



INSTRUCTIONS

Targeted Therapy for Cancer Adaptable Resource

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Instructions

Read the instructions carefully to prepare the adaptation of this resource to your local context, condition, and patient community and ensure its accuracy.

Find suggestions on how to use this tool throughout the resource.

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What will you find in this resource?

How to use the Targeted Therapy for Cancer Adaptable Resource

Adaptable Content

There are 8 sections that can be adapted in this resource.

Each section contains instructions for adaptation that will guide you through the necessary edits you will have to make to tailor this resource to your local context, condition, and patient community.

Introduction

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Annex

There are four additional components to this resource that may help you produce your adapted version.

Each annex provides additional information to support elaborating the main body of this resource, guide your adaptations, and inspire the expansion of your organization's toolkit for your patient community.

Annex 1

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INSTRUCTIONS FOR USE

What is this resource and why should you use it?

This Targeted Therapy for Cancer adaptable resource has been co-created to support patient advocates, patient organizations and other precision medicine champions in helping patients find the right information and make informed decisions about targeted therapies for cancer.

This resource can be tailored to a specific disease and geography. It builds on existing good practice resources and is developed in plain language to maximize the level of understanding.

This resource can support you to:

- Update existing resources on targeted therapies, or
- Create a new targeted therapy resource for your patient population.

What will you find in this resource?

This resource provides you with backbone content that can be adapted to a specific disease and local context. The content is accompanied by instructions to support you in adapting the resource for your patient community. Additional resources to help with adaptation are included in the [Annex](#).

You can also check [Precision Medicine Synapse](#) to find existing resources that you can leverage.

This resource is part of a suite of adaptable resources which also includes the [Precision Medicine Q&A Builder](#) and the [Biomarker testing for cancer treatment](#) resource.

These tools are part of a larger toolkit for PM champions, see [Annex 3](#) for more information or visit the [From Testing to Targeted Treatments \(FT3\) website](#).

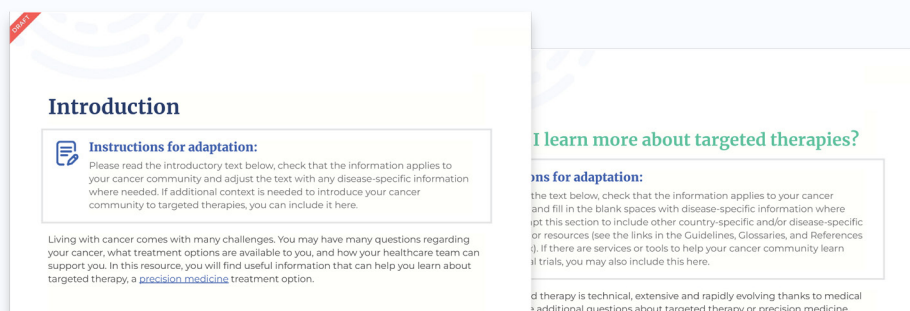


How to use the Targeted Therapy for Cancer Adaptable Resource

The following steps outline how to use this resource.

Similar to how this global adaptable resource has been developed (check [Annex 4](#)), we recommend following a co-creation approach by collaborating with different stakeholders (e.g. patient advocates, individual patients, healthcare professionals) to tailor the tool and ensure that different perspectives are taken into account and that information is clinically accurate.

Step 1: Download and open the adaptable resource content



Step 2: Adapt the text

- Read the text of each section of the resource, check that the information applies to your cancer community and edit it with disease-specific information where needed.
- If there is any additional information that should be included for your cancer community, include it in the relevant sections.
- Update and include relevant terms in the resource [Glossary](#) (we suggest marking glossary terms with bold font).
- Utilize the adaptable reference table in [Annex 1](#) to structure more detailed information on known biomarkers and accessible treatments.
- Consult the guidelines and glossaries in [Annex 2](#) for clinically relevant information and terminology as you adapt the resource.
- Make sure to delete all instructions for adaptation and sections that are relevant to you as the adapter, but not for your patient community.
- Need further help? Reach out to the [FT3 team](#) for support.



