

Precision Medicine Q&A Resource Builder (editable)

*Before starting, please make sure you have reviewed the instructions on how to use and adapt this resource!*

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# Section 1:



**Tips for your next appointment**

To prepare for your next medical appointment(s) and to ensure that it

runs smoothly, please consider the following:

Make a list of your **medical history** (including allergies, medical conditions, previous illnesses and/or surgeries, and relevant family history);

Make a **list of all the medications** you take;

Collect and bring all your relevant **medical reports;**

**Bring a notebook** with you to take notes;

Consider bringing a **friend or family member** to your appointment;

Consider the opportunity to ask for an **interpreter** if the appointment is held in a language different from your native one (if needed).

It may be helpful to prepare important questions and aspects that you would like to have clarified during your appointment. Use the following Q&A to prepare your list of questions and identify your concerns. The Q&A is organized around the most important steps of the patient pathway and you can therefore review those that are most relevant to you.

Some questions you may have might be addressed automatically in your appointments, be sure to bring any unanswered questions to your next appointment. However, if you think that some of the following questions were not answered or were not clear, don’t hesitate to ask.

# Section 2: Adaptable questions



**patients can ask their health provider at various stages of a disease**

**NEWLY DIAGNOSED Patients**

## UNDERSTANDING YOUR DISEASE

**Introductory text:** If you are newly diagnosed with cancer these are important questions to have in mind ahead of your next appointment(s).

*Your adapted version of the introductory text*

**Questions patients could ask:**

* What can be done to learn more about my disease and my diagnosis? Where can I find more

information?

* Would you recommend getting a second opinion, do you have a colleague you can recommend?
* Are there patient organizations or other patients like me that I can speak to?
* Might I need to pay towards my tests and/or treatment? If so, are there financial assistance

programs or resources you can recommend? (in countries where relevant)

*Your selected/ adapted questions*

*Copy paste here the questions you would like to use from above. Edit the question if needed to*

*adapt it to your diseases or geographic specificity*

## UNDERSTANDING DIAGNOSTIC PROCEDURES



**Introductory text:** Your doctor may order various diagnostic tests to help understand and diagnose your condition. These may include a biopsy, scans and/or blood tests. Please review below some important questions that you can ask your doctor in order to acquire a better understanding of diagnostic and testing options.

*Your adapted version of the introductory text*

**Questions patients could ask:**

* 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?
* Might I need to pay towards my tests? If so, are there financial assistance programs or resources

you can recommend? (in countries where relevant)

*Your selected/ adapted questions*

*Copy paste here the questions you would like to use from above. Edit the question if needed to*

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## UNDERSTANDING TREATMENT OPTIONS



**Introductory text:** Treatment options will depend on the specific type, stage or progression of your illness. Test results can be used to help you and your doctor decide about which care options and treatment(s) are best for you.

*Your adapted version of the introductory text*

**Questions patients could ask:**

* 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?
* Do I need to perform 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 long will it last?
* 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 tools available during my treatment to support me and/or my family members?
* Might I need to pay towards my treatment? If so, are there financial assistance programs or

resources you can recommend?

*Your selected/ adapted questions*

*Copy paste here the questions you would like to use from above. Edit the question if needed to*

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**Patients on TREATMENT**

## UNDERSTANDING DISEASE AND TREATMENT MONITORING

**Introductory text:** You will continue to be monitored once you have started your treatment. Over time your doctor will monitor how your illness is responding to the treatment, you may show an improvement or get better, or your condition might worsen. The questions below can support your upcoming conversation with your doctor in order to cover the most important aspects to you.

*Your adapted version of the introductory text*

**Questions patients could ask:**

* How will we know if my treatment is working? Will I need to have any further tests?
* What can I do to manage my treatment side effects?
* What happens if I experience severe side effects, will I need to stop my treatment?

*Your selected/ adapted questions*

*Copy paste here the questions you would like to use from above. Edit the question if needed to*

*adapt it to your diseases or geographic specificity*



**Patients with RELAPSED/REFRACTORY DISEASE**

## UNDERSTANDING ADDITIONAL TESTING AND/OR TREATMENT OPTIONS

**Introductory text:** When a treatment doesn’t work or stops working, you may need to explore other treatment options with your doctor. You may also have additional testing to inform additional potential treatment decisions. If there are few treatment options available for your condition you can speak to your doctor about the possibility of taking part in a clinical trial.

*Your adapted version of the introductory text*

**Questions patients could ask:**

* Do I need to change treatment or start a new treatment?
* What is the goal of a new treatment, what are we trying to achieve?
* What are the benefits and risks of different additional treatments? How might they affect my

quality of life?

