

# Virtual Multidisciplinary Summit on Treating Advanced Prostate Cancer in the Community

## EXECUTIVE SUMMARY

### INTRODUCTION

The term “advanced prostate cancer” refers to the disease state of patients experiencing any of the following:

- Biochemical recurrence without metastatic diagnosis after all other treatment options have been exhausted (local radiation, prostatectomy)
- Non-metastatic castration-resistant prostate cancer (nmCRPC)
- Metastatic castration-sensitive prostate cancer (mCSPC)
- Metastatic castration-resistant prostate cancer (mCRPC)

Approximately 8 percent of people with prostate cancer will be diagnosed with metastatic prostate cancer, and 10 percent to 20 percent of prostate cancers are hormone resistant.<sup>1,2</sup> Advanced prostate cancer is a complex disease state that often requires layers of different types of treatment, sequentially or concurrently, and can span long periods of a patient’s life. While engaging patients and their care partners in discussions about care decisions can improve quality of life and patient satisfaction, it’s not an easy task. In addition, many patients with advanced prostate cancer are affected by disparities in care, which can lead to suboptimal treatment outcomes.

To address these challenges, the Association of Community Cancer Centers (ACCC), along with its partners—the American Psychosocial Oncology Society (APOS), the Prostate Conditions Education Council (PCEC), and Zero-The End of Prostate Cancer—embarked on the project, “The Comprehensive Care of Patients with Advanced Prostate Cancer through

Shared Decision-Making” in 2021. Components of this project included a landscape analysis, a provider survey to explore their knowledge of and engagement in shared decision-making (SDM) a patient and care partner survey to understand their engagement in care decisions, and a multidisciplinary virtual summit to explore practical solutions to treating advanced prostate cancer in the community.

### PROVIDER, PATIENT, AND CARE PARTNER SURVEYS

To better understand patient engagement in care decision-making for advanced prostate cancer, ACCC and PCEC distributed surveys through their networks to healthcare providers, patients with advanced prostate cancer, and the care partners of patients with advanced prostate cancer. Surveys were distributed in August 2021, and responses were collected through early October 2021.

The provider survey brought in 97 responses, 85 percent of whom work directly with patients with advanced prostate cancer and help them make decisions about their care. Respondents were primarily physicians (84 percent) and represented academic centers, community cancer centers, and private practices in mostly urban or suburban settings. Respondents were asked about their and their colleagues’ roles in care decision conversations, their knowledge and attitudes regarding patient engagement in care decisions, and their perceived barriers to patient engagement. Providers were also asked about the training available at their institutions on topics related to engaging patients in care decisions.

**Table 1. Respondents' agreement with statements about shared decision-making**

	Provider (N=82)	Patient (N=60)
Provider wanted to know exactly how the patient wants to be involved in making decisions	90%	63%
Provider explained advantages and disadvantages of treatment options	93%	67%
Provider helped patient understand all the information	96%	68%
Provider asked patient which option they prefer	95%	75%
Provider and patient thoroughly weighed different treatment options	90%	63%

*ACCC Advanced Prostate Cancer Provider and Patient and Care Partner Surveys*

The patient and care partner survey brought in 94 responses, including 60 patients with advanced prostate cancer and 34 care partners. Care partners were asked about their involvement in making care decisions, while patients were asked about their level of engagement in care decision-making with their physicians and their most important considerations in the decision-making process.

Both providers and patients were asked the same questions about engagement using questions from the SDM-Q-9 and the SDM-Q-Doc, instruments developed to assess patients' and care providers' perceptions of SDM using nine questions. While the patients and care providers were not formal dyads, comparing the responses of the patients as a group with the providers as a group showed divergence in perceptions of experience.

In all questions, care providers perceived a higher level of patient engagement than patients did. This may mean patients are not as involved in shared decision-making as providers think they are, which indicates an opportunity for improvement.

Providers indicated several barriers to fully engaging patients in making their treatment decisions, including the patient feeling overwhelmed (51.5 percent), the patient wanting their clinicians to make treatment decisions for them (40.2 percent), the patient having limited health literacy (39.2 percent), the provider having inadequate time to discuss options in clinical interactions (32 percent), and the patient having little trust in the healthcare system (26.8 percent).

