

# **METASTATIC PROSTATE CANCER HANDBOOK**



A Guide to Optimizing Outcomes with  
Germline and Somatic Testing

# Table of Contents

---

- Executive Summary ..... 3
- Introduction ..... 4
- Background..... 4
- Spotlighting Practice Barriers and Solutions..... 7
- Spotlighting Patient Barriers and Solutions ..... 13
- From Theory to Practice..... 23
- Closing ..... 28
- References..... 28

# Executive Summary

---

## Prostate Cancer Key Takeaways

### Background

Prostate cancer is one of the most prevalent solid tumors in men and accounts for 6% of cancer-related deaths in the US. Treatment options depend on the stage, with systemic therapies being central to managing metastatic disease. Genetic factors play a critical role in treatment planning, as both germline mutations (inherited, linked to more aggressive cancers) and somatic mutations (acquired, non-hereditary) guide therapeutic decisions. Precision medicine—incorporating genomic, environmental, and lifestyle data—is increasingly utilized to tailor treatment approaches for individuals.

### Practice Level Barriers/Solutions

#### Barriers:

- Staying current with rapidly evolving advancements
- Limited access to genetic counselors
- Lack of standardized procedures
- Time constraints during patient visits
- Restricted availability of cutting-edge treatments and clinical trials.

#### Solutions:

- Improve care coordination through multidisciplinary teams
- Utilize molecular tumor boards to guide decision-making
- Rely on trusted medical updates to stay informed on the latest developments.

### Patient Level Barriers/Solutions

#### Barriers:

- Financial limitations for diagnostics and treatments
- Health disparities among different demographics
- Knowledge gaps regarding genetic risks and cancer awareness
- Fear of potential outcomes of genetic testing
- Confusion between germline and somatic testing
- Distrust in the medical system
- Limited access to cutting-edge treatments and clinical trials.

#### Solutions:

- Leverage nurse and patient navigators
- Implement shared decision-making
- Optimize access to genetic counseling
- Address health literacy and language barriers
- Enhance patient education through community outreach initiatives.

### Conclusion

This handbook provides a comprehensive guide for overcoming barriers to genetic testing in metastatic prostate cancer care, offering actionable steps for multidisciplinary teams to improve patient outcomes. It also includes a working section for using the Plan-Do-Study-Act (PDSA) cycle to implement and continuously refine strategies, ensuring ongoing progress in addressing barriers and optimizing care. While this handbook outlines a planning process for the first 3 months of implementation, addressing barriers to care is ongoing. By continuously evaluating and refining these strategies, health care teams can foster a more informed, patient-centric approach to genetic testing for metastatic prostate cancer.

# Introduction

## The Purpose of the Handbook

This handbook is designed to provide professionals in clinical care settings with a comprehensive understanding of germline and somatic testing for mutations and adequate tools to optimize outcomes for patients with metastatic prostate cancer.

Incorporating insights from the Association of Cancer Care Centers (ACCC) member multidisciplinary focus groups and relevant literature to spotlight barriers, this handbook offers solutions, tools, and resources for providers and patients concerning genetic testing for metastatic prostate cancer.



Prostate cancer is one of the most prevalent solid cancer affecting men worldwide.<sup>1</sup>



**1 in 8 men** will be diagnosed with prostate cancer during their lifetime.<sup>3</sup>

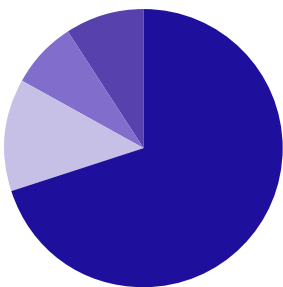
# Background

## Metastatic Prostate Cancer Overview

- Prostate cancer accounts for about 6% of all cancer-related deaths in the United States.<sup>2</sup>
- The American Cancer Society predicts that around 299,010 new cases of prostate cancer and 35,250 deaths related to this disease will occur in the United States in 2024.<sup>3</sup>
- A substantial proportion of prostate cancer cases are diagnosed at localized stages.

## Treatment Options Vary Depending on the Stage of the Cancer<sup>6</sup>

- **Localized prostate cancer**  
Management often involves active surveillance or local-regional therapy, such as surgery or radiation therapy, which can be effective in controlling the disease.
- **Regional prostate cancer**  
Management involves local-regional therapy with or without androgen deprivation therapy or castration.
- **Metastatic prostate cancer**  
Management typically requires systemic treatments, including androgen deprivation therapy, chemotherapy, and targeted agents. Metastatic prostate cancer poses significant challenges, as it remains incurable (albeit treatable) when it progresses to castration-resistant prostate cancer.



- **Localized:** 70.1% of diagnoses
- **Regional:** 13.2% of diagnoses
- **Distant (Metastatic):** 7.7% of diagnoses
- **Unstaged:** 9% of diagnoses<sup>4</sup>

- The probability of developing invasive prostate cancer increases with age.
- There has been a concerning annual increase in the proportion of cases diagnosed at an advanced stage over the past decade.<sup>5</sup>

Most patients with prostate cancer receive androgen deprivation therapy. This therapy involves reducing androgen production, targeting the androgen receptor pathway, or blocking androgen binding to receptors.<sup>7</sup> However, many patients develop resistance to androgen deprivation therapies within about 5 years of diagnosis, and it is expected that patients will eventually progress to castration-resistant prostate cancer.<sup>8</sup> Due to pharmacological advances in recent years, prostate cancer is still very treatable at advanced stages, but the sequence and combination of various therapeutic agents requires a physician that specializes in these treatments.

## The Role of Genetic Factors

Prostate cancer is a complex disease influenced by both genetic and environmental factors. Patients with genetic mutations often have worse outcomes with standard therapies, highlighting the crucial role genetic testing plays in the management of prostate cancer.

Genetic testing is a vital tool for improving patient outcomes and advancing the field of precision medicine. Test results can guide therapeutic decisions, as the genetic makeup of a tumor can determine eligibility for targeted therapies and personalized treatment approaches. In cases of hereditary/germline mutations, test results can have significant implications for the health and cancer risk of a patient's family.

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) recommend genetic testing as appropriate; these recommendations are regularly updated.<sup>6</sup>

Prostate cancer genetic testing focuses on identifying both germline (inherited) and somatic (acquired) mutations.

### Germline mutations

- Germline mutations are inherited with the potential to be passed on to offspring. They are present in all body cells.
- These mutations can increase the risk of developing prostate cancer and other cancers and may predispose individuals to more aggressive forms of the disease.<sup>7</sup>
- Mutations in DNA repair genes, such as *BRCA1*, *BRCA2*, *ATM*, *ATR*, *CDK12*, *CHEK2*, *FANCA*, *MLH1*, *MRE11A*, *NBN*, *PALB2*, *RAD51C*, *FANCL*, *BARD1*, and *RAD51D*, are linked to an increased risk of aggressive prostate cancer and may necessitate different treatment approaches.<sup>9,10</sup>
- Factors such as family history and ethnic background, particularly Ashkenazi Jewish origin, can influence the likelihood of carrying germline mutations and the risk of developing prostate cancer.<sup>11</sup>

### Somatic mutations

- Somatic mutations within the tumor cells occur over time as the disease progresses; they are not hereditary. They can provide valuable information about tumor characteristics

and guide treatment decisions.<sup>12</sup> Somatic mutations in DNA repair genes are also common in prostate cancer, particularly in more advanced stages of the disease.<sup>13</sup> Somatic testing is also known as biomarker testing or tumor testing.<sup>14</sup>



For more information on the distinctions between germline and somatic testing, please see the [ACCC Hereditary Cancer Syndromes tip sheet](#).

## The Impact of Precision Medicine on Treatment

The National Human Genome Research Institute (NIH-NHGRI) defines precision medicine as “an innovative approach that uses information about an individual's genomic, environmental, and lifestyle information to guide decisions related to their medical management.”<sup>15</sup> Precision medicine is often considered synonymous with personalized medicine.

Precision medicine has transformed cancer care by enabling:

- Earlier detection and improved diagnostic accuracy
- More precise disease prognosis
- Informed treatment choices
- Enhanced monitoring

By integrating phenotypic and genomic biomarkers with established and emerging medical imaging technologies, precision medicine has improved outcomes in more than 10 types of cancer, including prostate cancer.<sup>16</sup>

There have been several significant advancements in testing and treatment modalities in the last 30 years:

- **Prostate-specific antigen (PSA) testing**  
PSA testing has played a significant role in the decline of prostate cancer mortality. However, its limited sensitivity and specificity for distinguishing between prostate cancer and several nonmalignant conditions, like benign prostatic hyperplasia, requires additional diagnostic methods in clinical practice.<sup>8</sup>
- **Genetic biomarkers**  
Genetic biomarkers have predictive and prognostic value, improve metastatic cancer detection, and enable treatment to be tailored to individual patients.<sup>8</sup>

- **Targeted therapies**

Therapies targeting specific mutations have been shown to benefit patients presenting with metastatic castration-resistant prostate cancer by increasing overall survival.<sup>17</sup>

- **Novel imaging radiotracer and biology-guided radiotherapy**

The use of prostate-specific membrane antigen (PSMA) as a positron emission tomography (PET) tracer is a recent advancement that significantly enhances the detection sensitivity for prostate cancer metastases and helps to select patients for PSMA-based radiotherapy.<sup>18</sup>

## Emphasizing Patient-Centric Care

Patient-centric care has been recognized as 1 of the 6 key components of health care quality, together with safety, timeliness, effectiveness, efficiency, and equity.<sup>19</sup>

The main goal of patient-centric care is to achieve better outcomes for individuals, families, and communities supported by reliable health care systems that address their needs comprehensively and compassionately.<sup>20</sup>

In patient-centric care, patient values are considered in all decisions. Providers must consider and respect patient preferences<sup>21</sup> and how these intersect with making challenging choices among various therapeutic options.<sup>22</sup> Given the potential impacts of genetic testing on the patient and family, its inclusion as a standard of care should adopt a patient-centric approach, involving the patient in shared decision-making.<sup>22</sup>

According to the World Health Organization (WHO), patient-centric health care is based on the following values and principles:



**Human rights**



**Dignity**



**Nondiscrimination**



**Participation**



**Empowerment**



**Access**



**Equity**



**Equal partnerships<sup>20</sup>**

# Spotlighting Practice Barriers and Solutions

This handbook will guide your team through understanding and identifying barriers and solutions in your practice or program. Before you begin, identify who from your institution should be involved in this process.

