

Talking About Biomarker Testing



A WORKSHEET TO HELP YOU DISCUSS PRECISION MEDICINE AND BIOMARKER TESTING WITH YOUR HEALTH CARE TEAM

Precision medicine is a newer way to find the right treatment for each patient, based on cancer subtype. Before, the only option was to treat all cancers of one type (such as lung or breast cancer) with the same treatment. Instead, in precision medicine, doctors use biomarker testing to find your subtype of cancer. Cancer subtypes are smaller groups that cancer can be divided into, based on certain traits of the cancer cell. Biomarker test results show which treatment is likely to work best for you. Precision medicine is only available for certain types and stages of cancer.

It is important to know the subtype of a cancer in order to plan treatment and determine possible outcomes. Biomarker tests can find your specific subtype of cancer.

This worksheet can help you talk to your health care team about biomarker testing and decide if it's right for you. Inside, you will find more information about biomarker testing, questions to ask your doctor, and questions to ask yourself.

WHAT IS A BIOMARKER?

A biomarker is a sign of disease or abnormal function that can be measured in your blood, tissue, or bodily fluid. In cancer, biomarkers are often used to help choose the best treatment for you. These biomarkers can be proteins, genes, or gene mutations. Biomarkers tell your doctor about the subtype of cancer in your body.

Biomarkers are often referred to by a 3 or 4 letter abbreviation. Examples of biomarkers are HER2 in breast cancer or EGFR in lung cancer.

For many cancer types and stages, it is now standard of care for doctors to test the cancer's genes for biomarkers.

WHAT IS BIOMARKER TESTING?

Biomarker testing helps your doctor match the right drugs to the specific subtype of cancer you have. This can be a targeted therapy or immunotherapy.

In biomarker testing, a sample of your cancer is collected from your blood, bodily fluids, or tissue taken during surgery or biopsy. The test looks for biomarkers in your cancer sample. The test results can be used to help guide your treatment options.

Your doctor may call this type of testing biomarker testing, genomic testing, molecular profiling, tumor marker testing, mutation testing, or molecular testing. These are all the same kinds of tests.

WHAT ARE TARGETED THERAPY DRUGS?

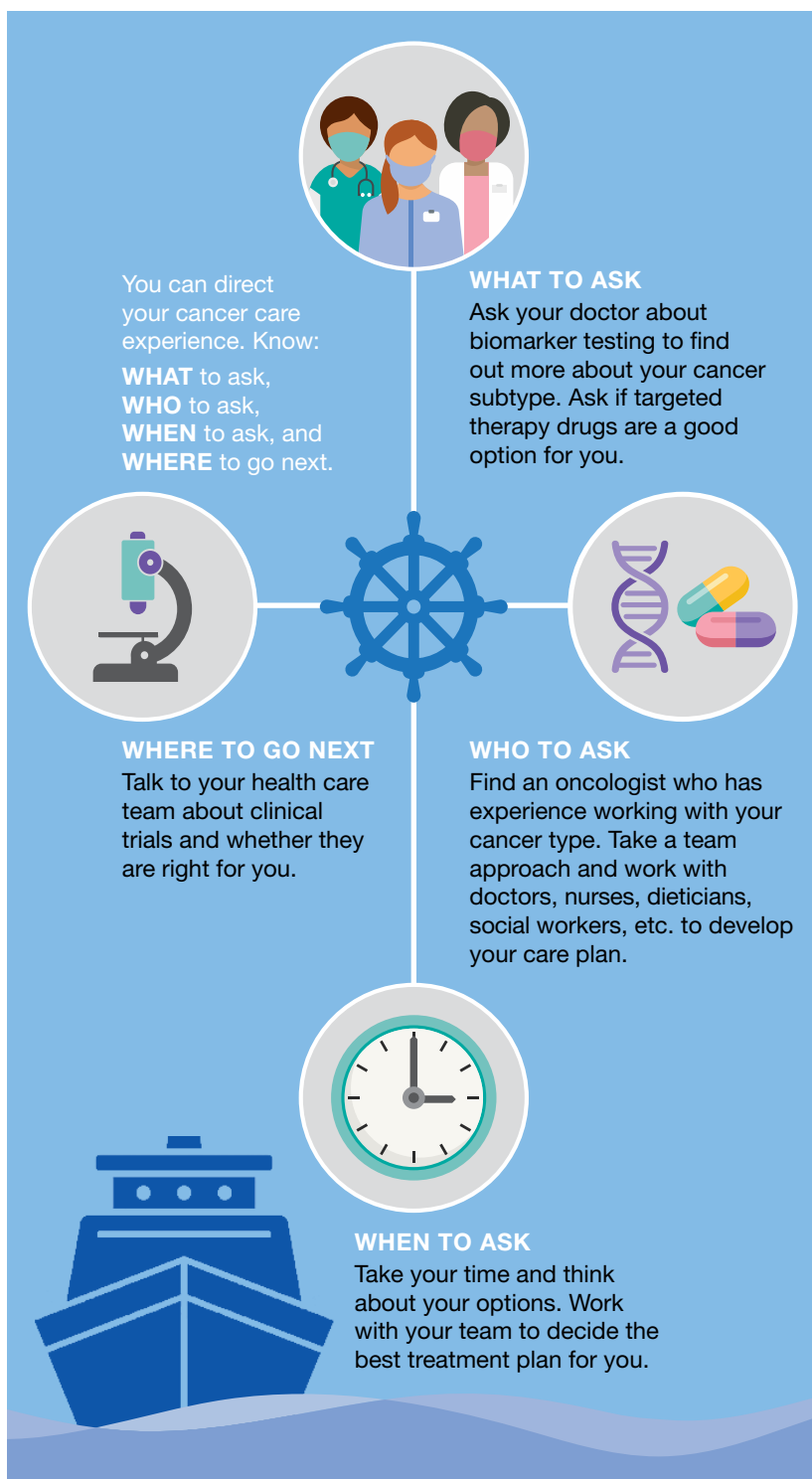
Targeted therapy drugs keep cancer from growing and spreading with less harm to cells that are not cancer. They may have different side effects than other treatments because they are better able to attack your cancer cells and leave healthy cells alone. These drugs "target" specific cancer subtypes. They are only likely to work in those specific subtypes.