Further survey results are discussed in the summit summary and appendix below.

## MULTIDISCIPLINARY SUMMIT

The Multidisciplinary Summit on Treating Advanced Prostate Cancer in the Community Setting was held on October 4, 2021. Approximately 25 prostate cancer experts participated, representing urology, radiation oncology, nursing, psychosocial support, genetic counseling, health disparities research, and patient advocacy.

The summit—which ran for half a day—was organized into two general sessions focused on two related goals:

- To identify strategies to support patient engagement in treatment decision-making in advanced prostate cancer
- To identify strategies to improve care for patients with advanced prostate cancer

At the start of the summit, participants were asked to share what they thought were the biggest challenges to delivering optimal care to patients with advanced prostate cancer. Among their responses:

- Access and adherence to screening recommendations
- Consistent use of comprehensive guideline-based evaluations (including genetic testing) and treatment protocols

- Patient understanding of information about options, side effects, and expected outcomes
- Lack of clarity about what decision-making looks like in the context of equity
- Lack of services such as navigation and survivorship support

Each session began with speakers framing the discussion by highlighting the current knowledge, strategies, and challenges regarding each topic. The following is a summary of the main themes of the conversation, along with associated opportunities.

## PATIENT ENGAGEMENT IN DECISION-MAKING

For some patients who receive a diagnosis of advanced prostate cancer, education starts with the basics, as it is common for patients to not know what the prostate is prior to their diagnosis. Other patients who are experiencing a recurrence or progression to advanced prostate cancer after earlier treatment may have a better understanding of the disease. Effectively engaging patients in conversations about their treatment options requires a tailored approach to shared decision-making.

The themes of inadequate patient trust, limited time during clinical interactions, and patients feeling overwhelmed were recurrent in conversations at the summit. Participants mentioned several strategies that they have found useful in overcoming these barriers to care and improving patient engagement in decision-making, including:

- Empower patients with reliable and accessible information
- Break down decisions into manageable parts
- Understand patient goals, values, and preferences
- Identify patients at risk for suboptimal outcomes
- Create a network of support throughout the care continuum
- Incentivize effective practices
- Use technology to improve care

## Empower Patients with Reliable and Accessible Information

Research on how decisions are made indicates that people use mental “shortcuts” to make decisions, and the information informing those shortcuts is not always helpful.<sup>3</sup> For example, if a patient’s neighbor had a bad experience with surgery, when that patient is presented with treatment options, they may decide not to have surgery because they heard about a negative experience from a peer. Once these cognitive shortcuts are in place, they are difficult to change.

In addition, emotions about a diagnosis can influence how information is sought, processed, and acted upon, often resulting in bias toward or against certain treatments.<sup>4</sup> Summit participants agreed that the development of appropriate information and educational tools that address such biases and support care decision-making is critical. Building patient trust in the healthcare system is important for this strategy to work. Information from reliable sources supports patient engagement in their conversations with their providers. It also helps overcome the challenges presented when the patient lacks comprehensive, easily understood information and seeks it from less reliable sources.

The key to creating trust—and supporting patients with low health literacy—is to streamline patient education, avoid medical jargon in favor of plain language, present information visually (pictures, diagrams, and illustrations), and use a variety of methods to communicate. A comprehensive education strategy may include information packaged in newsletters or topic-specific handouts. Enlisting community leaders to serve as educators, engaging patient advocacy organizations, and leveraging smart phone apps can also promote shared decision-making.

Decision aids can also contribute to empowering and engaging patients in discussions with their providers. One decision aid under development has increased patient understanding of what their decisions are, the nature of their disease, and their treatment options.<sup>5</sup> This decision aid has multiple components, including education about the disease and treatments, a decision balance sheet that helps set priorities, and audio CDs that share stories of how others have made similar decisions. While ACCC provider survey respondents indicated that lack of adequate time during clinical interactions was a barrier to engaging patients in treatment discussions, a pilot of the decision aid for patients with advanced prostate cancer showed that its use is feasible in a busy clinic setting. In

addition, patients said use of this decision aid helped them feel more comfortable expressing their concerns and being more involved in their treatment.

