Understanding Diagnostic Tests and Procedures to Monitor Prostate Cancer
Your journey is unique... like you.

Most people who are diagnosed with prostate cancer would call their diagnosis ‘an event.’ From a medical perspective, however, a prostate cancer diagnosis is rarely the result of one test or one medical procedure.

Diagnosis is generally the result of a longer process, including several screening and diagnostic tests and much analysis. This is true whether you are:

- receiving your first diagnosis
- monitoring your progress after receiving treatment, or perhaps facing recurrent disease.

The tests, tools, and screening procedures you experience in the diagnostic process are like signposts on a journey. They are designed to identify where you are and point out the most efficient and effective route toward your desired destination, a healthy you.

“My prostate cancer diagnosis was unlike anything I’d faced before. I quickly realized it was time to learn.”

A Time to Learn

At Us TOO, we encourage you to view this as a learning experience. While there is a lot to learn, we know that you CAN learn what you need to know to make the best decisions for you.

If you find yourself confused or distressed:

- reach out for support
- ask for information
- become informed.

It is time to learn and you CAN learn what you need to know. Sure, there is a lot to learn and there are certainly many unknown terms. Don’t let these terms scare you. Men and their loved ones are learning this information every day. The best defense is education and communication.

“My job was to learn all I could so I could make decisions about my treatment that met my values and needs.”

You are Not Alone

Us TOO is here for you as you learn. Our goal is to provide support for you and your loved ones, information to illuminate your decisions, and a safe place for you to share and learn. You are not alone. At Us TOO, we understand and we care.

This is NOT the time to be silent, self-sacrificing, or withdrawn. Talk to your loved ones and lean on their support. Remember, you will hear differing opinions from fellow patients, survivors and even the medical professionals in your care team based on their area of specialty. Their input is important but ultimately, using all of the information and suggestions you have collected, you and your loved ones are the ones who will make the best decision for YOU.

“My life depended on speaking up and reaching out.”

About this Brochure

This brochure is designed to help you understand the diagnosis process. You will find valuable information about the most basic diagnostic tests and procedures, as well as tests and tools that may be lesser known but can be equally important.

It is possible you may never experience some of these tests. It is also possible that you may experience several of these tests to help determine the extent of your cancer, or monitor any prostate cancer metastasis or disease progression abnormalities.

Armed with information and support, you and your loved ones, along with your medical care team, can make the best decisions for YOU.

“Thank you, Us TOO, for all the important information. The more we knew, the more empowered we felt. More than anything, Us TOO gave us hope.”
The Good News

This is a dynamic time in the diagnosis and treatment of prostate cancer. The field is changing rapidly and advances in research, screening and treatment, as well as exciting breakthroughs and new products, emerge every day.

We also know more about prostate cancer than ever before. Doctors are better equipped to understand, diagnose, and treat prostate cancer, and patients and their loved ones are better informed as well.

“As a fifteen year survivor, I have seen a world of change since my journey began.”

You are the Leader of Your Care Team

Now is the time to become an expert on YOU. If you are diagnosed with prostate cancer, the expectation in health care today is that you are an informed patient and actively involved in your care and your choices. (NOTE: Over one million men per year undergo prostate biopsies and are not diagnosed with prostate cancer.) You are the leader of your care team. Look for answers. Take time to learn and be informed.

It is vital for you to learn and become comfortable with the terms, tests, and procedures in this brochure. This information will help you work closely with your care team and understand why they are reaching their conclusions. When you are informed and involved, you can make the best decision for YOU.

“Everyone had an opinion about my life. But, ultimately, I was the one who had to live it.”

Understanding the Diagnosis Process—THE BASICS

Doctors use four key tools for an initial prostate cancer diagnosis:

• **Blood**: measuring the levels of various hormones (testosterone) and proteins (PSA) in your blood
• **Touch**: feeling the prostate for perceptible changes or abnormalities (DRE)
• **Tissue**: tissue samples from the prostate (taken during a biopsy) are analyzed for the presence of cancer
• **Image**: images of your internal organs and bones (MRI, CT Scan, Ultrasound) help determine the extent of the disease.