Step 3: Test & Refine

- When adapting this resource, it is encouraged to work collaboratively with different stakeholders to ensure that different perspectives are considered. For example, you can test the resource with other advocates or people living with cancer.
- Ensure that the plain language is appropriate for the target audience, and the language used addresses local, cultural, linguistic, and functional challenges/differences.
- Ensure to recognize and reference the original works that inspired this resource.
- It is recommended to have a healthcare professional review the content before finalization to ensure its clinical accuracy.
- You may want to consider what formats are most suitable for your target audience. When testing the resource check whether visuals or infographics can be included, or if the content could be repurposed in an audio or video format.

Step 4: Save your adapted resource as PDF & make it available as a download

Please reach out to the [From Testing to Targeted Treatments \(FT3\) team](#) if you need support in adapting this resource.



Introduction

Instructions for adaptation

Please read the introductory text below, check that the information applies to your cancer community and adjust the text with any disease-specific information where needed.

If additional context is needed to introduce your cancer community to targeted therapies, you can include it here.

Living with cancer comes with many challenges. You may have many questions regarding your cancer, what treatment options are available to you, and how your healthcare team can support you.

In this resource, you will find useful information that can help you learn about targeted therapy, a [precision medicine](#) treatment option.

What is targeted therapy?

Instructions for adaptation

Please read the text below, check that the information applies to your cancer community and adjust the text with any disease-specific information where needed.

You may want to consider the targeted therapies used with your cancer community and determine whether the definition covers them properly. If there is any additional information that should be included for your cancer community, add it on the next page.

Targeted therapy is a type of treatment that attacks specific **cells** in the body to stop or slow their growth. This precision treatment is based on the characteristics of an individual's own cells.¹

¹ LUNGeity Foundation (2021) Targeted Therapy Brochure.

Unlike **chemotherapy** or **radiotherapy**, targeted therapies can halt cancer growth and destroy cancer cells with less harm to normal cells. Targeted therapies do so by blocking the action of certain **enzymes**, **proteins** or other **molecules** involved in the growth and spread of cancer cells.



How do targeted therapies work?

Instructions for adaptation

Please read the text below, check that the information applies to your cancer community and adjust the text with any disease-specific information where needed. If any additional information should be added for your cancer community, include it below. For instance, depending on which targeted therapies are relevant to your cancer community, you may want to detail how they are administered (e.g. infusion, oral). If there are mechanisms of action specific to a therapy for a certain cancer type, you may also include this here.

You can refer to the template in [Annex 1](#), adapt it and include the information here to provide more information on relevant targeted therapies and how they work.

Targeted therapies “target” specific cancer cells in various ways. They can²:

- Block or turn off signals that tell cancer cells to grow and divide
- Prevent the cells from living longer than normal
- Destroy cancer cells

Targeted therapies are unlike chemotherapy or radiotherapy in that they seek out cancer cells with specific biomarkers, leaving healthy cells less affected³. They are only likely to work on cancer cells that have specific biomarkers⁴.

² Cancer.net from ASCO (2021) What is targeted therapy?

³ Cancer.org from American Cancer Society (2021) How Targeted Therapies Are Used to Treat Cancer.

⁴ Cancer Support Community. Precision Medicine Plain Language Lexicon.

How do I know if targeted therapy is right for me?



Instructions for adaptation

Please read the text below, check that the information applies to your cancer community and fill in the blank spaces with disease-specific information where needed. You may want to add content in this section to specify the biomarkers or other conditions applicable to your cancer community.

You may also want to adjust the text and provide more information on biomarker testing, such as different tests or sample types, or refer people to additional information on biomarker testing. You can refer to the template in [Annex 1](#), adapt it and include the information on biomarkers and their related treatments here.

To determine whether you are eligible for targeted cancer therapy, you will first need to undergo **biomarker testing**. Talk with your healthcare team ahead of time to decide whether biomarker testing is right for you and how likely it is that your cancer will respond to targeted therapy.

Biomarker testing seeks out biological molecules in your cancer cells - taken from either a tissue or blood sample - that can help diagnose or identify your cancer type.

A biomarker can also be referred to as a marker, tumor marker, genomic marker, signature molecule, molecular diagnostic or driver mutation.⁵

In _____ cancer, for example, the _____ biomarker can be targeted with the approved targeted therapy _____.

To learn more about biomarkers and biomarker testing in _____ cancer, please see _____.⁶

What can I expect while taking targeted therapy?