Creating reliable and accessible information that serves all patients has its challenges. Health literacy is often understood as reading comprehension, but that oversimplifies it. While mathematical literacy or numeracy can help a patient understand risk, cultural literacy can impact how a patient engages with information or the messengers of that information. The development of messaging that supports all patients requires leveraging narrative styles or linguistic patterns for effective information delivery.

But different populations have different needs and different ways of processing information. As a result, overly standardizing information may result in some groups being left out. One solution may be to create standardized education tools, decision aids, or apps, and then allow healthcare professionals, practices, and community centers to tailor them to meet the needs of their specific populations.

### Break Down Decisions into Manageable Parts

Almost 10 percent of provider survey respondents indicated that lack of time to engage patients in treatment discussions during the clinical interaction is a common barrier to shared decision-making. But even in the case of advanced prostate cancer, summit participants indicated that a patient generally does not have to make a care decision immediately. This allows for time to process what may feel like an overwhelming amount of information and come to a decision at a pace that feels less urgent.

Notably, in the provider survey, being overwhelmed by decisions was identified as the most common barrier to engaging patients in treatment discussions. Information overload is counter-productive to decision-making. Clinicians should consider allowing treatment decisions to be made over the course of several patient conversations. One participant described it in this way: “The [initial] consult is the way to set the table.” In that first visit, the clinician might review with the patient treatment options and potential risks and benefits to consider and then send that patient home to process the information. Deeper discussions can take place during follow-up consults. Breaking down information and allowing adequate time for patients to digest it can be an effective strategy in decreasing barriers to patient engagement.

Provider survey respondents cited their top barriers to engaging patients in treatment discussions:

- Patients are overwhelmed by the decisions (52%)
- Patients want their clinicians to make the decision(s) (40%)
- Patients have limited health literacy (39%)
- There is not enough time to engage patients in treatment discussions during the clinical interaction. (32%)
- Patients do not always trust the healthcare system (27%)

### Understanding Patient Goals, Values, and Preferences

Understanding patient goals, values, and preferences is the most important part of the clinician-patient interaction and one of the primary goals of shared decision-making. In the provider survey, 24 percent of respondents indicated that they had not received training in obtaining information about patient values, goals, preferences, and priorities, and 36 percent of respondents had only received training through self-directed online training modules. Summit attendees agreed that once clinicians understand their patients’ goals and priorities, they can help them develop a care plan that addresses those goals. Listening to the patient and asking, “What are you most worried about?” can elicit useful information about patients’ priorities and preferences.

Provider survey respondents had a varied amount of training in eliciting patient values, goals, preferences, and priorities:

- Self-directed online training module (36%)
- I have not been trained in this (24%)
- Didactic/lecture delivered in person (21%)
- Collaborative training with role play (19%)

To learn patient values and beliefs about different types of treatment, the healthcare professionals who provide psychosocial support to patients can help them better understand their disease. These professionals can support patient engagement in treatment decisions by providing another venue to discuss their concerns, preconceived ideas, and priorities.

**Table 2. When it comes to making decisions about your prostate cancer treatment, what considerations are most important to you?**

Most Important Decision Considerations	Least Important Decision Considerations
<ul style="list-style-type: none"> <li>• Prolonging survival 62%</li> <li>• Maintaining high quality of life 60%</li> <li>• Confidence in the doctor’s suggestions 37%</li> </ul>	<ul style="list-style-type: none"> <li>• Making a decision that I/we won’t regret 3%</li> <li>• Living long enough to make it to important family milestones 3%</li> <li>• Convenience of receiving treatment 2%</li> </ul>

ACCC Advanced Prostate Cancer Patient and Care Partner Survey

Of course, patient goals may change over time. Summit participants noted that when patients are first diagnosed with advanced prostate cancer, their goals and priorities may focus on how the disease and treatment will interfere with ordinary life. Issues such as urinary incontinence and sexual function often factor prominently in these discussions. Over time, priorities may shift to more existential concerns, such as maximizing quality of life and having energy to do enjoyable activities. Approximately 63 percent of the patients and care partners who responded to the ACCC survey reported that they/their partner had been living with advanced prostate cancer for more than a year, and 49 percent of patients said they have been treated with multiple modalities of care. Both time from diagnosis and choice of treatment modalities influence a patient’s goals, values, and preferences about treatment.

