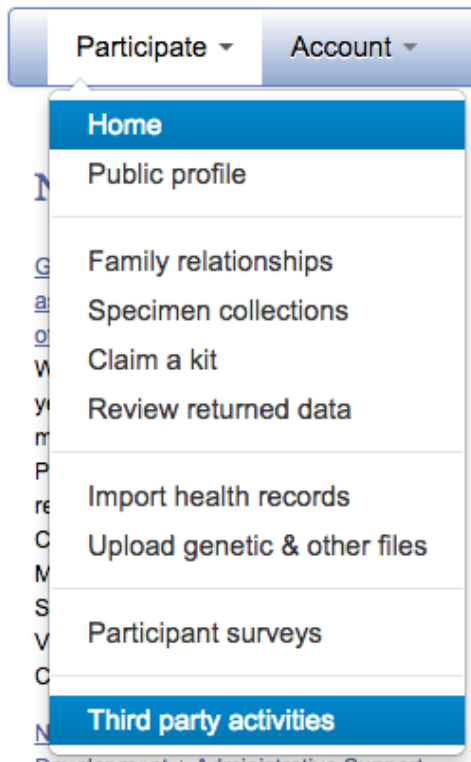
Apply to enroll

Enrollment Application Results: Participants are informed that they have been successful in their enrollment and are now PGP participants.

Step 2: Enroll in the PGP Memory Challenge

Participants log in to their [PGP account](https://my.pgp-hms.org/) (<https://my.pgp-hms.org/>) using the email address and password that they assigned in Step 1.

On their PGP profile page, go to:
Participate > Third party activities > PGP-Lumosity



Click on “Participate” to participate in the study.

PGP-Lumosity

As a participant, you will be invited to play 6 different games. The games are all done online and can be performed at your own convenience. Once you have completed all of the games, you will receive a summary report of your scores and your results will be counted in the study. You can repeat the test as many times as would wish.

The tests will require your full concentration to obtain the highest scores for you, and the most useful results for our study. To perform the tests, it will be best to set aside at least 30-minutes of time when you are well rested and comfortable without any distractions.

Researcher: Rigel Chan, Harvard Medical School

Clicking the “participate” button below will take you to the project’s web site. A token will be passed to confirm that you are a PGP participant — but the project will not yet be told *which* PGP participant you are. You may have an opportunity to make that linkage later to enable certain features, such as adding research data you receive from third party activities to your public PGP profile.

Participate



If you have any questions or would like more information, please contact Rigel Chan, Ph.D., and Elaine Lim, Ph.D. at pgpresearch@wyss.harvard.edu.