The results of these four types of tests provide basic diagnostic information, such as the stage of your cancer and your Gleason Score (see information on page 6). You and your care team can use the results of these tests and tools to determine the best individualized course of treatment for YOU.

Beyond the Basics—CLARIFICATION

As you review the chart on pages 3–5, you will notice several tests in addition to the basic diagnostic tests listed in the previous section. These additional tests can provide clarity on certain aspects of your prostate cancer diagnosis. Many decisions about treatment options become clearer based on the information provided by these test results.

**NOTE:** Be sure to get copies of all your test results. This can be vitally important as you move from one medical professional to another. You may also want to graph your test results for better communication and understanding.

THE GOOD NEWS? When caught and treated early, prostate cancer has a cure rate of over 90%.

About Prostate Cancer

Everyone is an individual and every body is unique. Your health and diagnosis are unique to you as well. You may be at greater risk for prostate cancer based on your family history. Your treatment choices may also be different based on your disease progression and age, considering different treatment options if you are in your 50’s than if you are in your 80’s. Despite the unique nature of prostate cancer, there are some basics you should know:

The prostate (pros-tate) gland is about the size of a walnut. It is found only in men, just below the bladder and in front of the bowel. The prostate is connected to the seminal vesicles, which produce fluid that mixes with prostatic fluid produced by the prostate to form semen, the substance that transports sperm.

The exact cause of prostate cancer is not known. Normal prostate cells within the prostate grow, divide, interact, and die to make sure the prostate functions properly. Cancer cells within the prostate have lost control and grow on top of each other, forming a tumor. These cancer cells can break away from the prostate and travel throughout the body, attach to other tissues and continue to grow, a process called metastasis.
**Signposts for the Journey:**
*Diagnostic Tests & Tools Will Help You Choose Your Path*

<table>
<thead>
<tr>
<th>Test or Procedure</th>
<th>DRE (Digital Rectal Exam) Physical Exam</th>
<th>PSA (Prostate Specific Antigen) Blood Serum</th>
<th>Free PSA (written PSA-f or fPSA)</th>
<th>Testosterone &amp; Dihydrotestosterone (DHT)</th>
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<tbody>
<tr>
<td><strong>What are they looking for?</strong></td>
<td>Enlargement or other obvious abnormalities (such as a lump) in the prostate gland.</td>
<td>Prostate specific antigen (PSA) is a protein that is normally produced by the prostate gland. It is normal for men to have low levels of PSA in their blood and changes in PSA results (called PSA velocity) vary from person to person.</td>
<td>PSA is found in several forms in the blood. Most are bound to proteins and some are free-floating. The amount of unbound (or ‘free floating’) PSA in the blood may be helpful for the urologist to determine whether or not you need further testing, specifically a biopsy.</td>
<td>These hormones have many activities. An adequate testosterone level is necessary for sexual desire. Prostate cancer cells utilize male hormones known as androgens (testosterone is the most well known). Blocking these hormones generally reduces prostate cancer growth, at least temporarily and sometimes for a very long time. The measurement of these hormones is important to see if your treatment is adequate.</td>
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<tr>
<td><strong>Why are they doing this test?</strong></td>
<td>DREs are recommended as part of a man’s annual physical exam. Us TOO recommends both annual PSA and DRE beginning no later than age 40, or earlier if you are African American or have a family history of prostate cancer.</td>