* Is there a need for another biopsy to be performed?
* Are there any additional types of tests available that might open up other treatment options?
* Do you recommend biomarker (mutation, genomic, or molecular testing) testing at this stage?
  + If so, what types of treatments might biomarker testing identify?
  + If so, which testing method is most appropriate at this stage and why?
  + If so, should my biomarker test results show I am a candidate for precision medicine, what

would the next steps be?

* Are there any additional research options or clinical trials we could explore? Can you refer me?

*Your selected/ adapted questions*

*Copy paste here the questions you would like to use from above. Edit the question if needed to*

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**Patients in REMISSION**

## UNDERSTANDING MONITORING AND LONG-TERM CARE

**Introductory text:** Your illness may be chronic or you may be in remission. Your doctor will continue to monitor your condition and how it responds to treatment. New or additional treatments may be considered overtime if needed. As you monitor your condition over time consider the following:

*Your adapted version of the introductory text*

**Questions patients could ask:**

* Are there any other treatments we could consider - either to treat or to manage my condition?
* How often should I see my doctor to monitor my condition after my treatment ends?
* What long-term or late side effects should I look out for based on the treatment I received?
* I’m worried about my condition recurring or worsening. What signs or symptoms should I look

out for? Is there anything I can do to reduce my risk?

* Where can I find additional information or patient organizations to support me? Are there any

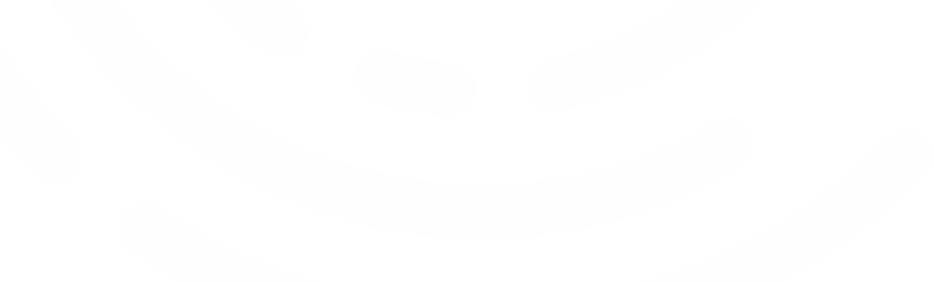
support groups available in my area where I can speak to other patients like me?

*Your selected/ adapted questions*

*Copy paste here the questions you would like to use from above. Edit the question if needed to*

*adapt it to your diseases or geographic specificity*

You can find here below a short **glossary of terms1** to help you navigate this resource:



**Glossary**

|  |
| --- |
| **Biomarker:** A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker can be a change in  DNA (mutation), RNA, or protein. A biomarker may be used to 1) detect a disease, 2) decide on a course of treatment, or 3) determine how well the body responds to a treatment of a disease or condition. Sometimes, a biomarker may perform more than one of these functions. |
| **Biopsy:** The removal of cells or tissues for examination by a pathologist. The pathologist may study the tissue under a microscope or perform other tests on the cells or tissue. |
| **Cancer stage:** The extent of a cancer in the body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body. |
| **Diagnosis:** The process of identifying a disease, condition, or injury from its signs and symptoms. A health history, physical exam, and tests, such as blood tests, imaging tests, and biopsies, may be used to help make a diagnosis. |
| **Diagnostic test:** A type of test used to help diagnose a disease or condition. |
| **Biomarker testing (mutation, genomic, or molecular testing):** Testing for any unique changes to the DNA or other biomarkers found in a person’s cancer. The information is used to identify and create targeted therapies that are designed to work for a specific cancer tumor profile. |
| **Genetic testing:** Genetic testing is the use of a laboratory test to look for genetic variations associated with a disease. The results of a genetic test can be used to confirm or rule out a suspected genetic disease or to determine the likelihood of a person passing on a mutation to their offspring. |
| **Refractory disease:** a disease or condition that does not respond to treatment. |
| **Relapsed disease:** The return of a disease or the signs and symptoms of a disease after a period of improvement. |
| **Remission:** A decrease in or disappearance of signs and symptoms of cancer. |

1 This glossary has been built based on the definitions reported in the following documents: LUNGevity Glossary: [https://www.lungevity.org/for-](https://www.lungevity.org/for-patients-caregivers/helpful-tools/glossary#g) [patients-caregivers/helpful-tools/glossary#g](https://www.lungevity.org/for-patients-caregivers/helpful-tools/glossary#g); National Human Genome Research Institute Glossary: [https://www.genome.gov/genetics-glossary/](https://www.genome.gov/genetics-glossary/g#glossary) [g#glossary](https://www.genome.gov/genetics-glossary/g#glossary); National Cancer Institute Dictionary of Cancer Terms: <https://www.cancer.gov/publications/dictionaries/cancer-terms/expand/D>