## IMPROVING PATIENT CARE

Summit participants discussed several other strategies to improve care, particularly focused on overcoming health disparities that can result in poorer outcomes for disadvantaged populations. While the lack of tailored therapeutic interventions in high-risk populations and the inconsistent application of treatment guidelines have been linked to health disparities, the factors contributing to those disparities can be layered and complex.

### Identify Patients at Risk for Suboptimal Outcomes

Patients with low health literacy have been shown to have a higher symptom burden, are more likely to be hospitalized, and are more likely to die because of non-adherence to care plans. Detecting risk factors such as low health literacy early on helps identify patients at higher

risk, enabling more timely interventions. When such patients are not helped and subsequently go into crisis, it should not be a surprise. As one participant observed:

*When we find out Friday at 5:00 PM that someone is going to lose their home on Monday, that process didn't start Friday at 4:00 PM.*

Another participant had a similar reaction:

*How often do I get a clear sense of the other competing priorities? Can [the patient] make the appointments to come to me if it takes them three hours to get there or they can't get off work? These proximal effects may be just as important. How is that factored into the surveys we give to patients when we are asking about medical history? How often are we asking about food insecurity or homelessness?*

Incorporating questions to understand barriers to care can help identify high-risk patients from the time of diagnosis.

### Create a Network of Support Throughout the Care Continuum

When it comes to advanced prostate cancer, the patient journey is complex. Building support around the patient from multiple angles may help improve outcomes. Patient navigation is a useful strategy for supporting patient engagement and ensuring patients can receive appropriate care. Because several months may elapse between clinical visits, patient navigation can be an effective tool to answer patient questions, identify patient problems, and overall enhance the patient experience.

Participants noted that, while patient navigation takes various forms and can employ clinical or non-clinical staff, what's most important is that navigators are able to identify barriers to optimal care.<sup>6</sup> Continued contact with a patient navigator can also help patients feel educated about their disease and connected to their care team. One participant talked about creating a map for patients to help them identify where they are on the prostate cancer journey and what treatment options might still be open to them. This type of map could also be used to identify what support options would be useful at various points along the care continuum.

While patient navigation is an important tool for tracking and monitoring patient care, many cancer centers are understaffed, and navigators sometimes have hundreds of patients for whom they are responsible. Without triage systems to determine which patients would most likely benefit from patient navigation, navigators can end up being firefighters, dealing with crisis after crisis—a scenario that can quickly lead to burnout.

Using patient-reported outcomes (PROs) could help providers identify who patient navigators should prioritize. By using technologies such as phone apps to identify physical, emotional, and spiritual symptoms early, a patient navigator's limited time can be spent on patients who are in more acute states of distress. Asking patients questions about social determinants of health can help identify the patients at most risk of suboptimal outcomes.

Patient advocacy organizations can supplement the work of cancer centers. These partnerships can provide a valuable source of education and patient navigation support, particularly when cancer centers do not have the capacity to provide such support themselves. Several of the patient advocacy representatives in attendance at the summit referred to tools, educational resources, and support programs they have available to patients, some of which can be used to help guide clinical conversations in a patient-friendly way.

Care partners are a significant source of support for patients with advanced prostate cancer. In the ACCC patient and care partner survey, 62 percent of care partners reported being extremely involved in care decisions. With care partners so engaged, a divergence in opinion about priorities and goals can cause friction in decision-making. Summit participants mentioned that

often these divergent priorities are centered on quality of life (a priority for patients) versus quantity of life (frequently a higher priority for care partners). Summit participants agreed that healthcare providers must educate both patients and their care partners and make sure they are on the same page about goals and priorities.

## Incentivize Effective Practices

When discussing strategies to improve care for patients with advanced prostate cancer, summit participants mentioned several challenges, including a reimbursement structure that prioritizes quantity of care over quality of care. Extensive patient engagement that is cultivated over time is not reimbursable in a fee-for-service reimbursement system. Tracking effective practices in patient management in data systems and then tying them to compensation or other financial incentives could lead to significant change.

The need for training and continuing education in effective patient communication was also noted by summit participants as an area for improvement. Of the respondents to the ACCC provider survey who indicated that they have direct involvement in decision-making conversations, approximately 20 percent said they have no training in how to have difficult conversations with patients. Fifty percent of respondents said they have received less than two hours of training in shared decision-making.