## Checklist:

Below is a list of commonly included members of the multidisciplinary cancer care team. Use the checklist below to identify members of your care team involved in prostate cancer care management, and work through the rest of the handbook together.

It is important to note that not all practices will have all of these roles represented, and that is okay. The key aspect of a multidisciplinary team is improving collaboration across disciplines to enhance care.

Multidisciplinary Team Member Checklist	
<input type="checkbox"/>	Dietitians or Nutritionists
<input type="checkbox"/>	Financial Counselors
<input type="checkbox"/>	Genetic Counselors
<input type="checkbox"/>	Medical Oncologists
<input type="checkbox"/>	Nurse Practitioners or Physician Assistants
<input type="checkbox"/>	Pathologists
<input type="checkbox"/>	Patient Navigators
<input type="checkbox"/>	Pharmacists
<input type="checkbox"/>	Primary Care Physicians
<input type="checkbox"/>	Psychologists
<input type="checkbox"/>	Radiation Oncologists
<input type="checkbox"/>	Research Coordinators (patients are involved in clinical trials)
<input type="checkbox"/>	Social Workers
<input type="checkbox"/>	Surgeons
<input type="checkbox"/>	Urologists
<input type="checkbox"/>	Other

Effective delivery of genetic testing depends on several key components:

- Identifying individuals who may benefit from genetic testing based on their risk factors.
- Ensuring that appropriate genetic testing is accessible and performed accurately.
- Standardizing testing processes and results reporting within the practice.
- Providing appropriate counseling, support, and management when delivering results.

## Practice Barriers

While genetic testing has the potential to improve health by targeting preventive and therapeutic care, various barriers hinder its integration into routine medical care.<sup>23</sup> The following section outlines common barriers to providing comprehensive genetic testing within health care practices.

### Staying up to date with advancements in genetic testing for prostate cancer

Some health care providers may lack adequate education on specific details concerning genetic testing for prostate cancer, which is crucial for effective patient care. A health care provider should be able to:

- Identify patients at high risk for prostate cancer.
- Explain the process of obtaining and requesting genetic testing.
- Interpret test results.
- Communicate with clinical genetics services.
- Determine how to incorporate test findings into patient care.
- Maintain competency in genetic testing by reviewing updates to national guidelines and standards and vetted educational resources.

## Accessing genetic counselors

Surveys indicate that health care providers typically refer patients to genetic counselors when there is a family history of cancer or when a positive result or a variant of uncertain significance is found after ordering germline genetic testing (post-test counseling).<sup>24,25</sup> However, there are barriers to accessing these specialists:

- **Referral difficulties**

Many health care providers are unsure of how to connect patients with genetics professionals or coordinate referrals.<sup>23,24</sup>

- **Genetic counselor workforce deficiency**

The shortage of genetic counselors is a frequently cited issue by health care providers.<sup>24,25</sup> This can be particularly problematic in rural areas, as approximately 99% of certified genetic counselors in the US live or work within metropolitan statistical regions (areas with populations greater than 50,000).<sup>26</sup>

## Establishing institutional procedures for genetic testing



### Helpful Tip

The National Society of Genetic Counselors provides a [Genetic Counselor Workforce](#) resource for finding genetic counselors who offer telehealth services or are located within the patient's geographical region. In addition, many companies that perform the genetic testing will provide genetic counseling through a telehealth visit.

Health care providers have reported a lack of established workflows for genetic testing in patients with prostate cancer at the clinic, department, or institutional level<sup>25,27</sup>:

- There is no clear consensus for identifying patients who meet the criteria for genetic testing.<sup>27</sup>
- The lack of an integrated clinic workflow impacts all steps of the genetic testing process, from identifying individuals to be tested to making decisions after receiving test results. Some patients may fail to undergo testing, which can lead to missed opportunities for personalized treatment and can potentially impact patient outcomes.<sup>25,27</sup>
- A significant gap identified by health care providers is the lack of electronic health record (EHR) integration that would facilitate routine patient identification and provide readily available family history data to determine eligibility for genetic

testing for prostate cancer.<sup>27</sup> The complexity of the genetic testing process, from referral recommendations to the care pathway for patients with positive results, poses challenges for integrating genetic testing into the EHR.<sup>23</sup>

## Confronting time constraints during patient visits

Many health care providers face time constraints that hinder their ability to identify patients who are eligible for genetic testing and to facilitate referrals for testing.<sup>25</sup>

- According to one study, 60% of health care providers at a tertiary cancer center identified time constraints as a major barrier to providing genetic testing for prostate cancer.<sup>24</sup>

## Lacking access to the latest treatments and clinical trials

Several practice and provider obstacles impact the accessibility of clinical trials, potentially preventing patients from benefiting from the latest advancements in biomarker-driven precision medicine.<sup>28</sup> These obstacles include patient, provider, study, and institutional factors.<sup>29</sup>

- **Patient-level barriers:**

Patients are not always aware of the difference between somatic and germline testing and may not receive education about their options.

- **Provider-level barriers:**

These include insufficient awareness of currently enrolling clinical trials, inadequate research staffing, and unconscious biases that limit the invitation of individuals from some racial and ethnic minority groups to participate in clinical studies.<sup>29</sup>

- **Study-level issues:**

Challenges arise from restrictive inclusion criteria and complex processes that require multiple study visits.<sup>29</sup>

- **Institutional-level barriers:**

These involve inadequate processes for screening and matching for trials and the absence of periodic self-assessments at institutions.<sup>29</sup>

- Additionally, some US counties with high incidences of prostate cancer may lack access to the latest treatments or trials, compromising optimal care.<sup>30</sup>



## Checklist:

Review the following list of barriers and put a check mark next to issues experienced by your practice or program.

Practice Barriers	
<input type="checkbox"/>	Staying up to date with advancements in genetic testing for prostate cancer
<input type="checkbox"/>	Accessing genetic counselors
<input type="checkbox"/>	Establishing institutional procedures for genetic testing
<input type="checkbox"/>	Confronting time constraints during patient visits
<input type="checkbox"/>	Lacking access to the latest treatments and clinical trials
Use the space below to note any additional comments or ideas.	

## Putting Practice Solutions Into Action

Once practice barriers have been identified, solutions can be developed. There are various strategies to address each barrier, as outlined below. The boxes below correspond to the most applicable barriers and solutions. Identify the barrier(s) that your practice faces and refer to the checked cells to find the suggested solution(s). If you identify a solution that is not indicated in the table, you may document on your own.

Barriers	Solutions			
	Implementing evidence-based practices	Optimizing care coordination across the multidisciplinary team	Utilizing molecular tumor boards	Consulting medical updates from trusted sources
Staying up-to-date with advancements in genetic testing for prostate cancer	✓	✓	✓	✓
Accessing genetic counselors		✓		
Establishing institutional policy or procedures for genetic testing	✓	✓	✓	
Confronting time constraints during patient visits		✓		
Lacking access to the latest treatments and clinical trials			✓	

The following sections include more information about the solutions listed above.

### ***Implementing evidence-based practices***

The NCCN Guidelines® for Prostate Cancer recommend inquiring about known high-risk germline mutations/ family history and performing somatic and/or germline testing at the time of diagnosis for all metastatic patients.<sup>6</sup>

These guidelines are updated regularly. Specific recommendations are provided for patients who present with metastatic disease at the time of diagnosis or who progress to metastatic cancer. For detailed information on metastatic prostate cancer, germline testing, and somatic tumor testing, refer to the NCCN Guidelines.<sup>6</sup>

An international research panel has proposed a framework for genetic testing in metastatic prostate cancer, from sample acquisition to result reporting. They also provide key elements for successful testing and describe the roles within a dedicated multidisciplinary team that can help implement genetic testing for patients with metastatic prostate cancer.<sup>31</sup>

### ***Optimizing care coordination across the multidisciplinary team***

Management by a multidisciplinary team involves collaborative, comprehensive care from a variety of health care providers and has been directly correlated with overall patient survival.<sup>32</sup> Multidisciplinary teams are invaluable when addressing challenges associated with prostate cancer management.<sup>33</sup>



### **Helpful Tip**

Primary care physicians are often a trusted resource for patients to help make care decisions and interpret genetic test results, making them an important member of the multidisciplinary team.<sup>34</sup>

### ***Utilizing molecular tumor boards***

A molecular tumor board is comprised of medical experts consulted to advise on individual cancer cases. Molecular tumor boards combine expertise from medical oncology, pathology, and genetics to inform clinical decisions in precision medicine.<sup>33</sup> While molecular tumor boards are currently underutilized in prostate cancer care management, they have the potential to support complex decision-making and even reduce health disparities.<sup>33,35</sup>

Recommendations for enhancing the use of multidisciplinary tumor boards include:

- Establish minimum requirements for the expertise and qualifications of multidisciplinary tumor board members<sup>36</sup>
- Create appropriate policy to manage unsolicited findings (ie, germline findings that may impact both patient and patient family members).<sup>36</sup>

### ***Consulting medical updates from trusted sources***

There are various sources of medical information that providers can seek out, although they may not be equally trusted. Some top sources for medical information trusted by oncology providers include:

- Peer-reviewed scientific journals<sup>37</sup>
- Scientific databases<sup>37</sup>
- Continuing medical education (CME) content<sup>38</sup>

Other sources of medical information to consider include professional societies, hospital or institutional communications, and the Centers for Disease Control and Prevention.