These drugs can work in several ways:

- They can find cancer cells.
- They can destroy cancer cells directly.
- Or they can cut off the blood supply that tumors need to grow and survive.

STEER YOUR SHIP

Even if your doctor does not bring up biomarker testing, you can bring it up with your doctor. Biomarker testing can impact the course of your treatment. As the patient, you can steer your ship and direct your cancer care experience. This worksheet can help you do that by helping you identify what to ask, who to ask, when to ask, and where to go next.



TIPS FOR STEERING YOUR SHIP

- Be an active part of your health care team. Write down your questions before each doctor's visit. Keep a journal to take notes during your visit. Use a binder to include all labs, imaging reports, and other receipts in one place, unless you have a patient portal that does this for you. Repeat back what you hear for clarity and understanding.
- Ask questions until you understand what is being said. Ask to hear or read information in your first language. You can ask your doctor to draw you a picture or compare it to something you already know.
- Take someone with you to appointments for support and an extra set of eyes and ears. They can help you take notes during the appointment. If your loved one can't be there in person, consider trying a video call on your phone or computer. If you go alone, ask your doctor if you can use a recorder or cell phone to record your conversation.
- Know who on your health care team to contact with questions or problems and who to contact after hours.
- Talk to your health care team or financial navigator about ways to manage treatment costs.

WHO TO ASK

- Ask your doctor if biomarker testing is an option for you.
- If your doctor's office cannot do biomarker testing, ask if your doctor can send your samples out for testing to a lab that offers biomarker testing services.
- If you are told that testing is not an option, you should consider getting a 2nd opinion, even if it is over phone or online, at a cancer center or hospital where these tests can be done.
- Talking with a 2nd doctor can often help you better understand your cancer and how to treat it.
- A 2nd opinion can also make you feel more confident that you are making the right choices.

BUILD YOUR HEALTH CARE TEAM

Ideally, you would find a whole team (doctors, nurses, dietitians, social workers, etc.) that works together with you on your care. This is called a “multidisciplinary” team.

You need to be able to trust and talk easily with your health care team.

Here are some questions to ask cancer care team members to decide if their team is the right one for you:

1. Do you have experience working with my cancer type or subtype?
2. Do you accept my insurance? Are there any out-of-pocket costs for me?
3. Do you work with a team of health care professionals that can help me with different aspects of my care?
4. What tests or treatments would you suggest for my cancer type?