Instructions for adaptation

Please read the text below, and check that the information applies to your cancer community. You can adapt this section by outlining the most common side effects of targeted therapies available to your patient community. If there is helpful information on limitations to targeted therapies for your cancer community, such as resistance mechanisms, you may add this information here.

You can refer to the template in [Annex 1](#), adapt it and include the information on treatments and their related side effects here.

⁵ NCI Dictionary of Cancer Terms. "Biomarker."

⁶ If you do not have a resource on biomarkers, you can utilize the FT3 co-created adaptable resource on [biomarker testing for cancer treatment](#) for your patient community.

Since targeted therapies generally have less effect on your healthy cells, you may experience fewer **side effects** from these treatments than with others, such as chemotherapy and radiotherapy.

Side effects will vary depending on where your cancer is located and your specific treatment. Most common side effects may include diarrhea, skin problems, high blood pressure, liver problems and problems with blood clotting or wound healing.

Targeted therapy for _____ cancer most commonly has _____ side effects.

Targeted therapy is an important method of cancer treatment. As researchers learn more about specific changes in cancer cells, they will develop additional treatment options. Currently only a few cancer types are routinely treated using solely targeted therapies. Most people may also need surgery, chemotherapy, radiotherapy or **hormone therapy**.⁷ Targeted therapy may also work best when combined with other types of cancer treatment⁸.

When considering targeted therapy, it is important to know its limitations including:

- A targeted treatment will not work if your cancer does not have the specific biomarker to target⁹
- Even if you have the specific biomarker, it is possible the cancer will not respond to the therapy
- The response to the treatment may not last over time

If a targeted therapy stops working or your cancer returns, that may mean that your tumor cells have become resistant to a treatment. Resistance can happen when the target — the biomarker — changes, and the targeted therapy is no longer effective or your cancer finds another way to grow. At that point, another biomarker test may be needed to understand how your cancer has changed. This could identify new biomarkers to target.¹⁰



Where can I learn more about targeted therapies?

Instructions for adaptation

Please read the text below, check that the information applies to your cancer community and fill in the blank spaces with disease-specific information where needed. Adapt this section to include other country-specific and/or disease-specific information or resources (see the links in the Guidelines, Glossaries, and References in the Annex). If there are services or tools to help your cancer community learn about clinical trials, you may also include this here.

The topic of targeted therapy is technical, extensive and rapidly evolving thanks to medical research. If you have additional questions about targeted therapy or precision medicine, please refer to the following resources:

- [Include here additional information and educational resources, including information on patient organizations and support services.]
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⁷ Cancer.org from American Cancer Society (2021) How Targeted Therapies Are Used to Treat Cancer.

⁸ National Cancer Institute (2022) Targeted Therapy to Treat Cancer.

⁹ Cancer.net from ASCO (2021) What is targeted therapy? Accessed here.

¹⁰ Cholangiocarcinoma Foundation (2020) For Cancer Patients, Biomarkers Matter.

Additionally, **clinical trials** with targeted therapies can offer an important treatment option to people affected by cancer.

Advances in targeted therapies are based on information learned from patients enrolled in clinical trials.¹¹ Speak to your healthcare team about clinical trials or find more information at [fromtestingtotargetedtreatments.org](https://www.fromtestingtotargetedtreatments.org).



What questions should I ask my healthcare team about biomarker testing and targeted therapies?

Instructions for adaptation

Please read the text below, check that the information applies to your cancer community where needed, and include any additional questions that might be helpful for your cancer community. For a more comprehensive set of questions to address with your healthcare team, please refer to the Q&A resource [here](#).

Understanding biomarker testing

- What **diagnostic tests** do you recommend for my condition and why? What can the test results tell us about my condition?
- What will the tests involve? Are they available to me? How much time/energy will it take of me?
- When and where will I have my testing completed? Will all testing be completed now or will some be done later?
- Is there a waiting period to have any tests done? How long will it take to get the results?
- How will I be given my results? Who can help me understand them? Can I have a copy of my test results?
- What is the difference between genetic and biomarker (mutation, genomic, or molecular) testing?
- Do you recommend biomarker (mutation, genomic, or molecular testing) testing?
 - If so, which biomarkers are important for this particular type of cancer?
 - If so, which testing method is most appropriate for this type of cancer and why?
 - If so, what types of treatments might biomarker testing identify? If my biomarker test results show I am a candidate for precision medicine, what would the next steps be?
- Might there be a genetic (hereditary) explanation for my condition? Do you recommend **genetic testing**? Should other members of my family get tested?
- Is there counseling available for me to discuss the outcome?
- May I need to pay towards my tests? If so, are there financial assistance programs or resources you can recommend? (in countries where relevant)

¹¹ LUNGeity Foundation (2021) Targeted Therapy Brochure.