By consulting trusted sources such as these, providers ensure that they can offer metastatic prostate cancer patients effective, evidence-based care in an evolving landscape of treatment options.

## Tools and Resources

<b>Implementing Evidence-Based Practices</b>	
Resource	Description
<a href="#">American Urological Association</a>	Guidelines and recommendations for evidence-based prostate cancer treatment. <sup>a</sup>
<a href="#">US Preventive Services Task Force</a> <a href="#">US Preventive Services Task Force Recommendation</a>	Recommendations for prostate cancer screening. <sup>b, c</sup>
<a href="#">American Cancer Society</a>	Recommendations for prostate cancer treatment based on stage and risk groups. <sup>d</sup>

<b>Ordering Somatic or Germline Testing</b>	
Resource	Description
<a href="#">Facing Hereditary Cancer Empowered (FORCE)</a>	Genetic testing recommendations for people with prostate cancer. <sup>e</sup>
<a href="#">Practical Methods for Integrating Genetic Testing into Clinical Practice for Advanced Prostate Cancer</a>  See Table 3: Suggested Reference Checklist of Considerations When Ordering Somatic or Germline Testing	For further guidance on integrating genetic testing into clinical practice for prostate cancer, Cheng et al developed a pre-test and post-test checklist for providers ordering somatic or germline testing. <sup>f</sup>

<b>Optimizing Care Coordination Across The Multidisciplinary Team</b>	
Resource	Description
<a href="#">Addressing Challenges and Controversies in the Management of Prostate Cancer with Multidisciplinary Teams</a>  See Table 2: The value of MDTs in addressing challenges/controversies across the prostate cancer disease continuum	Shore et al developed a table summarizing the value of multidisciplinary teams in addressing challenges along the prostate cancer care continuum. <sup>g</sup>
<a href="#">Addressing Challenges and Controversies in the Management of Prostate Cancer with Multidisciplinary Teams</a>  See Figure 2: Involvement of the prostate cancer MDT along the patient journey	Shore et al developed an infographic illustrating the involvement of multidisciplinary teams throughout the patient journey. <sup>g</sup>
<a href="#">Steps to Success: Improving Advanced Prostate Cancer Patient Management And Care Coordination</a>	The American Urological Association and Pfizer Oncology developed this resource featuring survey results and case studies on patient management and care coordination for patients with prostate cancer. <sup>h</sup>

## Utilizing Molecular Tumor Boards

Resource	Description
<a href="#">How to Maximize the Genomic Tumor Board Experience</a>	The Jackson Laboratory for Genomic Medicine developed a list of recommendations to get the most from a molecular tumor board consultation. <sup>i</sup>

## Consulting Medical Updates From Trusted Sources

Resource	Description
<a href="#">Association of Cancer Care Centers</a>	The Association of Cancer Care Centers (ACCC) is a community of cancer centers – representing members nationwide from all care delivery settings. <sup>j</sup>
<a href="#">The Centers for Disease Control and Prevention</a>	The CDC is a federal agency in the United States focused on public health and safety. <sup>k</sup>

## Sources

- a. Advanced Prostate Cancer: AUA/SUO Guideline. American Urological Association. Updated 2023. Accessed July 22, 2024. [auanet.org/guidelines-and-quality/guidelines/advanced-prostate-cancer](https://auanet.org/guidelines-and-quality/guidelines/advanced-prostate-cancer)
- b. Grossman DC, Curry SJ, Owens DK, et al. Screening for prostate cancer. *JAMA*. 2018;319(18):1901. [doi:10.1001/jama.2018.3710](https://doi.org/10.1001/jama.2018.3710)
- c. Prostate cancer: screening. U.S. Preventive Services Task Force. May 8, 2018. Accessed July 22, 2024. [uspreventiveservicestaskforce.org/uspstf/recommendation/prostate-cancer-screening](https://uspreventiveservicestaskforce.org/uspstf/recommendation/prostate-cancer-screening)
- d. Initial treatment of prostate cancer, by stage and risk group. American Cancer Society. Updated November 22, 2023. Accessed July 22, 2024. [cancer.org/cancer/types/prostate-cancer/treating/by-stage.html](https://cancer.org/cancer/types/prostate-cancer/treating/by-stage.html)
- e. Genetic testing guidelines for people diagnosed with prostate cancer. FORCE. Updated November 10, 2023. Accessed July 22, 2024. [facingourrisk.org/info/hereditary-cancer-and-genetic-testing/how-to-get-testing/testing-guidelines/prostate-cancer/guidelines-for-testing](https://facingourrisk.org/info/hereditary-cancer-and-genetic-testing/how-to-get-testing/testing-guidelines/prostate-cancer/guidelines-for-testing)
- f. Cheng HH, Powers J, Schaffer K, et al. Practical methods for integrating genetic testing into clinical practice for advanced prostate cancer. *Am Soc Clin Oncol Educ Book*. 2018;38:372-381. [doi:10.1200/edbk\\_205441](https://doi.org/10.1200/edbk_205441)
- g. Shore ND, Morgans AK, El-Haddad G, et al. Addressing challenges and controversies in the management of prostate cancer with multidisciplinary teams. *Target Oncol*. 2022;17(6):709-725. [doi:10.1007/s11523-022-00925-7](https://doi.org/10.1007/s11523-022-00925-7)
- h. American Urological Association; Pfizer Oncology. Steps to success: improving advanced prostate cancer patient management and care coordination. April 2021. Accessed July 22, 2024. [auanet.org/documents/practices-resources/quality/quality-improvement-library/Steps to Success Improving Advanced PCa Patient Management and Care Coordination.pdf](https://auanet.org/documents/practices-resources/quality/quality-improvement-library/Steps to Success Improving Advanced PCa Patient Management and Care Coordination.pdf)
- i. How to maximize the genomic tumor board experience. The Jackson Laboratory. Updated May 2023. Accessed July 22, 2024. [jax.org/education-and-learning/clinical-and-continuing-education/clinical-topics/tumor-testing/gtb-experience](https://jax.org/education-and-learning/clinical-and-continuing-education/clinical-topics/tumor-testing/gtb-experience)
- j. Association of Cancer Care Centers (ACCC). Accessed July 22, 2024. [acc-cancer.org](https://acc-cancer.org)
- k. Centers for Disease Control and Prevention (CDC). Accessed July 22, 2024. [cdc.gov](https://cdc.gov)

# Spotlighting Patient Barriers and Solutions

## Patient Barriers

Just as health care professionals face barriers to providing comprehensive prostate cancer care, patients experience barriers to accessing quality care and genetic testing. Patients with metastatic prostate cancer are often tasked with navigating a complicated medical system, systemic discrimination, and a genetic testing process that may be foreign to them. Understanding these barriers can help health care professionals provide the most comprehensive and equitable care to patients.

The following section outlines some common barriers to genetic testing that patients experience.

### Navigating financial limitations to diagnostics and treatments

Patients experience barriers and encounter uncertainties around cost-sharing and insurance coverage for genetic testing. Financial concerns often impact decision-making.

- Some health care systems do not cover preventive genetic testing for patients at high-risk for cancer, but only cover testing once cancer is diagnosed. Unexpected costs associated with genetic testing follow-up are a concern for many patients.<sup>23</sup>
- Lower-income patients with prostate cancer are greatly impacted by indirect out-of-pocket expenses related to treatment, travel time for treatment, and missing work for appointments. Patients often resort to using savings to pay for treatment.<sup>23,39,40</sup>

### Persisting health disparities

Cancer care disparities exist across race, ethnicity, socioeconomic status, and more.

- Prostate cancer diagnosis and mortality rates are twice as high in Black men compared with White men, yet most patients who undergo germline testing are White men.
- Most clinical studies on germline testing predominantly involve White men, leading to insufficient data collection from marginalized racial/ethnic groups, such as Black, Asian/Pacific Islander, and Hispanic populations. Expanding research could determine if the higher incidence of variants of uncertain significance in minority populations corresponds to mutations that increase cancer risk.<sup>41</sup> This is crucial, as genetic testing disparities could result in inequitable outcomes.

### Knowledge gaps in genetic risk and cancer awareness

There is limited awareness regarding the importance of cancer-specific genetic testing in patients with prostate cancer.

- Fewer than 20% of patients with a history of prostate cancer are aware of cancer-specific genetic testing, with the internet being their most common source of information. In contrast, about 65% of patients with breast or ovarian cancer are aware of genetic testing, primarily informed by health care providers. This suggests the need for enhanced patient education about genetic testing, especially for patients with prostate cancer.<sup>42</sup>
- Patients who undergo testing may understand its importance in predicting tumor aggressiveness but may not grasp the distinction between somatic and germline testing. Some are unaware that genomic testing of biopsy specimens can impact their treatment choices.<sup>43</sup>

### Genetic testing outcome uncertainty/fear among high-risk patients

Many patients fear the outcome of genetic testing.

- Healthy male relatives of women with breast or ovarian cancer often hesitate to undergo genetic testing due to fear of testing positive for a pathogenic variant.<sup>44</sup> There is also a fear of the burden associated with a positive test result and uncertainty about the clinical relevance of testing, which are the primary reasons for avoiding predictive genetic testing.<sup>45</sup>
- Although some patients with various cancers experience fear of genetic testing outcomes, some prostate cancer patients still express interest in undergoing genetic testing to determine the aggressiveness of their cancer.<sup>46</sup> This suggests that even though fear is influential, it does not completely deter interest in testing.

### Understanding genetic testing

Genetic testing is a complex process, and patients may need support to understand their testing options.

- Many patients are unaware of the difference between certified genetic health risk tests and direct-to-consumer genetic tests, which may lead to false positive or false negative results. Educating the population about genetic counseling and providing personalized advice on undergoing a genetic test is important.<sup>47</sup>

### Distrusting the medical system

Persisting health care disparities, as mentioned previously, can be intertwined with distrust of the medical system. Due to a long history of discrimination and systemic racism in the medical field, some patients may be hesitant to trust health care providers.