The percentages below represent the providers who say they have not had training in the following aspects of shared decision-making:

- How to run a family meeting (45%)
- Using patient decision aids (37%)
- Incorporating what matters most to patients into treatment decisions (31%)
- The role of families and caregivers in supporting treatment decision-making (29%)
- Having difficult conversations (e.g., discussing prognosis, bad news, and death and dying) (26%)
- Cultural competency, sensitivity, or humility (26%)
- Communicating treatment risks and benefits to patients (26%)

- Eliciting patient values, goals, preferences, and priorities (24%)
- Diversity training on gender identity and gender expression (20%)

Respondents to the questions above include all survey respondents, not just those directly engaged in decision-making conversations.

One participant pointed out that most of the training in patient communication skills targets medical school students and residents. For physicians, once formal medical training in the non-clinical aspects of care ends, they are less likely to pursue these skills in continuing education. But in the context of health disparities, constantly evolving science and new information mean there is always room for improvement. Participants urged providers to determine what optimal training on shared decision-making should look like and what continuing education is necessary.

Bringing together both clinical and non-clinical team members for training can help leverage different skillsets to learn how to enhance the patient experience and promote shared decision-making. This is particularly important when learning different communication styles, how to build rapport with patients, how to approach and educate patients, and how to make space for acknowledging the traumatic experience of being diagnosed with cancer. For example, there are social work tools that can train clinicians in how to show empathy and work toward a collaborative relationship with patients.

### Use Technology to Improve Care

Making the case for obtaining technology to help improve patient care and outcomes is often perceived as a heavy lift, but there are demonstrable benefits to the investment. One summit participant reported that her county invested \$10 million to integrate an electronic health record (EHR) across the public hospital system. This integration has improved tracking patients across different institutions when they seek different types of care. When elevated COVID-19 cases required hospitals to divert patients with cancer to other institutions, the EHR allowed healthcare providers to access case management notes and get up to speed on patients' situations faster. This shared information also helps the county track how social determinants of health impact different groups, which in turn helps identify barriers to access and continuation of care.

Creating a census through data collection allows insight into quality care at the cancer center or healthcare system level. This allows providers to see what they are doing compared to others within the same department or across departments, which can help them identify specific changes that need to be made. As one participant noted, "No one says 'I contribute to disparities,' but then when you show them their data and they are seeing differences that they didn't appreciate [before], that shows them that there is room to improve."

Participants expressed concern about over-reliance on EHR tools to improve care due to the potential of putting excessive burden on healthcare providers. It may be more effective to use banners in EHRs, which can provide limited information that can more easily prompt decisions like recommending prostate cancer screening. When using technology to improve care, efforts should be made to use it judiciously and to make the data useful, avoiding, as one participant put it, "death by a thousand clicks."

### Other Strategies

There were additional topics that participants agreed are worthy of discussion if a future opportunity presents itself. These include:

- Palliative care and hospice care
- Adoption of tissue-based genomic testing
- Use of support groups to provide decision support
- Potential for multi-disciplinary clinics to improve shared decision-making and care quality

## CONCLUSION

Summit participants agreed that, while there are challenges and barriers to optimal care for patients with advanced prostate cancer, there are also opportunities to improve. When it comes to engaging patients in decision-making about their care, improving how healthcare providers communicate and seeking to understand patients' goals and priorities become more feasible. Identifying patients at risk for suboptimal outcomes will require attention to the factors that make them vulnerable. Supporting them using a multi-pronged approach throughout the treatment journey, incentivizing effective practices, and implementing creative uses of technology can all be leveraged to improve quality of care.