WHAT TO ASK ABOUT GETTING BIOMARKER TESTING

QUESTIONS FOR YOUR HEALTH CARE TEAM

Biomarker testing is the standard of care for some cancer types and stages so your doctor may suggest it for you. However, even if your doctor does not bring it up, you can always ask your doctor if biomarker testing is right for your cancer type and stage. Write down your questions before your doctor's visit so you remember what you would like to know. Below are some suggested questions and discussion points:

- Does my insurance pay for biomarker testing? If not, is there any financial assistance available for paying for biomarker testing?
- Does your office have a social worker or financial counselor or navigator that can help me determine if my insurance covers biomarker testing or help me figure out how to cover costs?
- Was my tissue or blood sample sent for biomarker testing? If so, which biomarkers did you test for?
 - If not, how can I get a sample of my cancer tested for biomarkers, to learn if there are any targeted therapies that might be right for me?
- Is there enough biopsy tissue for this testing? Will I need another tissue biopsy or a liquid (blood) biopsy?
- How long will it take for all results to be returned?
- How will you use the information to recommend a treatment plan?
- I am interested in getting a 2nd opinion about biomarker testing to make sure I am making the best decision for me. How do I access my medical records so that I may share them?

Notes/Additional questions:

WHAT TO ASK ABOUT YOUR BIOMARKER TEST RESULTS

QUESTIONS FOR YOUR HEALTH CARE TEAM

- Which biomarkers came back positive after the biomarker test?
- Where do I fall on the range for this biomarker test result?
- Were the test results clear enough or should I get tested again?
- Are there targeted therapy drugs, immunotherapies, or other treatments for this biomarker? If yes, what is this drug or treatment called, and do you recommend it?
- Can I start on one of those therapies now?
- Is this different from the treatment you would have recommended otherwise?
- Do the drugs, immunotherapy, or treatment have any major side effects?
- How long will this medication work and what happens if it stops working?
- Are there other biomarker tests that should be done?
- Will my insurance cover the cost of the recommended treatment? Does your office have a financial counselor that can help me determine if my insurance covers the cost of treatment or help me figure out how to cover costs?

Notes/Additional questions:

TALK TO YOUR DOCTOR

Because biomarker testing is based on the cancer type and stage, you should talk to your doctor about getting a biomarker test as soon as you would like.

Sometimes biomarker testing may be done when you have been diagnosed with an advanced form of cancer. It usually takes 2 to 4 weeks for biomarker test results to return from the lab. This may cause you to feel nervous, scared, or anxious about waiting to start treatment until your test results are back. Talk to your doctor about this. Your doctor may recommend you wait for the test results since they can help determine the best treatment for you.

WHERE TO GO NEXT

If your test results are positive for biomarker, talk to your doctors about getting targeted therapy drugs, immunotherapy, or other treatment options.

If your doctor performs biomarker testing, and there are no biomarkers found or no treatments options available based on your test results, ask your doctor if a clinical trial is right for you.

Clinical trials are research studies that help health care providers find the best cancer treatments. There are clinical trials for every type and stage of cancer. For more information about clinical trials, visit www.CancerSupportCommunity.org/ClinicalTrials

WHAT TO ASK ABOUT CLINICAL TRIALS

QUESTIONS FOR YOUR HEALTH CARE TEAM

- Am I a good candidate for a clinical trial?
- Are there any clinical trials you would recommend for me based on my test results?
- Did my test results find any biomarkers with targeted therapy drugs being tested in clinical trials?
- How can I learn more about clinical trials?
- How can I sign up for a clinical trial?
- Where can I learn more about clinical trials?

WHAT BIOMARKERS SHOULD YOU LOOK FOR?

Use this table to keep track of your biomarker test results and whether your doctor recommends a treatment for any positive biomarker test results. For a list of biomarkers that are commonly found in different cancer types, visit the National Cancer Institute: www.cancer.gov/about-cancer/diagnosis-staging/diagnosis/tumor-markers-list

BIOMARKER	TESTED FOR? (YES OR NO)	POSITIVE RESULT? (YES OR NO)	ARE THERE TREATMENTS AVAILABLE FOR THIS BIOMARKER?	DO YOU RECOMMEND THIS TREATMENT FOR ME? WHY OR WHY NOT?

Notes/Additional questions:

THINK ABOUT YOUR TREATMENT & PERSONAL GOALS

When you talk to your doctor about your treatment options, ask about the goals of the treatment and how each treatment might affect the goals that you have for your life. If you choose not to receive treatment, think about your goals for the care that you receive. Possible goals may be to live as long and/or as well as possible or make it to a special event/milestone. Let your health care team know about your treatment and personal goals.