Understanding targeted therapy options



- Which treatment or combination of treatments would you recommend for me and why? Are there other treatment options available, such as clinical trials?
- What does each treatment aim to do and how effective is it likely to be? Is there anything I can do myself to help?
- Will I need any further tests before initiating the treatment? Will we wait to get all of the test results back before starting treatment?
- When will the treatment start? Is there time to wait and see, and time for me to consider my options?
- What are the potential side effects of the recommended treatments? How might they affect my quality of life? And what can we do to manage them?
- Will the recommended treatment interact with other medications I am taking for my condition or vice versa? How can we manage this?
- How do I take my treatment and how often? How will I know if it is still working? What will we do when it stops working?
- I would like to get a second opinion before I commit to my treatment plan. Can you suggest a suitable specialist?
- Is there any psychological/social/emotional support or tool available during my treatment to support me and/or my family members?
- Might I need to pay for my treatment? If so, are there financial assistance programs or resources you can recommend?

Glossary



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 are often referred to by a 3 or 4 letter abbreviation. Examples of biomarkers are HER2 in breast cancer or EGFR in lung cancer (Cancer Support Community, Precision Medicine Plain Language Lexicon).

Biomarker testing

(also referred to as Comprehensive biomarker testing, Gene-based cancer testing, Genetic testing of the cancer, Cancer marker testing, Next generation sequencing, Genomic profiling, Mutation biomarker testing, Genomic testing, Molecular profiling, Tumor marker testing, Mutation testing, Molecular testing)

Biomarker testing helps your doctor match the right drugs to the specific subtype of cancer you have. In biomarker testing, a sample of your cancer is collected from your blood, bodily fluids, or tissue taken during surgery or biopsy. Your sample is sent to a lab. The test looks for biomarkers in your cancer sample. The test results can be used to help guide your treatment options. Biomarkers tell your doctor about the subtype of the cancer in your body (Cancer Support Community, Precision Medicine Plain Language Lexicon).

Cells

In biology, the smallest unit that can live on its own and that makes up all living organisms and the tissues of the body. A cell has three main parts: the cell membrane, the nucleus, and the cytoplasm. The cell membrane surrounds the cell and controls the substances that go into and out of the cell. The nucleus is a structure inside the cell that contains the nucleolus and most of the cell's DNA. (National Cancer Institute, Dictionary of Cancer Terms).

Chemotherapy

A treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing. Chemotherapy may be given by mouth, injection, or infusion, or on the skin, depending on the type and stage of the cancer being treated. It may be given alone or in combination with other therapies (National Cancer Institute, Dictionary of Cancer Terms).

Clinical trials

A type of research study that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease. Also called clinical study (National Cancer Institute, Dictionary of Cancer Terms).

Diagnostic test

A type of test used to help diagnose a disease or condition (National Cancer Institute, Dictionary of Cancer Terms).

Enzymes

A protein that speeds up chemical reactions in the body (National Cancer Institute, Dictionary of Cancer Terms).

Genetic testing

The process of analyzing human cells or tissue to look for changes in inherited genes, chromosomes, or proteins that may be a sign of a disease or condition, such as cancer. These changes may also be a sign that a person has an increased risk of developing a specific disease or condition. Genetic testing may be done on tumor tissue to help diagnose cancer, plan treatment, or find out how well treatment is working (National Cancer Institute, Dictionary of Cancer Terms).



Hormone therapy

Treatment that adds, blocks, or removes hormones. For certain conditions (such as diabetes or menopause), hormones are given to adjust low hormone levels. Hormones can also cause certain cancers (such as prostate and breast cancer) to grow. To slow or stop the growth of cancer, synthetic hormones or other drugs may be given to block the body's natural hormones, or surgery is used to remove the gland that makes a certain hormone. Also called endocrine therapy, hormonal therapy, and hormone treatment (National Cancer Institute, Dictionary of Cancer Terms).