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# APPENDIX

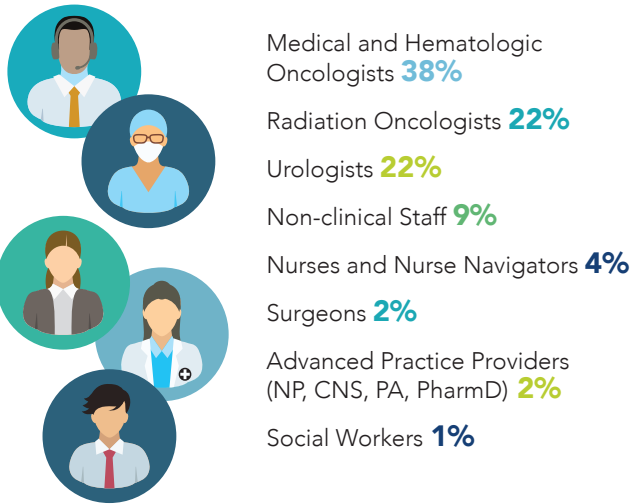
Highlights from the 2021 ACCC Comprehensive Care of Patients with Advanced Prostate Cancer through Shared Decision-Making Provider and Patient Surveys.

The Association of Community Cancer Centers (ACCC)—in partnership with Prostate Conditions Education Council (PCEC)—collected data to understand patient priorities and their experiences with engagement in

shared decision-making. The surveys also sought to identify existing practice patterns, barriers to optimal care, and improvement strategies for community cancer centers. The surveys were administered nationwide to multidisciplinary cancer team members and patients and their care partners in August and September 2021. The following provides an overview of the results of each survey.

## PROVIDER SURVEY (N=97)

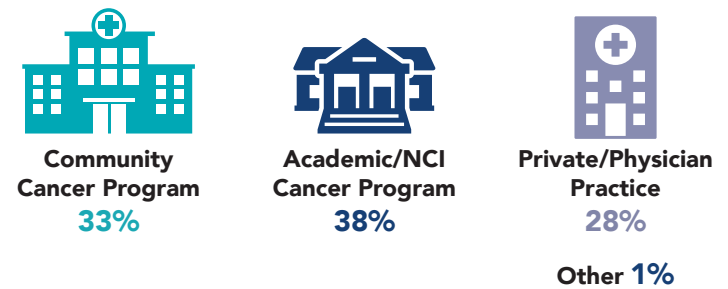
### Respondents indicated the following professions:



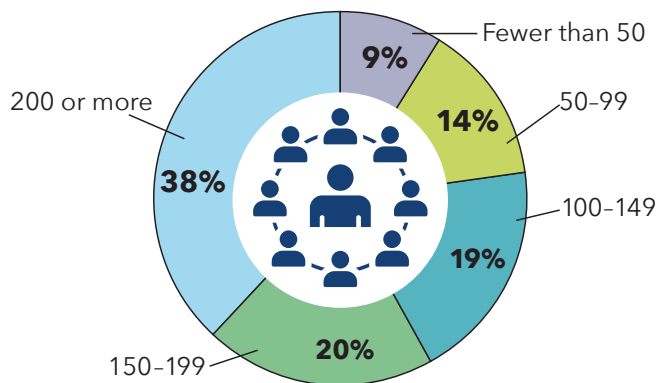
### Respondents described the area in which their cancer program is located as:



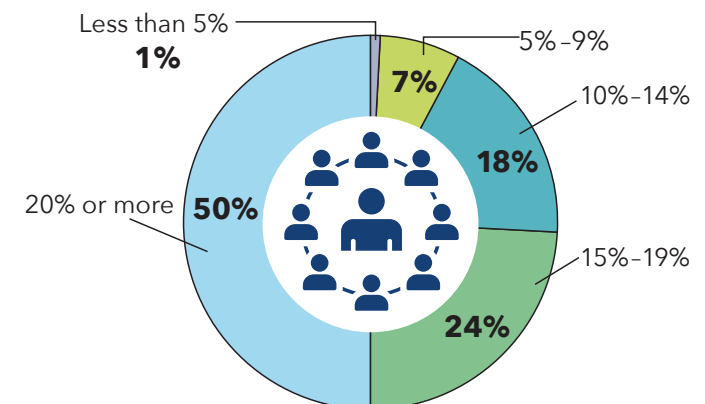
### Respondents' primary cancer program affiliations were:



### Estimated number of patients with prostate cancer treated annually by respondents' cancer programs:



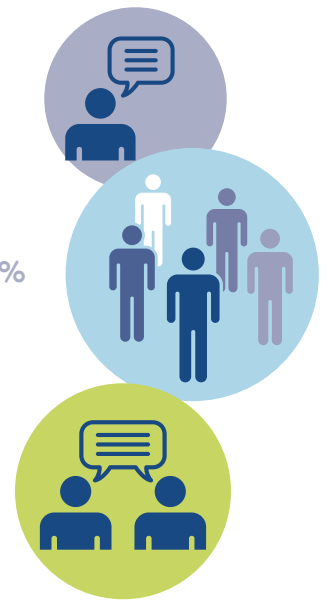
### Percentage of patients being treated for ADVANCED prostate cancer at respondents' cancer programs:





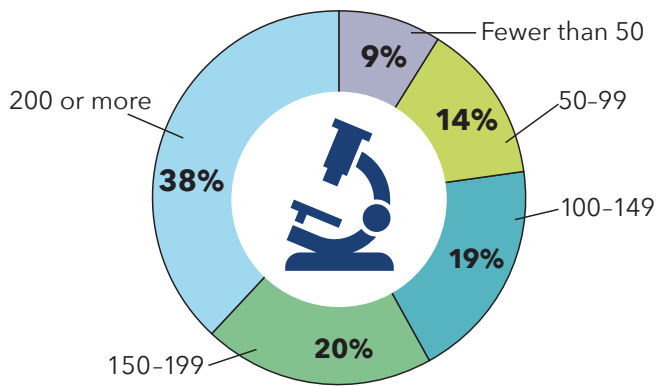
**Areas in which respondents report they have not received training:**

- How to run a family meeting **45%**
- Using patient decision aids **37%**
- Incorporating what matters most to patients into treatment decisions **31%**
- The role of families and caregivers in supporting treatment decision-making **29%**
- Having difficult conversations (e.g., discussing prognosis, bad news, and death and dying) **26%**
- Cultural competency, sensitivity, or humility **26%**
- Communicating treatment risks and benefits to patients **26%**
- Eliciting patient values, goals, preferences, and priorities **24%**
- Diversity training on gender identity and gender expression **20%**

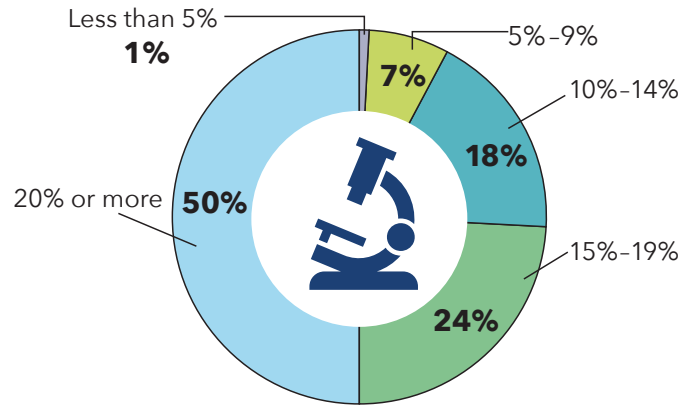


**The following questions were answered by provider survey respondents who reported that they work directly with patients with advanced prostate cancer to help them make care decisions. (N=82)**