Physical, Emotional, & Sexual Health and Well-Being:	<i>What is most important for you to be able to do? How is the new treatment going to impact your life?</i>
Family and Social Relationships:	<i>What's going on in the lives of others that is important to you?</i>
Work/School/Home:	<i>How does timing of the treatment work with what's going on in your life? Do you want or need to continue working? Can you adjust your schedule, responsibilities, or career goals? Are you getting the help you need for tasks at home?</i>
Community/Involvement:	<i>Are you getting the support you need from your community? Are you able to stay active/involved in your community?</i>
Personal and Spiritual Growth:	<i>Are you taking care of yourself spiritually and emotionally?</i>
Other	<i>What else is important to you?</i>

GETTING SUPPORT

Think about people in your life who can help. It might be your spouse or partner, adult children, friends, faith community, support group, or co-workers. Make a list of the specific ways each of them can help (childcare, meal prep, housework, transportation, laundry, etc.). Consider using **MyLifeLine.org** to help you stay organized and let friends know what you need. Ask your health care team about resources for social, emotional, physical, and practical support. If you search for information online, make sure that you are using trusted websites. Turn to the back page for a list of trusted organizations. CSC and many of these organizations have helplines, online discussion boards, and more ways to seek support from others who have cancer.

FINANCIAL RESOURCES

Even with health insurance, treatment is expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help. Talk with your health care team and your pharmacist about the cost of your treatment. Ask your doctor to refer you to an oncology social worker, patient navigator, financial counselor, or nonprofit organization for help managing the financial issues and costs. Ask if there are prescription assistance programs that can help cover all or part of the cost of your medications. The more you know about your specific treatment plan, the more you can help to reduce unexpected costs. To learn more about ways to manage the cost of treatment, visit: **www.CancerSupportCommunity.org/cost**.

COPING WITH YOUR EMOTIONS

As in any other aspect of your cancer journey, going through biomarker testing can lead to a range of different emotions.

- (1) You may start off confused about biomarker testing and how it can help your diagnosis. It's important to be prepared for your doctor's visits and come ready to ask any and all the questions you need. Remember it is your right to get a 2nd opinion.
- (2) After you get your biomarker test results you may feel sad, disappointed and scared if you learn that there were no biomarkers found. Talk to your doctor about your options for what comes next. Be sure to ask about clinical trials.
- (3) If your test results find that there may be a targeted therapy drug available for you, then you may feel excited, nervous, and still scared. You may be scared to learn that you have mutations but remember that finding mutations can actually help you find more treatment options.

Whatever you feel about the process is valid. It may help to talk to others who have experienced biomarker testing. Find a support group that fits your needs at your local CSC or Gilda's Club:

www.CancerSupportCommunity.org/FindLocation

BIOMARKER TESTING TOOL

Check out CSC's Biomarker Testing Online Tool to learn more about known biomarkers in lung cancer (more information on biomarkers for other cancer types will be added soon). Answer a few questions about the kind and stage of lung cancer you have and then our online tool will tell you what biomarkers matter for you and why. The tool will also highlight which biomarkers have approved targeted therapy drugs and which have therapies being tested in clinical trials. You can access the tool at: **www.CancerSupportCommunity.org/BiomarkerTool**.

Precision Medicine Information, Survivorship & Support

Cancer Support Community • 888-793-9355 • www.CancerSupportCommunity.org

American Cancer Society • 800-227-2345 • www.cancer.org

CancerCare • 800-813-4673 • www.cancercares.org

Cancer.net • 888-651-3038 • www.cancer.net

Fight Colorectal Cancer • 877.427.2111 • www.FightColorectalCancer.org/biomarked

GO2 Foundation for Lung Cancer • 800-298-2436 • www.go2foundation.org

Lazarex Cancer Foundation • 877-866-9523 • www.lazarex.org

Library of Medicine's Clinical Trials Search • www.clinicaltrials.gov

LUNgevity Foundation • 321-407-6100 • www.LUNgevity.org

National Cancer Institute (NCI) • 800-422-6237 • www.cancer.gov

NCI Precision Medicine Information • 800-422-6237 • www.cancer.gov/about-cancer/treatment/types/precision-medicine

Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org

Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET and Sat-Sun 9am - 5pm ET.

Open to Options® — Need help making a cancer treatment decision? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

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For more information and resources, please visit the CSC's Precision Medicine page at www.CancerSupportCommunity.org/Precision-Medicine. For print copies of this worksheet or other information, visit Orders.CancerSupportCommunity.org or call 888-793-9355.

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