Molecule

The smallest particle of a substance that has all of the physical and chemical properties of that substance. Molecules are made up of one or more atoms. (National Cancer Institute, Dictionary of Cancer Terms).

Precision medicine

A form of medicine that uses information about a person's own genes or proteins to prevent, diagnose, or treat disease. In cancer, precision medicine uses specific information about a person's tumor to help make a diagnosis, plan treatment, find out how well treatment is working, or make a prognosis (National Cancer Institute, Dictionary of Cancer Terms).

Protein

A molecule made up of amino acids. Proteins are needed for the body to function properly. They are the basis of body structures, such as skin and hair, and of other substances such as enzymes, cytokines, and antibodies (National Cancer Institute, Dictionary of Cancer Terms).

Radiotherapy

The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy or brachytherapy). Systemic radiotherapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that travels in the blood to tissues throughout the body. Also called irradiation and radiation therapy (National Cancer Institute, Dictionary of Cancer Terms).

Targeted Therapy

Targeted therapy drugs keep cancer from growing and spreading with less harm to cells that are not cancer. They may have fewer 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. (Cancer Support Community, Precision Medicine Plain Language Lexicon).

Side effect

(also referred to as adverse event) a problem that occurs when treatment affects healthy tissues or organs. Some common side effects of cancer treatment are nausea, vomiting, fatigue, pain, decreased blood cell counts, hair loss, and mouth sores (National Cancer Institute, Dictionary of Cancer Terms).



Annex 1. Reference table for relevant biomarkers and approved targeted therapies

Instructions for adaptation

Please read the reference table below. You may want to adapt the content and include the information in the relevant sections above. Adapt the content as it applies to your cancer patient community and the approved and available biomarker testing and targeted therapies in your local context.

You may also want to add content to the table to include additional information helpful to your patient community, or use only the pieces most relevant to you and your patient community.

You can also find useful clinical guidelines and patient guides in [Annex 2](#) to support the adaptation of this content.

Biomarker	Approved targeted therapy	How does this therapy work?	How is this therapy administered?	What are the potential side effects of this therapy?



Annex 2. Useful guidelines and glossaries to support the adaptation of this resource

When adapting your resource you can make use of the following materials that can help you find the information you need.

Guidelines

- **American Society of Clinical Oncology (ASCO)**
Guidelines by Clinical Area.
Available at: <https://www.asco.org/practice-patients/guidelines>.
These clinical practice guidelines provide recommendations to serve as a guide for doctors and outline appropriate methods of treatment and care.
- **European Society for Medical Oncology (ESMO)**
Cancer Guides for Patients.
Available at: <https://www.esmo.org/for-patients/patient-guides>.
These guides translate complex medical information into a language understandable to patients. The medical information is based on the ESMO Clinical Practice Guidelines.
- **European Society for Medical Oncology (ESMO)**
ESMO Clinical Practice Guidelines.
Available at: <https://www.esmo.org/guidelines>.
Read about and find all available clinical practice guidelines by cancer type on this webpage.
- **European Society for Medical Oncology (ESMO).**
Handbook of Targeted Therapies and Precision Oncology.
Available for ESMO members at: <https://oncologypro.esmo.org/education-library/esmo-handbooks/targeted-therapies-and-precision-oncology>.
This handbook provides a better understanding of the molecular biology of several tumor types.
- **National Comprehensive Cancer Network (NCCN).**
Guidelines for Patients.
Available at: <https://www.nccn.org/patientresources/patient-resources/guidelines-for-patients>
This library of over 62 guidelines for patients with cancer offers plain-language recommendations on diagnostic procedures and treatment options from the NCCN Guidelines.

Glossaries



- **Cancer Support Community.**

Precision Medicine Plain Language Lexicon.

Available at: https://www.cancersupportcommunity.org/sites/default/files/fsac/Precision_Medicine_Lexicon_w_Introduction-Nov_2021-Updated_with_survey_results.pdf

- **Lungevity.**

Glossary.

Available at: <https://www.lungevity.org/for-patients-caregivers/helpful-resources/glossary>

- **National Cancer Institute.**

Dictionary of Cancer Terms.