**Percentage of respondents who report discussing clinical trial participation as a care option:**



**According to respondents, after discussing clinical trials, the percentage of patients who enroll:**

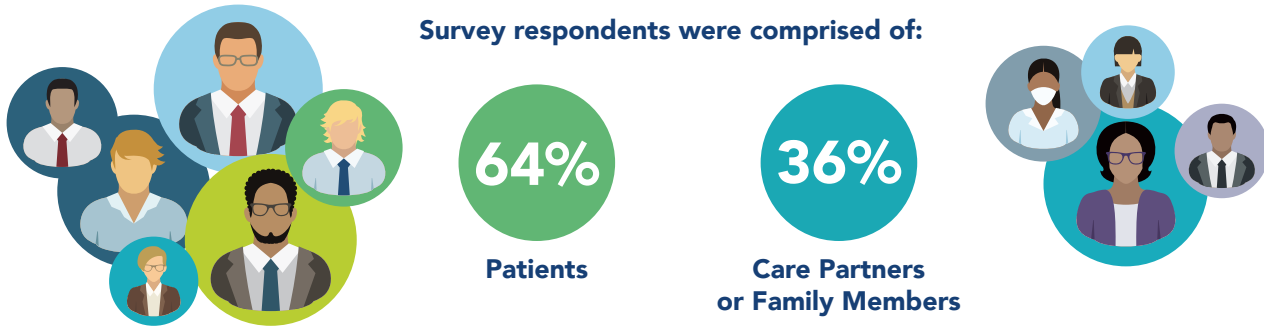


**Five most common barriers respondents cite to engaging patients in treatment discussions:**

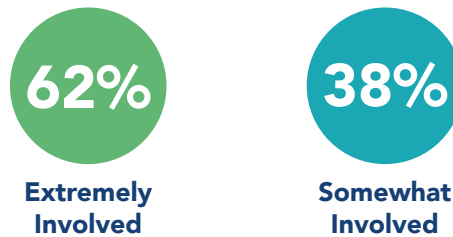
- Patients are overwhelmed by the decisions **52%**
- Patients want their clinicians to make the decision(s) **40%**
- Patients have limited health literacy **39%**
- There is not enough time to engage patients in treatment discussions during the clinical interaction **32%**
- Patients do not always trust the healthcare system **27%**

## PATIENT AND CARE PARTNER SURVEY (N=94)

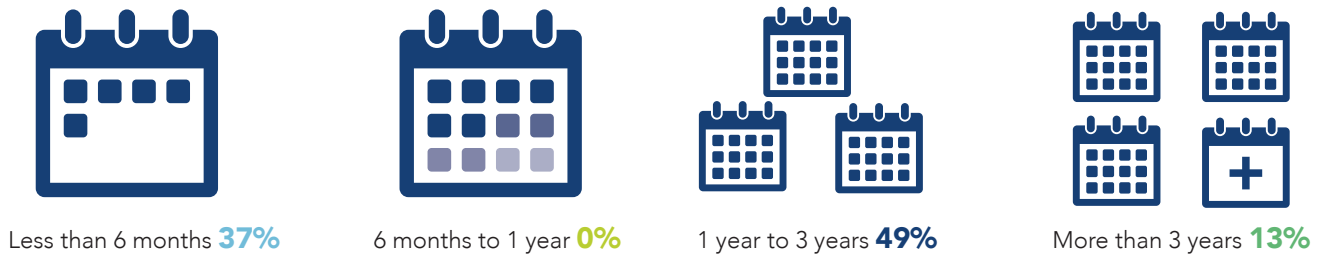
Survey respondents were comprised of:



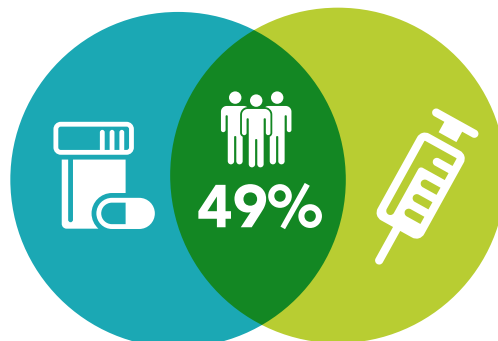
Extent of involvement in patient treatment decisions cited by care partners:



Time elapsed since patient respondents' advanced prostate cancer diagnosis:



The percentage of patients reported receiving multiple treatment modalities



## Perceived Engagement in Decision-Making

Providers and patients were asked the same set of questions about engagement in decision-making. Providers tended to perceive higher levels of patient engagement, while patients perceived lower levels (though still high). This may indicate a disconnect between how patients and providers view decision-making interactions.

## Agreement with statements about shared decision-making

	Provider (N=82)	Patient (N=60)
Provider wanted to know exactly how the patient wants to be involved in making decisions	90%	63%
Provider explained advantages and disadvantages of treatment options	93%	67%
Provider helped patient understand all the information	96%	68%
Provider asked patient which option they prefer	95%	75%
Provider and patient thoroughly weighed different treatment options	90%	63%



# ACKNOWLEDGMENTS

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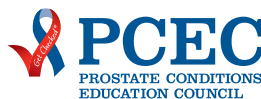
A publication from the ACCC education program, Comprehensive Care of Patients with Advanced Prostate Cancer through Shared Decision-Making. Learn more at [acc-cancer.org/advanced-prostate-SDM](http://acc-cancer.org/advanced-prostate-SDM).

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