<td>The PSA test is one indicator of abnormal activity in the prostate gland. It is not as much about the result, but the change of the results over time. All subsequent PSA test results are measured against prior results to detect changes. Your doctor will watch to see if and how quickly the PSA rises and how long it takes for the PSA reading to double.</td>
<td>Combined with prostate volume, percent free PSA calculation helps reduce the number of biopsies based on false positive PSA test results. This may spare you an unnecessary biopsy.</td>
<td>Tracking testosterone and dihydrotestosterone (DHT) measures the effectiveness of hormonal blockade treatment. It also is useful in assessing causes of sexual dysfunction.</td>
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<tr>
<td><strong>How do they do the test?</strong></td>
<td>The urologist gently inserts a lubricated gloved forefinger into the rectum in order to feel the prostate gland through the rectal wall.</td>
<td>Blood is drawn from the arm and examined in the lab. <strong>NOTE:</strong> Certain things can impact your PSA test result, such as sexual activity or certain types of physical activity prior to the test.</td>
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<tr>
<td><strong>Who does the test?</strong></td>
<td>Your doctor or urologist.</td>
<td>The doctor or a technician generally draws the blood and analyzes the results.</td>
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<td><strong>What do the results mean?</strong></td>
<td>The DRE is not a definitive cancer test, but regular exams help the urologist detect any cancerous or pre-cancerous conditions.</td>
<td>PSA test results report the level of PSA detected in the blood. The test results are usually reported as nanograms of PSA per milliliter (ng/mL) of blood and vary by age. The lower the PSA value the better, though prostate cancer can be present even if there is a low PSA level. If the prostate begins to make too much PSA, it could be a sign of an enlarged prostate (also known as BPH – benign prostatic hyperplasia), inflammation, or cancer. The result can signal your doctor that further tests are necessary.</td>
<td>The ratio of free PSA to the total PSA is reported as a percentage. Low percentage of free PSA may indicate prostate cancer. Percentages higher than 25% are much less likely to be associated with prostate cancer.</td>
<td>The results measure whether your treatment to block hormones, in order to reduce the growth and spread of prostate cancer, is effective.</td>
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<tr>
<td><strong>When would I have this test?</strong></td>
<td>The DRE is often used in combination with the PSA as part of a man’s regular health screening. It can be used anytime, however, to help your doctor identify prostate problems.</td>
<td>Us TOO recommends both annual PSA and DRE beginning no later than age 40, or earlier if you are African American or have a family history of prostate cancer. This establishes a ‘baseline’ result to which future results are compared. If you are experiencing prostate problems, this test could be done more frequently.</td>
<td>This test is used following a nonsuspicious DRE &amp; a slightly elevated PSA test (between 4 and 10 ng/mL).</td>
<td>Benchmark testosterone levels are usually established at the beginning of hormone blockade treatment. Levels are measured occasionally during treatment if levels remain stable, and more frequently if hormone treatment fails. They are also used in the evaluation of sexual dysfunction.</td>
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**NOTE:** Testing technology in all areas is improving every day. At the same time, technology does have its limits. Prostate cancer patients and survivors need to be persistent, vigilant and engaged in their care and follow up. On-going monitoring is a critical part of your care and well-being.