- Increased medical mistrust is correlated with heightened apprehensions regarding tumor molecular profiling among Black patients with oncological conditions. Concerns include testing expenses, potential insurance discrimination, privacy breaches, physical discomfort during testing, and provider communication proficiency regarding inconclusive test outcomes.<sup>48</sup>

### Accessing the latest treatments and/or clinical trials

As some providers can lack access to the latest treatments and/or clinical trials, patients may experience limited benefits from these advancements. Patients face various systemic and individual barriers to care that can affect their access to the latest treatments.

- Belonging to a marginalized group, distrust, lack of awareness, financial constraints, geographic limitations, social support unavailability, and logistical challenges contribute to disparities in treatment access.<sup>28,29,49</sup>

### Checklist:

Place a check mark next to all barriers faced by the patient population(s) treated at your institution.

Patient Barriers	
<input type="checkbox"/>	Navigating financial limitations to diagnostics and treatments
<input type="checkbox"/>	Persistent health care disparities
<input type="checkbox"/>	Knowledge gaps in genetic risk and cancer awareness
<input type="checkbox"/>	Genetic testing outcome uncertainty/fear among high-risk patients
<input type="checkbox"/>	Understanding germline and somatic testing
<input type="checkbox"/>	Distrusting the medical system
<input type="checkbox"/>	Accessing the latest treatments and/or clinical trials
<input type="checkbox"/>	Is your institution able to address the checked barriers and make changes?

Use the space below to note any additional comments or ideas.

## Putting Patient Solutions Into Action

Once patient barriers have been identified, solutions can be developed. There are various strategies to address each barrier, as outlined below. The boxes below correspond to the most applicable barriers and solutions. Identify the barrier(s) that your practice faces and refer to the checked cells to find the suggested solution(s). If you identify a solution that is not indicated in the table, you may add your own.

Barriers	Solutions				
	Utilizing nurse/patient navigators	Implementing shared decision-making	Optimizing genetic counseling	Addressing health literacy and language barriers	Enhancing patient education and community outreach
Navigating financial limitations to diagnostics and treatments	✓				
Persisting health care disparities	✓			✓	
Knowledge gaps in genetic risk and cancer awareness	✓	✓		✓	✓
Genetic testing outcome uncertainty/fear among high-risk patients	✓	✓	✓	✓	✓
Understanding germline and somatic testing	✓	✓	✓	✓	✓
Distrusting the medical system	✓	✓		✓	✓
Accessing the latest treatments and/or clinical trials	✓				✓

The following sections include more information about the solutions listed above.

### **Utilizing nurse/patient navigators**

A nurse navigator plays a crucial role in guiding patients through the complexities of the medical system. The primary functions of a nurse navigator are to:

- Assess patient needs
- Educate and inform patients
- Support patients and their families
- Coordinate care.

Nurse navigators act as liaisons between patients and the care team, improving communication and enhancing patient satisfaction with their care.<sup>50</sup>

### **Implementing shared decision-making to enhance patient-centric care**

Shared decision-making is a process intended to engage patients in medical decisions when there are multiple care strategies supported by clinical evidence.<sup>51</sup> It can empower patients to address barriers to genetic cancer screening, which will impact their ongoing cancer treatment and family monitoring.<sup>52</sup>

The best decision considers evidence-based information about available options, the provider's expertise, and the patient's values and preferences. These factors allow shared decision-making to be a powerful approach to patient-centric care.<sup>53</sup>

Care teams can be trained in patient-centered communication skills using the [SHARE approach](#), a technique developed by the Agency for Healthcare Research and Quality (AHRQ), to structure patient-centered conversations.<sup>52,54</sup> The 5 steps comprising the SHARE acronym are as follows:

**S**

Seek your patient's participation

**H**

Help your patient explore and compare intervention options

**A**

Assess your patient's values and preferences

**R**

Reach a decision with your patient

**E**

Evaluate your patient's decision

### **Optimizing genetic counseling to enhance patient-centric care**

To enhance the patient-centric delivery of genetic counseling, providers should focus on:<sup>53</sup>

- Explaining germline and somatic testing in plain language, using educational aids tailored for this purpose.<sup>55</sup>
- Acknowledging the potential psychological impacts that stem from the genetic testing process or outcomes. For example, testing results could impact lives and family relationships, and many results come with diagnostic uncertainty.
- Using shared decision-making tools for cancer genetic testing.<sup>56</sup>
- Involving families and caregivers in the genetic counseling process (with patient consent). They can offer valuable perspectives on patient situations and values, and they may also be impacted by positive germline testing results.

### **Addressing health literacy and language barriers**

The following are potential strategies to reduce cultural and linguistic barriers to genetic screening among patients with metastatic prostate cancer:

- Partner with trusted and respected community leaders and organizations to disseminate information. Their deep understanding of cultural nuances within their communities makes them well-suited to communicate effectively with their peers.<sup>57</sup>
- Train health care providers and equip them with the skills to offer genetic counseling sessions using content that is culturally and linguistically appropriate.
- Offer patients educational materials in various languages and formats, such as pamphlets, videos, and online resources, at different literacy levels and language preferences.<sup>55</sup> Ensure that advice, strategies, and data are tailored to the target population. The following tips can aid in enhancing understanding:<sup>58</sup>
  - Use plain, conversational language.
  - Write in short sentences using an easy-to-read font.
  - Break information into short sections.
  - Use simple diagrams to help patients visualize internal processes.
- Create a supportive and nonjudgmental environment where patients can ask questions and seek clarification, thereby building trust and open communication.



- Organize educational workshops or seminars that are culturally tailored to raise awareness about prostate cancer genetic testing within specific communities.
- Embrace cultural humility by acknowledging and respecting the diverse backgrounds, beliefs, and experiences of patients, which enhances patient-centered care.
- Regularly evaluate and adjust educational strategies based on feedback from patients and community stakeholders to ensure their effectiveness and relevance.<sup>58</sup>

**Enhancing patient education and community outreach**

Reaching and educating patients is essential for supporting them in making informed decisions that are aligned with their preferences and values.

Communication with patients about genetic testing should be:



Clear



Inclusive



Highly personalized.<sup>43</sup>

Consider the various formats of patient education that are available and what patients may prefer. The table below may be utilized to determine the most effective ways to provide patient education. Keep in mind that using multiple formats is often beneficial.

Example resources are included below. Cancer programs and practices should also consider creating their own patient-facing resources. Use this table to write down your thoughts about the use of each resource format.

Resource Format	Is this resource available to your patients?	How will your patients benefit from this resource?	What are some potential drawbacks to using this resource?	Will you use it?
<a href="#">Short handout<sup>a</sup></a>				
<a href="#">Detailed booklet<sup>b</sup></a>				
<a href="#">Online video<sup>c</sup></a>				
<a href="#">In-clinic video<sup>d</sup></a>				
<a href="#">Worksheet<sup>e</sup></a>				
Phone/video consultation				
In-person consultation				
<a href="#">Social media<sup>f</sup></a>				
Community outreach initiatives				

## Sources

- a. Genetic Testing for Prostate Cancer: Talking to Your Doctor. American Urological Association (AUA). 2023. Accessed July 26, 2024. [urologyhealth.org/documents/Product-Store/English/ProstateCancer-GeneticTesting-TalkingToDoctor-FS-2023-English.pdf](https://urologyhealth.org/documents/Product-Store/English/ProstateCancer-GeneticTesting-TalkingToDoctor-FS-2023-English.pdf)
- b. Guides. Prostate Cancer Foundation. 2024. Accessed July 26, 2024. [pcf.org/guide](https://pcf.org/guide)
- c. "It Had Affected My Family As Much As It Affected Me." Myriad Genetics. March 14, 2019. Accessed July 26, 2024. [myriad.com/urology/blog/ripples-in-a-pond](https://myriad.com/urology/blog/ripples-in-a-pond)
- d. Is Cancer Hereditary? Prostate Cancer Foundation. November 21, 2018. Accessed July 26, 2024. [youtube.com/watch?v=KEEX7kl-RmQ](https://youtube.com/watch?v=KEEX7kl-RmQ)
- e. Talking With Your Care Team About Genetic Testing. Janssen Oncology. 2023. Accessed July 26, 2024. [brcaimen.com/documents/DoctorDiscussionGuide.pdf](https://brcaimen.com/documents/DoctorDiscussionGuide.pdf)
- f. Social Media Toolkit. Prostate Cancer Foundation. 2024. Accessed July 26, 2024. [pcf.org/pcam2024/social](https://pcf.org/pcam2024/social)

Here are some population-specific resources that you can also access and use:

Resource	Description
<a href="#">Prostate Cancer Support</a>	ZERO Prostate Cancer offers in-person and virtual peer support resources, including support groups, meetings, online forums, Facebook groups, and mentorship opportunities. <sup>a</sup>
<a href="#">Resources for Veterans</a>	Offers resources for veterans, including support groups and mentorship opportunities. <sup>b</sup>
<a href="#">Support for the LGBTQIA+ Community</a>	Support for the LGBTQIA+ community, including support groups, online communities, cancer networks, and support meetings. <sup>c</sup>
<a href="#">Resources for Black Men</a>	Resources for Black men, including support services and support groups and town hall conversations. <sup>d</sup>
<a href="#">Resources for Caregivers &amp; Loved Ones</a>	Features resources for caregivers and loved ones, including guides, videos, support groups, and town hall conversations. <sup>e</sup>
<a href="#">Genetic Testing and Prostate Cancer</a>	Information about genetic testing and prostate cancer, including stories, videos, and discussion guides. <sup>f</sup>
<a href="#">ANCAN: The Home of Peer-to-Peer Virtual Support Groups</a>	ANCAN is an advocacy, navigation, and support resource featuring peer-to-peer virtual patient support groups. <sup>g</sup>

