ARGO UHN

ACTION

Addressing global inequities in breast cancer genetic testing, counselling, and management among breast cancer patients in Nigeria

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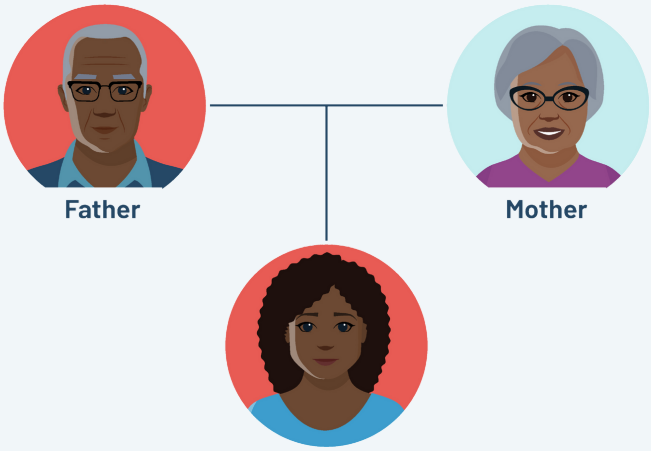
Patient Educational Brochure

Understand genetic testing

This brochure aims to support patients in having conversations about genetic testing with their healthcare provider (HCP) and family members. It provides general education for patients considering genetic testing.

What is a gene?

Genes are pieces of your DNA. Your DNA is found inside every cell in your body. Your genes tell your body how to work. Each gene has a role in your body. Some genes affect traits like your hair colour, eye colour and height. Other genes affect your risk for certain diseases, like cancer.



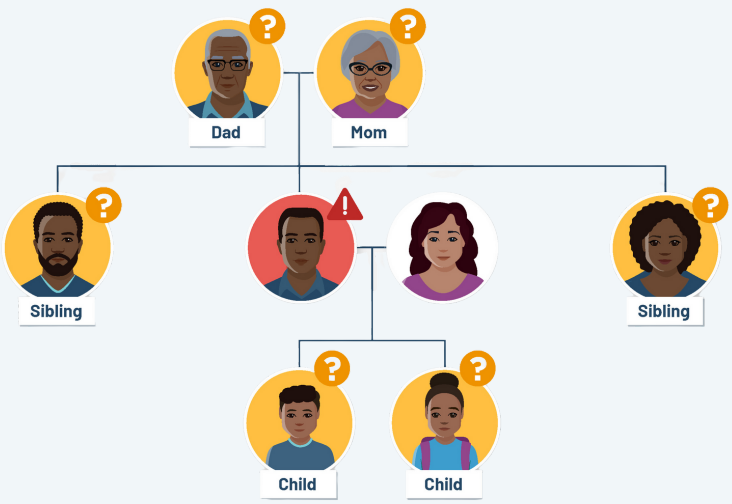
You get your genes from your parents. Half of your genes are from your mother. The other half of your genes are from your father.

What is hereditary (inherited) cancer?

Hereditary (inherited) cancer means a gene mutation is passed from one generation to another. A gene mutation is a change in a gene that stops the gene from working as it should. A gene mutation can raise your risk for cancer.

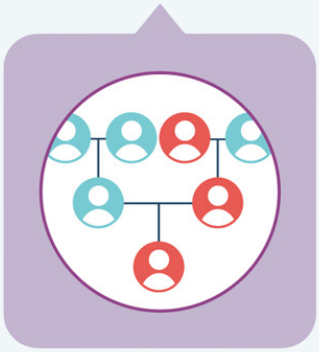
Families with hereditary cancers can have:

- Cancer at a young age
- More than one cancer in the same person
- Rare types of cancers such as ovarian cancer
- Many family members with cancer



A small number of people get cancer because of an inherited gene mutation.

- Approximately 10 to 15 people out of 100 (10-15%) get their cancer because of a gene mutation
- Most people who have cancer get their cancer by chance. 90 people out of 100 (90%) get their cancer by chance.



What is genetic testing?

Genetic testing is a saliva test that looks at your genes. Genetic testing looks for mutations (unwanted changes) in your genes. Your cancer risk depends on many factors. Some important factors linked to your cancer risk are gene mutations and family history of cancer. The genes most commonly affected in hereditary breast cancer are the *BRCA1* and *BRCA2* genes. Your cancer risk also changes depending on the gene mutation found.

For example, mutations to your *BRCA1* gene raise the risk for breast, ovarian, cancer and prostate cancer in male carriers. Your doctor will discuss if genetic testing is right for you.

How can genetic testing help me?

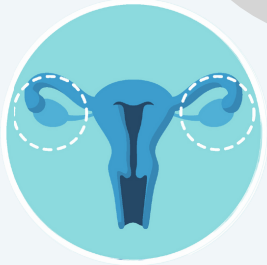
Genetic testing can help you in many ways. Genetic testing can help you:

1. Know why you got cancer

2. Decide your cancer care

Risk reduction means lowering your risk of cancer. For example, women with a high risk for ovarian cancer may have their ovaries removed before cancer occurs. Having their ovaries removed lowers their risk of ovarian cancer.

3. Know your risk of getting other cancers



4. Make choices about cancer screening and risk reduction

How can genetic testing help my family?

If you have a gene mutation, your family members may also have this gene mutation. Your gene mutation was likely passed down to you from one of your parents.

This mutation can also be passed on to your children. Your brothers, sisters, aunts, uncles, and cousins may also have this gene mutation.

If you have a gene mutation, genetic testing may be offered to your family members. This testing helps figure out whether your family members have a higher risk for cancer. If your family members have the gene mutation, their health care team may suggest changes to their health care. Health care changes may include cancer screening and risk reduction.

What are the possible results of my genetic testing?

There are 3 possible results of your genetic test

1 Mutation detected

This result means you have a mutation in one of the genes tested. Your lab report may say that a “pathogenic variant” has been detected. Mutations can also be called “pathogenic variants”. This result means:

- **You have a higher risk for some cancer types**
- **There may be changes to your cancer screening, treatment, and/or risk reduction plans**
- **Your family members may consider genetic testing**

2 No mutation detected

This test result means a gene mutation was not found. This result means:

- **You likely do not have a hereditary cancer syndrome**
- **Your cancer risk is based on personal risk factors and family history of cancer**
- **Your family members will likely not be offered genetic testing**

3 Variant of uncertain significance detected

This result means that a change was found in one of the genes tested but the genetics experts do not know if it is linked to cancer risk.

A variant of uncertain significance (VUS) is the medical term used to describe this result. You may notice this medical term used on your genetic testing results. This result means:

There is no change in your cancer screening, treatment, and/or risk reduction plan

Your cancer risk is based on personal risk factors and family history of cancer

Your family members will likely not be offered genetic testing

The healthcare provider that ordered your test will notify you if new information becomes available about your VUS.

What are the limitations to this testing?

The field of cancer genetics is always changing. If you receive a negative or VUS result it is still possible that:

- You may have a mutation in another gene that we did not test for
- You may have a mutation in one of the genes tested that we could not find with today's technology
- You may have a mutation in a gene that has not yet been discovered
- There may be a mutation in your family member(s) that you did not inherit

What if I have more questions about genetic tests?

Talk to your doctor if you have any questions about genetic testing.