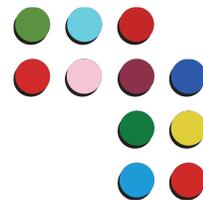


FREE THE DATA: HOW IT WORKS



What We (And You!) Are Doing with This Data

Free the Data is working to build an open access database of *BRCA1* and 2 mutations and associated clinical data, available to researchers and clinicians working to improve our understanding of hereditary breast and ovarian cancer. What's different about this database, though, is that it's open access on the terms of the person who's sharing. Free the Data does share mutation data with ClinVar, the open access database of genetic variant data at the National Institutes of Health... but access to any other health information you provide through Free the Data is **controlled by you**.

Free the Data uses a different kind of platform: PEER, the Platform for Engaging Everyone Responsibly. PEER is a platform from Free the Data partners Genetic Alliance and Private Access that empowers women and men to **take control of their health** and **drive medical research that matters**, by safely sharing medical test results and answering survey questions. When you create an account with PEER the first thing you do is decide who can and cannot access your health information. This means that the data in PEER is only available to specific researchers, advocacy groups and other health organizations with the permission of the person who shares it.

How to Share Data & Get Involved

Step 1: Create an account at www.Free-the-Data.org/freemydata and choose your personalized privacy settings. You select who can and cannot see and use your anonymous data, and who must ask first! You can change these settings at any time.

Step 2: Upload your deidentified *BRCA* report or hereditary cancer panel. We provide instructions on how to remove identifying information from your report. With your permission, your report will be shared with the open access database of genetic variation, ClinVar.

Step 3: Share additional health information with researchers and other groups of your choice, by answering some questions about your health. You can answer as many or as few questions as you would like. Depending on your personalized privacy settings investigators may want to use this information in a study.

Step 4: Visit www.Free-the-Data.org/join and help us spread the word: genetic information is more valuable when shared!

Note: If you'd like to opt out of creating an account with Free the Data and just share your report, that's okay too! Simply click on "Upload your BRCA Report" at www.Free-the-Data.org/freemydata. If you decide to share your report without creating an account, however, you will not be able to share additional clinical information with researchers or other groups of your choice who are working to improve our understanding of hereditary breast and ovarian cancer.

For more information on sharing reports, including information about who can share, please visit www.Free-the-Data.org/learn.