## Sources

- a. ZERO Prostate Cancer connects people to lifesaving support. ZERO Prostate Cancer. 2024. Accessed July 22, 2024. [zerocancer.org](https://zerocancer.org)
- b. ZERO Prostate Cancer Veterans. ZERO Prostate Cancer. 2024. Accessed July 22, 2024. [zerocancer.org/help-and-support/resources-for/veterans](https://zerocancer.org/help-and-support/resources-for/veterans)
- c. Support for the LGBTQIA+ Community with Prostate Cancer. ZERO Prostate Cancer. 2024. Accessed July 22, 2024. [zerocancer.org/help-and-support/resources-for/lgbtq](https://zerocancer.org/help-and-support/resources-for/lgbtq)
- d. Black Men and Prostate Cancer. ZERO Prostate Cancer. 2024. Accessed July 22, 2024. [zerocancer.org/black-men](https://zerocancer.org/black-men)

- e. Resources for Caregivers & Loved Ones. ZERO Prostate Cancer. 2024. Accessed July 22, 2024. [zerocancer.org/help-and-support/resources-for/caregivers](https://zerocancer.org/help-and-support/resources-for/caregivers)
- f. Genetic Testing and Prostate Cancer. ZERO Prostate Cancer. 2024. Accessed July 22, 2024. [zerocancer.org/risk-factors/genetic-testing](https://zerocancer.org/risk-factors/genetic-testing)
- g. ANCAN: The Home of Peer-to-Peer Virtual Support Groups. ANCAN. February 15, 2024. Accessed July 22, 2024. [ancan.org](https://ancan.org)

Further education about the patient experience is needed for providers. Patients should be made aware of their options, their care team members, and the importance of their family history.

#### Key questions to ask patients:

- Have you received education about germline (inherited) and somatic (acquired) testing? What questions do you have?
- Have you been made aware of your genetic testing options? You might have heard of genetic testing types, such as hereditary, tumor, genomic, or biomarker testing.
- Have you spoken to or met with various members of your care team (eg, genetic counselor, nurse, and medical oncologist)?
- Have you discussed your family history with your provider?

#### Social media

Social media platforms, such as Facebook, X (formerly Twitter), and Instagram, serve as powerful tools for the rapid dissemination of targeted health messages to a broad audience. These platforms can improve awareness and encourage proactive health behaviors, particularly in the context of prostate cancer.<sup>59</sup>

The following are strategies for effective social media engagement:

- Partner with influential figures in the community to promote cancer awareness messages and foster greater engagement among followers.<sup>59,60</sup>
- Ensure that social media content delivers accurate, concise, and actionable information about cancer screening and early diagnosis, guiding followers through steps to safeguard their health.<sup>61</sup>

- Leverage compelling images, graphics, and videos in social media posts to capture attention and enhance the likelihood of content being shared and liked.<sup>60,62</sup>
- Craft messages that resonate with groups facing lower screening rates or higher barriers to access, using social media to bridge information gaps and reduce health care disparities.<sup>60</sup>
- Engage in bidirectional communication by responding to comments and questions, building trust, and encouraging active participation in health discussions.<sup>60,62</sup>
- Engage in social media groups discussing scientific information with patients, families, and other health care providers.<sup>59</sup>
- Create campaigns specifically tailored to various demographics, considering factors such as age, gender, and ethnicity to ensure content relevance and engagement.<sup>60</sup>
- Track key performance indicators, such as likes, shares, comments, and reach, to assess the effectiveness of social media campaigns and make data-driven adjustments as needed.<sup>60,62</sup>

#### Community outreach initiatives

Actively involving communities in outreach initiatives about prostate cancer is essential to ensure that these efforts are culturally appropriate, responsive, and sustainable. Including the community helps to build trust, improves understanding of health information, and increases the acceptance of interventions, leading to improved cancer outcomes and reduced disparities.<sup>61,63</sup> Strategies for community engagement are discussed below.

#### Partnerships:

- Develop strong partnerships with community organizations, leaders, and stakeholders to ensure active participation and collaboration. For example, a strong partnership might involve

regularly collaborating with local health clinics and community leaders to host educational workshops and screenings, ensuring that these efforts are culturally tailored and responsive to the specific needs of the community.

- Engage with grassroots organizations deeply embedded in the community to build trust and extend outreach efforts.
- Foster partnerships to facilitate access to care and navigate structural barriers like transportation.<sup>61</sup> For example, mobile health clinics can effectively reach communities with men at high risk of prostate cancer, offering health checks and PSA testing.<sup>59</sup>
- Partner with initiatives giving scientific and financial support to enhance community outreach to reduce cancer burden, like the National Outreach Network and the Cancer Center Support Grant programs from the National Cancer Institute.<sup>64</sup>

#### Community Health Workers:

- Community engagement in health care has been shown to reduce disparities in cancer care.<sup>61</sup> Employ community health workers to bridge the gap between health care systems and communities, providing culturally tailored education, outreach, and support.<sup>61</sup>
- Train community health workers to navigate insurance challenges, facilitate access to care for underserved populations, and implement programs like ride-share for patient transportation.<sup>61</sup>

#### Tailored Messaging:

- Personalize messages and materials to align with the community's cultural context, language preferences, and specific needs.
- Use simple and plain language. Address misconceptions to demystify health topics, and encourage open discussions about sensitive issues like prostate cancer.
- Include diverse volunteers to share the messages, particularly those with personal experiences with prostate cancer, to foster relatability and trust.<sup>61</sup>

#### Technology:

- Add educational information to websites that can be accessed using tablets and smartphones to expand outreach efforts.
- Consider implementing telehealth services and other technological solutions to overcome transportation barriers and improve access to care for remote or underserved populations.<sup>61</sup>

#### Additional Considerations:

- Be mindful that some states require insurance companies to pay for genetic testing.
- Provide education and resources to empower communities, enhance health literacy, and build patients' capacity for active participation.
- Offer educational sessions in community settings, such as churches and other faith communities and barbershops, to reach men at the highest risk.
- Create spaces that attract men and encourage open discussions about their health.<sup>61</sup>

## Tools and Resources

### Utilizing Nurse/Patient Navigators

Resource	Description
<a href="#">Patient Navigation Job Roles by Levels of Experience: Workforce Development Task Group, National Navigation Roundtable</a>	The American Cancer Society (ACS) National Navigation Roundtable developed a 1-page resource on entry, intermediate, and advanced level navigators for patients with cancer. <sup>a</sup>
<a href="#">Oncology Navigation Standards of Professional Practice</a>	The Academy of Oncology Nurse & Patient Navigators (AONN+) created a 12-page resource summarizing standards and best practices for clinical oncology nurse navigators, social work navigators, and patient navigators. <sup>b</sup>

## Implementing Shared Decision-Making To Enhance Patient-Centric Care

Resource	Description
<a href="#">Implementation of Shared Decision Making Into Urological Practice</a>	The American Urological Association (AUA) developed an article about shared decision-making for urological providers. <sup>c</sup>
<a href="#">The SHARE Approach—Essential Steps of Shared Decision-Making</a>	AHRQ published an expanded reference guide that details the steps of shared decision-making for a broad health care audience. <sup>d</sup>

## Optimizing Genetic Counseling To Enhance Patient-Centric Care

Resource	Description
<a href="#">Genetic testing in prostate cancer management: Considerations informing primary care</a>	Giri et al created a process flowchart highlighting the integrated genetic evaluation process for primary care providers and genetic counselors. <sup>e</sup>
See Figure 1: Integrated Genetic Evaluation Process for Primary Care Providers and Genetic Counselors	

## Engaging patients

Resource	Description
<a href="#">A Framework for Promoting Diversity, Equity, and Inclusion in Genetics and Genomics Research</a>	Rebbeck et al created a framework for engaging diverse patients in genetics and genomics research. <sup>f</sup>
See Table 3: A Framework for Engagement of Diverse Participants in Genetics and Genomics Research	
<a href="#">Practical Considerations and Challenges for Germline Genetic Testing in Patients with Prostate Cancer: Recommendations from the Germline Genetics Working Group of the PCCTC</a>	Szymaniak et al developed talking points regarding the benefits, risks, and limitations of genetic testing. <sup>g</sup>
See Table 3: Pre-test Talking Points Regarding the Benefits and Risks/Limitations of Genetic Testing	

## Addressing Health Literacy And Language Barriers

Resource	Description
<a href="#">Ask Me 3® Tool</a>	ACCC includes information about the Ask Me 3® tool, created by the Institute for Healthcare Improvement, for patients and social workers with tips for providers to improve communication. <sup>h</sup>
<a href="#">ACCC Learning: Health Literacy and Clear Communication eCourse</a>	ACCC developed a Health Literacy and Clear Communication eCourse for cancer care team members. <sup>i</sup>

## Enhancing Patient Outreach and Education

Resource	Description
<a href="#">Patient Education: Importance, Evaluating Understanding, &amp; Methods</a>	For patient education communication strategies, Lecturio Nursing published this YouTube video. <sup>j</sup>