Available at: <https://www.cancer.gov/publications/dictionaries/cancer-terms/expand/B>

- **National Cancer Institute.**

NCI Dictionary of Genetics Terms.

Available at: <https://www.cancer.gov/publications/dictionaries/genetics-dictionary/expand/B>

- **National Human Genome Institute.**

Talking Glossary of Genetic Terms.

Available at: <https://www.genome.gov/genetics-glossary/s#glossary>

- **Oncology Nursing Society.**

Genomics Taxonomy.

Available at: <https://www.ons.org/genomics-taxonomy>

- **U.S. Food and Drug Administration and the National Institutes of Health.**

BEST (Biomarkers, EndpointS, and other Tools) Glossary.

Available at: <https://www.ncbi.nlm.nih.gov/books/NBK338448/>



Annex 3. Toolbox for Precision Medicine Champions: additional adaptable resources

The precision medicine toolbox is a co-created and integrated set of resources and support for champions of precision medicine, providing a starting point that any advocate can adapt to a specific condition and local context.

Find here some additional adaptable resources from the toolbox and visit fromtestingtotargetedtreatments.org to find more information and resources.

1. Questions & Answers Resource Builder

An adaptable resource that includes a series of questions that patients can ask their healthcare providers at different moments in time to guide shared decision making in precision medicine.

2. Biomarker Testing for Cancer Treatment

A co-created adaptable resource for patients on biomarkers testing for cancer treatment.

3. Country and Condition Cards

The Country and Condition Cards provide a framework to detail a snapshot of the current situation of precision medicine availability in a given country and for different conditions.

The Cards provide an overview of the key parameters that have been identified as the first information that advocates and patients typically look for, such as the availability and reimbursement of testing and targeted treatments, available Comprehensive Cancer Centers and Molecular Tumor Boards.

See examples [here](#).

4. Patient Information Needs Map

A customizable resource to guide and organize information resources and other ongoing efforts to support patient education and awareness.



Annex 4. Acknowledgements and References

This resource was co-created by a global, multi-stakeholder working group of the [From Testing to Targeted Treatments](#) (FT3) Program.

FT3 brings together diverse stakeholders and activities in precision medicine to identify shared needs, build on existing good practices and learnings and make them replicable through practical and actionable tools and resources for precision medicine champions to drive real change and impact, starting with cancer and testing.

Ultimately, the goal is to develop integrated and optimized resources for different stakeholders to improve their understanding of precision medicine, and to develop a positive momentum to improve patient outcomes and experiences.

This resource is the result of the aggregation and consultation of resources developed by patient organizations and medical societies, which emerged as good resources in terms of scientific credibility, patient centricity, plain language, and ease of use. We thank them for their good practice inspiration.

The following resources were consulted in developing this adaptable resource:

- Bowel Cancer UK (2022) Targeted Therapy. Accessed [here](#).
- Cancer.net from ASCO (2021) What is targeted therapy? Accessed [here](#).
- Cancer.org from American Cancer Society (2021) How Targeted Therapies Are Used to Treat Cancer. Accessed [here](#).
- Cancer Research UK (2022) What are targeted cancer drugs. Accessed [here](#).
- Cancer Support Community (2019) Precision Medicine: Targeted Therapy. Accessed [here](#).
- Cancer Support Community (2021) Precision Medicine Lexicon. Accessed [here](#).
- Cholangiocarcinoma Foundation (2020) For Cancer Patients, Biomarkers Matter. Accessed [here](#).
- Cholangiocarcinoma Foundation (2022) Targeting the Mutations Seen in Cholangiocarcinoma. Accessed [here](#).
- Colorectal Cancer Canada (2021) Colorectal Cancer and Biomarker Testing: What Patients need to know. Accessed [here](#).
- Common Cancer Testing Terms (2019) Consistent Common Cancer Testing Terms. Accessed [here](#).

- LUNGeivity Foundation (2021) Targeted Therapy Brochure.
Accessed [here](#).
- LUNGeivity Foundation (2022) NoOneMissed.
Accessed [here](#).
- National Cancer Institute (2022) Targeted Therapy to Treat Cancer.
Accessed [here](#).
- Research Advocacy Network (2021) Precision Medicine in Oncology Educational Resources.
Accessed [here](#).