(continued on next page)
<table>
<thead>
<tr>
<th>Test or Procedure</th>
<th>MRI/MRS (Magnetic Resonance Imaging/Magnetic Resonance Spectroscopy)</th>
<th>Monoclonal Antibody Scan (ProstaScint™)</th>
<th>Bone Scans</th>
<th>Lymph Node Dissection (Pelvic Lymphadenectomy)</th>
</tr>
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<tbody>
<tr>
<td><strong>What are they looking for?</strong></td>
<td>MRI/MRS tests do not involve any radiation and use magnetic fields to scan tissue and can involve the use of an endorectal coil. These tests are best used for evaluating the prostate gland for local spread beyond the prostate border, cancer diagnosis, staging and treatment planning. MRI/MRS can be used to look for lymph node involvement but, like CT, the lymph nodes have to be large to be detected. They can also be used to confirm spread to the bones, or to detect recurrent cancer after treatment.</td>
<td>Prostate cancer can spread to lymph nodes. The ProstaScint™ scan is best used with a CT or MRI which identifies the anatomic location of any activity on the ProstaScint™ scan. This is called fusion imaging when the two are used together.</td>
<td>A bone scan is used to check for osteopenia, osteoporosis, and/or cancer arising from or spread to the bones. Prostate cancer is a common source for metastasis spread to bones.</td>
<td>The goal of pelvic lymph node dissection (LPLND) is to detect prostate cancer spread to the most commonly involved pelvic region lymph nodes.</td>
</tr>
<tr>
<td><strong>Why are they doing this test?</strong></td>
<td>To measure and gage cellular activity and metabolic processes in the pelvis and abdomen for prostate cancer, and to verify bone metastasis. MRI/MRS are also used to guide needle biopsies.</td>
<td>To look for prostate cancer spread to lymph nodes in order to stage prostate cancer.</td>
<td>A possible outcome of hormone deprivation therapy is loss of bone health. To determine if prostate cancer has spread to the bones. Bone involvement by prostate cancer will help determine treatment choices.</td>
<td>To assist in making the most appropriate therapeutic/treatment choices.</td>
</tr>
<tr>
<td><strong>How do they do the test?</strong></td>
<td>The MRI/MRS usually takes between 40 minutes to just over 1 hour, during which the patient remains as still as possible, sometimes with the help of a sedative. An endorectal wire coil inside a small, flexible plastic tube, is inserted into the rectum, then a balloon is inflated to hold the coil in place during the scan. Multiple cross sections are obtained at small intervals like CT. An external coil may also be used.</td>
<td>Patients receive an intravenous injection and a single photon emission computed tomography (SPECT) scan is usually taken about 4 days later in the nuclear medicine department or facility.</td>
<td>The patient is injected with an imaging agent containing tiny radioactive particles which are detected by a special type of camera. The patient lies still and the whole body is scanned under a special camera. The results are usually available a few hours later.</td>
<td>Lymph nodes in the pelvis are surgically removed at the time of a radical prostatectomy or before selection of therapy; tissue is then examined by the pathologist under a microscope to see if they contain cancer. The dissection is done when a physician is concerned about spread of the disease, so they look for spread to the lymph nodes.</td>
</tr>
<tr>
<td><strong>Who does the test?</strong></td>
<td>A nurse or physician will insert the wire coil in preparation for the MRI/MRS, and the radiologist and technologist will work with the equipment to perform the test.</td>
<td>The scan is performed by a technologist and a nuclear medicine physician or technologist will interpret the scan.</td>
<td>A radiology technician.</td>
<td>Surgeon.</td>
</tr>
<tr>
<td><strong>What do the results mean?</strong></td>
<td>The doctor can use the high resolution images to better see the prostate gland and determine if prostate cancer is present. If present, to determine if cancer is confined to the prostate. These images may be used for better diagnosis, staging, treatment, planning and assessment of recurrent disease.</td>
<td>If there is no activity on the scan, there is a low likelihood of lymph node disease. If there is activity on the scan, it is evaluated for its location. If it is not in lymph nodes, there is no cancer spread. If it is in the lymph nodes, the prostate cancer has likely spread. This gives information to your doctor about what treatment is best for you.</td>
<td>Treatment options will be determined based on whether or not the cancer has spread to the bones. <strong>NOTE:</strong> A bone scan will not pick up metastatic tumors until they are 1cm in size. A negative bone scan only definitively proves there is no tumor larger than 1cm. Vigilance and on-going monitoring are critical.</td>
<td>The spread of disease (or not) will determine follow-up or on-going treatment. Prostate cancer involvement in the lymph nodes may likely change the method of treatment.</td>
</tr>
<tr>
<td><strong>When would I have this test?</strong></td>
<td>To assist with initial diagnosis, staging, treatment, planning and as a follow-up tool after treatment if a recurrence is suspected.</td>
<td>If you have an increased risk to have cancer spread to lymph nodes at the time of diagnosis, the ProstaScint™ scan combined with CT or MRI (fusion imaging) will evaluate your lymph node status. If you have had previous treatment for prostate cancer and have a rising PSA, the fused scan will help determine the next step of your treatment.</td>
<td>Bone scans are obtained after the diagnosis is made if the PSA or the Gleason grade of the tumor on the pathological evaluation is high enough to increase the risk of bone involvement. Bone scans are also obtained as part of the evaluation if recurrence is suspected after treatment or if there is unusual bone-related pain in a patient known to have prostate cancer whose disease may be progressing.</td>
<td>Lymph nodes in the pelvis may be surgically removed at the time of a radical prostatectomy or before selection of therapy.</td>
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Cancer Stages Help Plan Your Route