## Sources

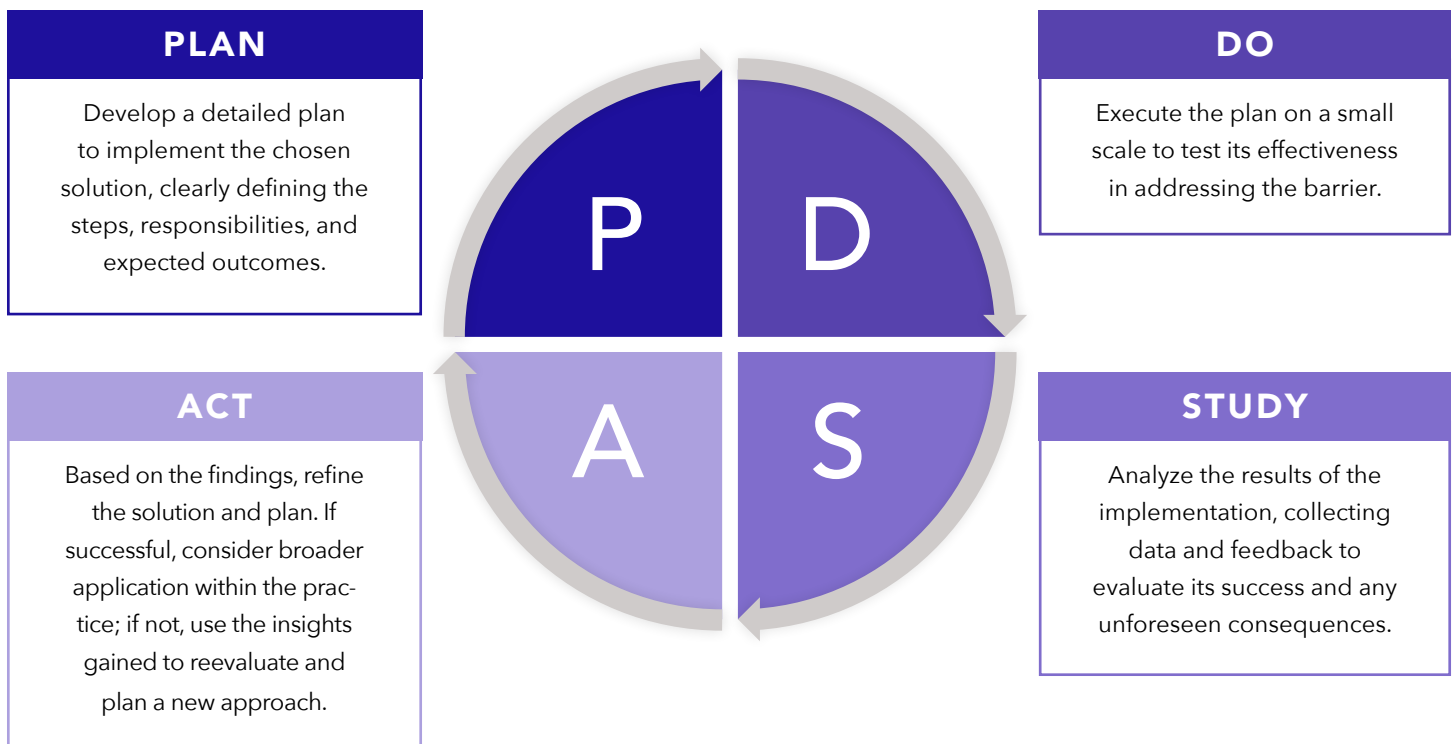
- a. National Navigation Roundtable. Patient navigation job roles by levels of experience: Workforce Development Task Group, National Navigation Roundtable - National Navigation Roundtable. National Navigation Roundtable. January 10, 2024. Accessed July 22, 2024. [navigationroundtable.org/resource/patient-navigation-job-roles-by-levels-of-experience-workforce-development-task-group-national-navigation-roundtable](https://navigationroundtable.org/resource/patient-navigation-job-roles-by-levels-of-experience-workforce-development-task-group-national-navigation-roundtable)
- b. National Navigation Roundtable. Oncology navigation standards of professional practice - National Navigation Roundtable. National Navigation Roundtable. Published January 22, 2024. Accessed July 22, 2024. [navigation-roundtable.org/resource/oncology-navigation-standards-of-professional-practice](https://navigation-roundtable.org/resource/oncology-navigation-standards-of-professional-practice)
- c. Implementation of shared decision making into urological practice - American Urological Association. Updated 2022. Accessed July 22, 2024. [auanet.org/guidelines-and-quality/quality-and-measurement/quality-improvement/clinical-consensus-statement-and-quality-improvement-issue-brief-\(ccs-and-qibb\)/shared-decision-making](https://auanet.org/guidelines-and-quality/quality-and-measurement/quality-improvement/clinical-consensus-statement-and-quality-improvement-issue-brief-(ccs-and-qibb)/shared-decision-making)
- d. The SHARE Approach—Essential steps of shared decision-making: expanded reference guide with sample conversation starters. Agency for Healthcare Research and Quality. Updated September 2020. Accessed July 22, 2024. [ahrq.gov/health-literacy/professional-training/shared-decision/tool/resource-2.html](https://ahrq.gov/health-literacy/professional-training/shared-decision/tool/resource-2.html)
- e. Giri VN, Morgan TM, Morris D, et al. Genetic testing in prostate cancer management: considerations informing primary care. *CA*. 2022;72(4):360-371. doi:10.3322/caac.21720
- f. Rebbeck TR, Bridges JFP, Mack JW, et al. A framework for promoting diversity, equity, and inclusion in genetics and genomics research. *JAMA Health Forum*. 2022;3(4):e220603. doi:10.1001/jamahealthforum.2022.0603
- g. Szymaniak BM, Facchini LA, Giri VN, et al. Practical considerations and challenges for germline genetic testing in patients with prostate cancer: recommendations from the Germline Genetics Working Group of the PCCTC. *JCO Oncol Pract*. 2020;16(12):811-819. doi:10.1200/op.20.00431
- h. Ask Me 3 Tool. Association of Cancer Care Centers (ACCC). Accessed July 22, 2024. [accancer.org/home/learn/comprehensive-cancer-care-services/health-literacy/lets-be-clear/ask-me-3-tool](https://accancer.org/home/learn/comprehensive-cancer-care-services/health-literacy/lets-be-clear/ask-me-3-tool)
- i. ACCC Learning: Health Literacy and Clear Communication eCourse. Association of Cancer Care Centers (ACCC). Accessed July 22, 2024. [courses.accancer.org/products/health-literacy-and-clear-communication-ecourse](https://courses.accancer.org/products/health-literacy-and-clear-communication-ecourse)
- j. Patient education: importance, evaluating understanding, & methods. Lecturio Nursing. YouTube. August 6, 2021. Accessed July 22, 2024. [youtube.com/watch?v=mx66NPHAYuc](https://youtube.com/watch?v=mx66NPHAYuc)

# From Theory to Practice

Practices and programs can use this handbook to implement actions to improve genetic testing and optimize outcomes for patients with metastatic prostate cancer. The following section offers strategies for use in the first 3 months after implementation to help address an identified key barrier.

## Plan-Do-Study-Act (PDSA)

Consider using the Plan-Do-Study-Act (PDSA) cycle to understand your top barriers and to implement solutions.



## Timeline

### Month 1

**Plan:** Begin by assessing the landscape of your practice or program using the resources available in this handbook and the worksheet below.

Step	Description	Notes
Convene a project group.	Assemble a team from your site to develop the action plan. Keep in mind the diversity of roles and responsibilities.	List your team members below:
Assess and complete the practice and patient barriers checklists.	Review the practice and patient barriers checklists individually and as a team to assess the most prominent barriers at your institution.	List your top barriers below:
Assess and complete the practice and patient solutions matrices.	Review the practice and patient solutions matrices individually and as a team to understand feasible solutions to your top barriers.	List your feasible solutions below:
Choose a barrier and solution to address.	Select 1 barrier and corresponding solution that your practice or program can realistically implement within the next month.	List your selected barrier and solution:
Begin brainstorming implementation activities for Month 2.	Consider feasible steps your team could take in the next month to carry out your solution.	List your feasible steps below:



## Month 2 PDSA Cycle

**Plan:** Develop a detailed plan to implement the chosen solution, clearly defining the steps, responsibilities, and expected outcomes using the action planning template below.

**Do:** Execute the plan on a small scale to test its effectiveness in addressing the barrier.

### Actions

What will we do? <i>eg, Identify who needs to be informed of the change we are trying to implement</i>	Who will do it? <i>eg, All team members</i>	By when will they do it? <i>eg, In the next 2 weeks</i>

**Month 2 PDSA Cycle continued**

Needs

What do we need? *eg, Talking points*

Who will provide it? *eg, All team members*


Impacts

What will our impact be? *eg, We will ensure that all key players have bought into this effort*


### Month 3 of the PDSA Cycle

**Study:** Analyze the results of this test implementation, collecting data and feedback to evaluate its success and any unforeseen consequences.

Lessons learned:	What needs to be refined?

## Month 4 of the PDSA Cycle and Beyond

**Act:** Based on the findings, refine the solution and plan. If successful, consider broader application within the practice; if not, use the insights gained to re-evaluate and plan a new approach.

Continuously monitor the impacts of the implemented solutions and adjust plans as needed. Consider setting a regular check-in time with the project group to ensure that action plans remain on track and to address any issues as they arise.

## Closing

This handbook offers a comprehensive guide to overcoming barriers to genetic testing in your practice or program, with the goal of optimizing outcomes for patients with metastatic prostate cancer. The interactive format is designed to support members of multidisciplinary teams in working through the unique barriers and solutions to implement actionable next steps for improving care.

While this handbook outlines a planning process for the first 3 months of implementation, addressing barriers to care is ongoing. By continuously evaluating and refining these strategies, health care teams can foster a more informed, patient-centric approach to genetic testing for metastatic prostate cancer.



### Share Your Insights with ACCE

Submit actions or ideas that your team is pursuing for future endeavors.

