

PERSONAL GENOMES PROJECT: BACKGROUND

The Personal Genome Project (PGP) is a project dedicated to creating a totally unique scientific resource. The project involves recruiting people to have their entire genome sequenced and to have their results, together with personal data about their health and their lives, made publicly available online. The idea is to create a resource that researchers worldwide can use to advance our collective understanding of genetics, biology, and health.

Who are the participants?

The first 10 people to have their genomes sequenced by the PGP are called 'the PGP 10'. The PGP 10 were recruited in the USA in 2007, and included the genetics professor who founded the PGP (Dr George Church), and a mix of men and women of different ages.

The project aims to recruit a total of 100,000 people worldwide, from a diverse range of genetic, social and environmental backgrounds. Theoretically, anyone who meets the eligibility requirements (e.g. being at least 18 years old) can volunteer to participate. So far, the project is up and running in the USA, UK and Canada. There have been discussions about a PGP Australia.

What does being part of the PGP involve?

People can sign up online to be part of the PGP. When they sign up, they consent to have their entire genome sequenced and shared on the internet. They give samples of their blood, saliva, and skin cells, and provide detailed information about their health and lifestyle.

Giving consent to have your genome sequenced

People who sign up for the PGP are doing so on the basis that it's not anonymous, that information about them will become publicly available, and that any researcher anywhere can use their data.

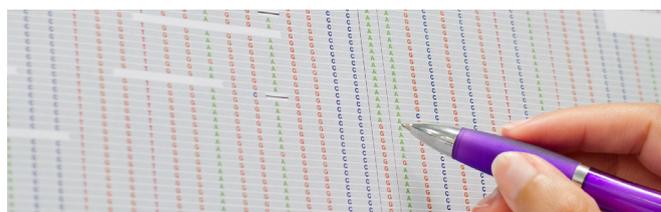
The people running the PGP take informed consent very seriously. Every participant is required to take an exam to show that they understand the risks and protocols involved, and to score 100% on that exam. However, some people believe that this type of test doesn't capture whether a person is informed enough.

What kinds of results are people getting?

People who have had their genomes sequenced are getting some results that have serious implications for their health. For example, a young woman found out she has an increased risk of Alzheimer's disease. A grandmother found out she has a high risk of breast cancer. A middle-aged journalist found out he has a genetic predisposition to a rare heart condition.

Who has access to the results generated by the PGP?

The results of the PGP are available online for anyone to access (see <https://my.pgp-hms.org/>). The intention is to make the results accessible to scientists worldwide so they can use the data for their research. In reality, though, anyone with access to the internet can see the results.



How would you feel about releasing your information to the world?

Credit: P. Morris/Garvan

Connect with the Garvan Institute's Kinghorn Centre for Clinical Genomics:

Visit us <http://www.garvan.org.au/kccg>

Follow our newsfeed on Twitter @kinghorngenomes

Email us at kccgenquiries@garvan.org.au

KINGHORN
CENTRE
FOR CLINICAL
GENOMICS