Knowing the stage of your cancer provides important information for you and your care team as you explore your treatment options. There are treatment options that are specific to the various stages of the disease, whether it is caught early, at the advanced stages of cancer, or somewhere in between.

<table>
<thead>
<tr>
<th>Stage I (T1 tumor)</th>
<th>Found only in the prostate. Small enough that no tumor can be felt by a doctor during the digital rectal exam (DRE). A DRE can help a physician determine the size, shape, and texture of the prostate.</th>
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<tbody>
<tr>
<td>Stage II (T2 tumor)</td>
<td>Found only in the prostate. May be big enough to be felt by a physician during the DRE.</td>
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<tr>
<td>Stage III (T3 tumor)</td>
<td>No longer confined to the prostate gland. Has not yet spread (metastasized) to tissues outside the pelvic area. T3 tumors may have spread to the nearby seminal vesicles.</td>
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<tr>
<td>Stage IV (T4 tumor)</td>
<td>Detected in tissues far from the prostate. T4 tumors may have invaded other nearby tissues. N+ indicates that the cancer has begun to spread to the lymph nodes. M+ indicates that the cancer has metastasized, or spread, beyond the pelvic area to more distant tissue such as bone.</td>
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</tbody>
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Gleason Score Provides a Compass for Decision-Making

A Gleason Score describes different types of cells to classify tumors by their microscopic appearance. The score helps to estimate:
- how fast the cancer is likely to grow
- a patient’s life expectancy.

The Gleason Score is made up of two numbers which are determined by a pathologist and then added together. The first number indicates the type of cancer cells that are most numerous in the tissue sample. The second number indicates the type of cancer cells that are second most numerous. The total Gleason Score is determined by adding a primary and secondary score pattern for each lesion i.e. 3 + 4 = 7.

Gleason Scores and What They Mean

The lower the score, the better the prognosis.
- 2 to 4 Cancer is very low on an aggression scale
- 5 to 6 Cancer is mildly aggressive
- 7 Cancer is moderately aggressive
- 8 to 10 Cancer is highly aggressive

This score helps to determine the appropriate type of treatment.

Assemble Your Care Team

Now is the time to assemble your medical team. Understand what each team member provides and their area of specialty. Your doctors will certainly look to their training and area of expertise, but they will also look to:

- **Nationally Recognized Resources and Clinical Guidelines:** The National Comprehensive Cancer Network (NCCN), a not-for-profit alliance of 21 of the world’s leading cancer centers, is dedicated to improving the quality and effectiveness of care provided to patients with cancer. Through the leadership and expertise of clinical professionals at NCCN Member Institutions, NCCN develops resources and clinical practice guidelines appropriate for use by patients, clinicians, and other health care decision-makers. The NCCN Prostate Cancer Treatment Guidelines provide invaluable information and guidance for both patients and medical professionals. (www.nccn.org)

- **Clinical Data:** Large amounts of clinical data, such as those represented in the Partin tables, were originally developed based on accumulated data from hundreds of patients who had been treated for prostate cancer. Now the tables have been updated with the knowledge gained from having treated thousands of patients, to reflect the trends for newly diagnosed patients. Correlating the three things that were known benchmarks—PSA level, Gleason Score, and estimated clinical stage—the tables were designed to help doctors predict the definitive Pathological Stage and best course of treatment.

You Are Your Best Advocate

This is the time to be your best advocate. Take the time to learn about the diagnostic process. Understand your diagnosis and what is happening in your body. Reach out for support and ask questions.

Us TOO is here for you as you learn. Our goal is to provide support, information, and a safe place for you to share and learn. You are not alone.
Us TOO International is a 501-c-3 nonprofit, grassroots organization started in 1990 by prostate cancer survivors for prostate cancer patients, survivors, and their loved ones, and has grown to more than 325 peer-to-peer support group chapters in the U.S. and abroad.

Us TOO provides the finest global prostate cancer volunteer network, offering support, education, and awareness. Us TOO does not give medical advice in its support chapters or literature, but we are dedicated to helping men and their families learn more about prostate cancer, so they can make better decisions on treatment options and cope with emotional and quality of life issues they may face.

Us TOO produces and provides FREE information and materials for prostate cancer patients and their loved ones, available in both print format and on our comprehensive website, www.ustoo.org. Us TOO's materials span the full range of prostate cancer, from early detection to new diagnosis and advanced disease.

For additional information, contact Us TOO at 800-80-UsTOO (800-808-7866) or visit www.ustoo.org.

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