## References

1. Siegel RL, Miller KD, Wagle NS, et al. Cancer statistics, 2023. *Ca Cancer J Clin.* 2023;73(1):17-48. doi:10.3322/caac.21763
2. Cancer of the prostate - cancer stat facts. SEER. Accessed April 22, 2024. [seer.cancer.gov/statfacts/html/prost.html](https://seer.cancer.gov/statfacts/html/prost.html)
3. Key statistics for prostate cancer | Prostate Cancer Facts. American Cancer Society. Updated January 19, 2024. Accessed July 22, 2024. [cancer.org/cancer/types/prostate-cancer/about/key-statistics.html](https://cancer.org/cancer/types/prostate-cancer/about/key-statistics.html)
4. SEER\*Explorer. National Cancer Institute Surveillance, Epidemiology, and End-Results Program. Accessed April 22, 2024. [seer.cancer.gov/statistics-network/explorer/application.html?site=66&data\\_type=1&graph\\_type=4&compareBy=race&chk\\_race\\_1=1&hdn\\_sex=2&age\\_range=1&advopt\\_precision=1&hdn\\_view=0&advopt\\_show\\_apc=on&advopt\\_display=2#resultsRegion0](https://seer.cancer.gov/statistics-network/explorer/application.html?site=66&data_type=1&graph_type=4&compareBy=race&chk_race_1=1&hdn_sex=2&age_range=1&advopt_precision=1&hdn_view=0&advopt_show_apc=on&advopt_display=2#resultsRegion0)
5. Desai MM, Cacciamani GE, Gill K, et al. Trends in incidence of metastatic prostate cancer in the US. *JAMA Network Open.* 2022;5(3):e222246. doi:10.1001/jamanetworkopen.2022.2246

6. Referenced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Prostate Cancer. V.4.2024. National Comprehensive Cancer Network, Inc. 2024. All rights reserved. Accessed August 1, 2024. To view the most recent and complete version of the guideline, go online to [NCCN.org](https://www.nccn.org). NCCN makes no warranties of any kind whatsoever regarding their content, use, or application and disclaims any responsibility for their application or use in any way.
7. Militaru FC, Militaru V, Crisan N, et al. Molecular basis and therapeutic targets in prostate cancer: A comprehensive review. *Biomol Biomed*. 2023;23(5):760-771. [doi:10.17305/bb.2023.8782](https://doi.org/10.17305/bb.2023.8782)
8. Davoudi F, Moradi A, Becker TM, et al. Genomic and phenotypic biomarkers for precision medicine guidance in advanced prostate cancer. *Curr Treat Options Oncol*. 2023;24(10):1451-1471. [doi:10.1007/s11864-023-01121-z](https://doi.org/10.1007/s11864-023-01121-z)
9. Doan DK, Schmidt KT, Chau CH, et al. Germline genetics of prostate cancer: prevalence of risk variants and clinical implications for disease management. *Cancers (Basel)*. 2021;13(9):2154. [doi:10.3390/cancers13092154](https://doi.org/10.3390/cancers13092154)
10. Catalano M, Generali D, Gatti M, et al. DNA repair deficiency as circulating biomarker in prostate cancer. *Frontiers in Oncology*. 2023;13. [doi:10.3389/fonc.2023.1115241](https://doi.org/10.3389/fonc.2023.1115241)
11. Struewing JP, Hartge P, Wacholder S, et al. The risk of cancer associated with specific mutations of BRCA1 and BRCA2 among Ashkenazi Jews. *N Engl J Med*. 1997;336(20):1401-1408. [doi:10.1056/NEJM199705153362001](https://doi.org/10.1056/NEJM199705153362001)
12. Horlings HM, Shah SP, Huntsman DG. Using somatic mutations to guide treatment decisions: context matters. *JAMA Oncol*. 2015;1(3):275-276. [doi:10.1001/jamaoncol.2015.35](https://doi.org/10.1001/jamaoncol.2015.35)
13. Cotter K, Rubin MA. The evolving landscape of prostate cancer somatic mutations. *The Prostate*. 2022;82(S1). [doi:10.1002/pros.24353](https://doi.org/10.1002/pros.24353)
14. Biomarkers & genomic testing. ZERO prostate cancer. Accessed July 22, 2024. [zerocancer.org/stages-and-grading/biomarkers-genomic-testing#:~:text=The%20test%20looks%20for%20gene,choose%20the%20best%20treatment%20option](https://zerocancer.org/stages-and-grading/biomarkers-genomic-testing#:~:text=The%20test%20looks%20for%20gene,choose%20the%20best%20treatment%20option)
15. Biesecker LG. Precision medicine. Genome.gov. Accessed April 22, 2024. [genome.gov/genetics-glossary/Precision-Medicine](https://genome.gov/genetics-glossary/Precision-Medicine)
16. Precision or personalized medicine. American Cancer Society. Accessed April 22, 2024. [cancer.org/cancer/managing-cancer/treatment-types/precision-medicine.html](https://cancer.org/cancer/managing-cancer/treatment-types/precision-medicine.html)
17. Henríquez I, Roach M 3rd, Morgan TM, et al. Current and emerging therapies for metastatic castration-resistant prostate cancer (mCRPC). *Biomedicines*. 2021;9(9):1247. [doi:10.3390/biomedicines9091247](https://doi.org/10.3390/biomedicines9091247)
18. Saffar HA, Chen DC, Delgado C, et al. The current landscape of prostate-specific membrane antigen (PSMA) imaging biomarkers for aggressive prostate cancer. *Cancers*. 2024;16(5):939. [doi:10.3390/cancers16050939](https://doi.org/10.3390/cancers16050939)
19. Six domains of healthcare quality. Agency for Healthcare Research and Quality (AHRQ). Updated December 2022. Accessed April 22, 2024. [ahrq.gov/talkingquality/measures/six-domains.html](https://ahrq.gov/talkingquality/measures/six-domains.html)
20. People-centered health care: a policy framework. World Health Organization (WHO). 2007. Accessed April 22, 2024. [iris.who.int/bitstream/handle/10665/206971/9789290613176\\_eng.pdf?sequence=1](https://iris.who.int/bitstream/handle/10665/206971/9789290613176_eng.pdf?sequence=1)
21. Jayadevappa R, Chhatre S, Gallo JJ, et al. Patient-centered approach to develop the patient's preferences for Prostate Cancer Care (PreProCare) tool. *MDM Policy Pract*. 2019;4(1):2381468319855375. [doi:10.1177/2381468319855375](https://doi.org/10.1177/2381468319855375)
22. Brausi M, Hoskin P, Andritsch E, et al. ECCO Essential Requirements for Quality Cancer Care: Prostate cancer. *Critical Reviews in Oncology/Hematology*. 2020;148:102861. [doi:10.1016/j.critrevonc.2019.102861](https://doi.org/10.1016/j.critrevonc.2019.102861)
23. Dusic EJ, Theorin T, Wang C, et al. Barriers, interventions, and recommendations: improving the genetic testing landscape. *Front Digit Health*. 2022;4:961128. [doi:10.3389/fgth.2022.961128](https://doi.org/10.3389/fgth.2022.961128)
24. Suri Y, Yasmeh JP, Basu A. Understanding the uptake and challenges of genetic testing guidelines for prostate cancer patients. *Cancer Treat Res Commun*. 2022;32(100588):100588. [doi:10.1016/j.ctarc.2022.100588](https://doi.org/10.1016/j.ctarc.2022.100588)

25. Paller CJ, Antonarakis ES, Beer TM, et al. Germline genetic testing in advanced prostate cancer; Practices and barriers: Survey results from the Germline Genetics Working Group of the Prostate Cancer Clinical Trials Consortium. *Clin Genitourin Cancer*. 2019;17(4):275-282.e1. doi:10.1016/j.dgc.2019.04.013
26. Triebold M, Skov K, Erickson L, et al. Geographical analysis of the distribution of certified genetic counselors in the United States. *J Genet Couns*. 2021;30(2):448-456. doi:10.1002/jgc4.1331
27. Gunn CM, Li EX, Gignac GA, et al. Delivering genetic testing for patients with prostate cancer: moving beyond provider knowledge as a barrier to care. *Cancer Control*. 2023;30:10732748221143884. doi:10.1177/10732748221143884
28. McKay RR, Gold T, Zarif JC, et al. Tackling diversity in prostate cancer clinical trials: a report from the Diversity Working Group of the IRONMAN registry. *JCO Glob Oncol*. 2021;7(7):495-505. doi:10.1200/GO.20.00571
29. Acuña-Villaorduña A, Baranda JC, Boehmer J, et al. Equitable access to clinical trials: how do we achieve it? *Am Soc Clin Oncol Educ Book*. 2023;43:e389838. doi:10.1200/EDBK\_389838
30. Stensland KD, Kaffenberger SD, George AK, et al. Prostate cancer clinical trial completion: the role of geography. *Contemp Clin Trials*. 2021;111(106600):106600. doi:10.1016/j.cct.2021.106600
31. Schostak M, Bradbury A, Briganti A, et al. Practical guidance on establishing a molecular testing pathway for alterations in homologous recombination repair genes in clinical practice for patients with metastatic prostate cancer. *European Urology Oncology*. 2024;7(3):344-354. doi:10.1016/j.euo.2023.08.004v
32. Zhu S, Chen J, Ni Y, et al. Dynamic multidisciplinary team discussions can improve the prognosis of metastatic castration-resistant prostate cancer patients. *Prostate*. 2021;81(11):721-727. doi:10.1002/pros.24167
33. Shore ND, Morgans AK, El-Haddad G, et al. Addressing challenges and controversies in the management of prostate cancer with multidisciplinary teams. *Target Oncol*. 2022;17(6):709-725. doi:10.1007/s11523-022-00925-7
34. Giri VN, Morgan TM, Morris DS, et al. Genetic testing in prostate cancer management: considerations informing primary care. *CA*. 2022;72(4):360-371. doi:10.3322/caac.21720
35. Slootbeek PHJ, Kloots ISH, Smits M, et al. Impact of molecular tumour board discussion on targeted therapy allocation in advanced prostate cancer. *Br J Cancer*. 2022;126(7):1108. doi:10.1038/s41416-022-01765-y
36. Van Der Velden D, Van Herpen CML, Van Laarhoven HWM, et al. Molecular tumor boards: current practice and future needs. *Ann Oncol*. 2017;28(12):3070-3075. doi:10.1093/annonc/mdx528
37. Ciarlo G, Liebl P, Zell J, et al. Information needs of oncologists, general practitioners and other professionals caring for patients with cancer. *Eur J Cancer Care*. 2016;25(6):1015-1023. doi:10.1111/ecc.12557
38. When advertising to oncologists, first impressions are everything. Wolters Kluwer. July 29, 2022. Accessed July 22, 2024. [wolterskluwer.com/en/expert-insights/when-advertising-to-oncologists-first-impressions-are-everything#:~:text=For%20example%2C%20as%20with%20all,treatment%20options%20and%20patient%20outcomes](https://wolterskluwer.com/en/expert-insights/when-advertising-to-oncologists-first-impressions-are-everything#:~:text=For%20example%2C%20as%20with%20all,treatment%20options%20and%20patient%20outcomes)
39. Rai K, Mann U, Harasemiw O, et al. A prospective evaluation of patient perspectives and financial considerations during prostate cancer treatment decision-making. *Can Urol Assoc J*. 2023;17(9). doi:10.5489/cuaj.8228
40. Joyce DD, Schulte PJ, Kwon ED, et al. Coping mechanisms for financial toxicity among patients with metastatic prostate Cancer: a survey-based assessment. *J Urol*. 2023;210(2):290-298. doi:10.1097/ju.0000000000003506v
41. Weise N, Shaya J, Javier-Desloges J, et al. Disparities in germline testing among racial minorities with prostate cancer. *Prostate Cancer Prostatic Dis*. 2021;25(3):403-410. doi:10.1038/s41391-021-00469-3
42. Thakker S, Loeb S, Giri VN, et al. Attitudes, perceptions, and use of cancer-based genetic testing among healthy U.S. adults and those with prostate or breast/ovarian cancer. *Urol Pract*. 2023;10(1):26-32. doi:10.1097/upj.0000000000000352

