

Appendix 1E - Privacy and Security Information Sheet:



Questions about participating in the community health research program, The Gene Health Project?

We've got answers!



How much will getting my DNA tested cost me?

WellSpan is offering The Gene Health Project to participants at no cost. The program will look at how your DNA affects your health. It may also help improve access to personalized health care and support new research discoveries for our community.



How do I know my DNA information is safe with WellSpan and their genetic testing partner Helix?

Your privacy and security are a top priority to us. Your information will be securely stored, protected and monitored by a dedicated team of information security professionals. Some of the technical safeguards include making sure only people who are approved can access information. Access to information is also closely monitored. All information is encrypted (coded) both while it is stored and during any approved transfer of data.



Is my data shared with law enforcement?

Signing the research consent form does not mean that WellSpan or Helix will share your research information with law enforcement. WellSpan and Helix take genetic privacy very seriously and would only share your research information with law enforcement in connection with a valid legal process requiring disclosure of such data or where disclosure is required by law (like a valid warrant or court order). All such requests would be reviewed on a case-by-case basis and you would be notified of such a request before sharing of any data occurs unless WellSpan or Helix is legally barred from doing so. Helix will object to any request that does not meet legal standards.



Will participating impact my health insurance?

To answer this very common question, it is important to know about a federal law that was implemented about 10 years ago called GINA (Genetic Information Nondiscrimination Act of 2008). GINA makes it illegal for health insurance companies and group health plans to discriminate against you based on your genetic information.

In addition, the Affordable Care Act of 2010 ("ACA") prohibits health insurance companies from refusing to cover you or from charging you more simply because you have a "pre-existing condition."



Will participating impact my life insurance, disability insurance, or long-term care insurance?

While the federal law GINA provides protection related to health insurance and employers, GINA does not prohibit providers of life, disability, and long-term care insurance from asking about and using genetic information. Some companies may require a review of your medical information, that may include genetic information returned to your medical record as part of participating in this study, prior to making a coverage decision. Some states do have additional protections for these types of insurance, so you may want to learn more about laws in your state. If you already have a policy, new information about your health (including genetic information) generally may not be used to deny you continuing coverage under those policies.



Will participating impact my employment?

GINA makes it illegal for employers to make decisions about whether to hire or fire employees based on genetic information. The law also prohibits labor organizations from discriminating against an individual based on genetic information.

Note: GINA's employment protections do not extend to all employees or in all circumstances.

For more information about The Gene Health Project, please visit WellSpan.org/GeneHealthProject.

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