43. Leapman MS, Sutherland R, Gross CP, et al. Patient experiences with tissue-based genomic testing during active surveillance for prostate cancer. *BJUI Compass*. 2023;5(1):142-149. [doi:10.1002/bco2.277](https://doi.org/10.1002/bco2.277)
44. Fasulo V, Buffi NM, Chiarelli G, et al. Male awareness of prostate cancer risk remains poor in relatives of women with germline variants in DNA-repair genes. *BJUI Compass*. 2023;4(6):738-745. [doi:10.1002/bco2.252](https://doi.org/10.1002/bco2.252)
45. Blomen CL, Pott A, Volk AE, et al. Communication processes about predictive genetic testing within high-risk breast cancer families: a two-phase study design. *Sci Rep*. 2021;11(1). [doi:10.1038/s41598-021-98737-8](https://doi.org/10.1038/s41598-021-98737-8)
46. Roy S, Gwede CK, Malo TL, et al. Exploring prostate cancer patients' interest and preferences for receiving genetic risk information about cancer aggressiveness. *Am J Men Health*. 2020;14(3):155798832091962. [doi:10.1177/1557988320919626](https://doi.org/10.1177/1557988320919626)
47. Cheng H. The Problem with Direct-to-Consumer Genetic Tests. *Scientific American*. March 10, 2020. Accessed July 22, 2024. [scientificamerican.com/blog/observations/the-problem-with-direct-to-consumer-genetic-tests](https://scientificamerican.com/blog/observations/the-problem-with-direct-to-consumer-genetic-tests)
48. Hoadley A, Bass SB, Chertock Y, et al. The role of medical mistrust in concerns about tumor genomic profiling among Black and African American cancer patients. *Int J Environ Res Public Health*. 2022;19(5):2598. [doi:10.3390/ijerph19052598](https://doi.org/10.3390/ijerph19052598)
49. Disparities in clinical research and cancer treatment. American Association for Cancer Research (AACR) Cancer Progress Report. June 29, 2022. Accessed July 22, 2024. [cancerprogressreport.aacr.org/disparities/cdpr22-contents/cdpr22-disparities-in-clinical-research-and-cancer-treatment](https://cancerprogressreport.aacr.org/disparities/cdpr22-contents/cdpr22-disparities-in-clinical-research-and-cancer-treatment)
50. Loiselle CG, Attieh S, Cook E, et al. The nurse pivot-navigator associated with more positive cancer care experiences and higher patient satisfaction. *Can Oncol Nursing J*. 2020;30(1):48-53. [doi:10.5737/236880763014853v](https://doi.org/10.5737/236880763014853v)
51. The SHARE approach: a model for shared decision making - fact sheet. Agency for Healthcare Research and Quality (AHRQ). Updated September 2020. Accessed July 22, 2024. [ahrq.gov/health-literacy/professional-training/shared-decision/tools/factsheet.html](https://ahrq.gov/health-literacy/professional-training/shared-decision/tools/factsheet.html)
52. The SHARE approach—essential steps of shared decision-making: expanded reference guide with sample conversation starters. Agency for Health Care Research and Quality (AHRQ). Updated September 2020. Accessed July 22, 2024. [ahrq.gov/health-literacy/professional-training/shared-decision/tool/resource-2.html](https://ahrq.gov/health-literacy/professional-training/shared-decision/tool/resource-2.html)
53. Shickh S, Leventakos K, Lewis MA, et al. Shared decision making in the care of patients with cancer. *Am Soc Clin Oncol Educ Book*. 2023;(43). [doi:10.1200/edbk\\_389516](https://doi.org/10.1200/edbk_389516)
54. Professional education and training in shared decision making. Agency for Health Care Research and Quality (AHRQ). Updated March 2023. Accessed July 22, 2024. [ahrq.gov/health-literacy/professional-training/shared-decision/index.html](https://ahrq.gov/health-literacy/professional-training/shared-decision/index.html)
55. Genetic testing and prostate cancer. ZERO Prostate Cancer. 2024. Accessed July 22, 2024. [zerocancer.org/risk-factors/genetic-testing](https://zerocancer.org/risk-factors/genetic-testing)
56. Patients' digital guide to their genetic testing journey. Genetics Adviser. 2023. Accessed July 22, 2024. [geneticsadviser.com](https://geneticsadviser.com)
57. Aristizabal C, Suther S, Yao Y, et al. Training community African American and Hispanic/Latino/a advocates on prostate cancer (PCa): a multicultural and bicoastal approach. *J Cancer Educ*. 2023;38(5):1719-1727. [doi:10.1007/s13187-023-02326-4](https://doi.org/10.1007/s13187-023-02326-4)
58. How much of what you say do your patients really understand? Prostate Cancer UK. Accessed July 22, 2024. [prostatecanceruk.org/for-health-professionals/email/health-literacy](https://prostatecanceruk.org/for-health-professionals/email/health-literacy)
59. James ND, Tannock IF, N'Dow J, et al. The Lancet Commission on prostate cancer: planning for the surge in cases. *Lancet*. 2024;403(10437):1683-1722. [doi:10.1016/s0140-6736\(24\)00651-2](https://doi.org/10.1016/s0140-6736(24)00651-2)
60. Plackett R, Kaushal A, Kassianos AP, et al. Use of social media to promote cancer screening and early diagnosis: scoping review. *J Med Internet Res*. 2020;22(11):e21582. [doi:10.2196/21582](https://doi.org/10.2196/21582)

61. Kale SS, Hirani SAA, Vardhan S, et al. Addressing cancer disparities through community engagement: lessons and best practices. *Curēus*. 2023;15(8):e43445. [doi:10.7759/cureus.43445](https://doi.org/10.7759/cureus.43445)
62. Ponce SB, McAlarnen LA, Teplinsky E. Challenges of reaching patients with cancer on social media: lessons from the failed #CancerRealTalk experience. *JCO Oncol Pract*. 2023;19(2):63-65. [doi:10.1200/op.22.00515](https://doi.org/10.1200/op.22.00515)
63. Merport K, Benoit G, Labban M, et al. Prostate cancer: challenges of community outreach with the Mass General Brigham Prostate Cancer Outreach Clinic - American Urological Association. *AUA News*. September 19, 2023. Accessed July 22, 2024. [auanews.net/issues/articles/2023/september-extra-2023/prostate-cancer-challenges-of-community-outreach-with-the-mass-general-brigham-prostate-cancer-outreach-clinic](https://auanews.net/issues/articles/2023/september-extra-2023/prostate-cancer-challenges-of-community-outreach-with-the-mass-general-brigham-prostate-cancer-outreach-clinic)
64. PAR-21-321: Cancer center support grants (CCSGS) for NCI-designated cancer centers (P30 clinical trial optional). October 12, 2021. Accessed July 22, 2024. [grants.nih.gov/grants/guide/pa-files/PAR-21-321.html#:~:text=CCSG%20grants%20provide%20funding%20for,and%20education%2C%20and%20centralized%20clinical](https://grants.nih.gov/grants/guide/pa-files/PAR-21-321.html#:~:text=CCSG%20grants%20provide%20funding%20for,and%20education%2C%20and%20centralized%20clinical)

## ACKNOWLEDGMENTS

ACCC is grateful to the Advisory Committee and others who graciously gave their knowledge and time to contribute to this handbook.

### Archana Ajmera, MSN, ANP-BC, AOCNP

Adult Nurse Practitioner  
UC San Diego Health  
San Diego, CA

### Pedro Barata, MD, MSc, FACP

Assistant Professor, Deming Department of Medicine,  
Division of Hematology/Oncology, Genitourinary Cancers  
Tulane University  
New Orleans, LA

### Evan Goldfischer, MD, MBA

Director of Research, Urology Division,  
President, LUGPA 2022-2024  
Premier Medical Group  
Poughkeepsie, NY

### Kimberly King-Spohn

Director of Genetic Counseling, Center for Genetics  
Wellstar Health System, Wellstar Cancer Program  
Marietta, GA

### Shelby Moneer, MS, CHES

VP, Patient Education & Programs  
ZERO Prostate Cancer  
St Louis, MO

In partnership with:



This project is made possible by support from:



Explore additional resources on metastatic prostate cancer at [acc-cancer.org/prostate](https://acc-cancer.org/prostate).

The **Association of Cancer Care Centers** (ACCC) provides education and advocacy for the cancer care community. For more information, visit [acc-cancer.org](https://acc-cancer.org).

© 2024. Association of Cancer Care Centers. All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means without written permission.