

# Primary Care Physician and Urologist Perspectives on Optimizing Active Surveillance for Low-Risk Prostate Cancer

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## ABSTRACT

**PURPOSE** We conducted a study to understand primary care physician (PCP) and urologist perspectives on determinants of active surveillance care delivery for men with low-risk prostate cancer.

**METHODS** We conducted in-depth, semistructured, virtual interviews with a purposive sample of 19 PCPs and 15 urologists between June 2020 and March 2021. We used the behavioral theory–informed Theoretical Domains Framework to understand barriers to and facilitators of active surveillance care delivery. Interviews were recorded, transcribed, and deductively coded into framework domains and constructs by 3 independent coders. Participant recruitment continued until data saturation by group.

**RESULTS** Our study included 19 PCPs (9 female; 4 in community practices, 15 in academic medical centers) and 15 urologists (3 female; 5 in private practice, 3 in academic medical centers). The most commonly reported Theoretical Domains Framework domains affecting active surveillance care were (1) knowledge and (2) environmental context and resources. Although urologists were knowledgeable about active surveillance, PCPs mentioned limitations in their understanding of active surveillance (eg, what follow-up entails). Both groups noted the importance of an informed patient, especially how a patient's understanding of active surveillance facilitates their receipt of recommended follow-up. Physicians viewed patient loss to follow-up as a barrier, but identified a favorable organizational culture/climate (eg, good communication between physicians) as a facilitator.

**CONCLUSIONS** With patients increasingly involving their PCPs in their cancer care, our study presents factors both PCPs and urologists perceive (or identify) as affecting optimal active surveillance care delivery. We provide insights that can help inform multilevel supportive interventions for patients, physicians, and organizations to ensure the success of active surveillance as a management strategy for low-risk prostate cancer.

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## INTRODUCTION

For men with low-risk prostate cancer, national guidelines, such as those of the American Urological Association and the American Society of Clinical Oncology, recommend active surveillance as the primary management strategy.<sup>1,2</sup> This shift reflects a change in recommendations that has occurred over the past 20 years, moving away from definitive treatment with surgery or radiation, with the aim of reducing overtreatment and its harms. Active surveillance involves routine urologist visits, prostate-specific antigen (PSA) laboratory testing, and serial tumor burden reassessment with magnetic resonance imaging or prostate biopsy. Ensuring men receive all of these components (ie, true *active* surveillance) at recommended intervals is key to its success as a management strategy, including timely identification of disease progression.<sup>3</sup>

Although active surveillance rates nationally have increased from 10% in 2010 to nearly 60% in 2021,<sup>4,5</sup> evidence suggests many men are not adhering; some are not receiving recommended follow-up, whereas others are undergoing definitive treatment despite stable disease.<sup>6,7</sup> For example, in a statewide cohort of men with favorable-risk prostate cancer in Michigan, only one-half received recommended PSA testing and tumor burden reassessment.<sup>8</sup> Up to one-third of men on active surveillance in other studies were treated despite no evidence of cancer progression.<sup>9,10</sup> Although cancer specialists have traditionally managed all aspects of cancer treatment, patients are increasingly involving primary care physicians (PCPs) in their

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cancer care, creating opportunities to support high-quality adherence to active surveillance.<sup>11,12</sup>

Prior literature has focused on understanding the role of PCPs in the delivery of team-based cancer care during survivorship. Whether and to what extent PCPs can be involved in active surveillance, however, is not known.<sup>11,13,14</sup> Guided by the behavioral theory–informed Theoretical Domains Framework (TDF),<sup>15</sup> the overall goal of our qualitative study was to understand how PCPs and urologists perceive their roles in active surveillance for low-risk prostate cancer. We found that clinicians often discussed factors that enabled or impeded their effective involvement in active surveillance. This article therefore focuses on characterizing clinician perspectives on determinants (barriers and facilitators) related to active surveillance care delivery and their possible impacts on active surveillance adherence.

## METHODS

### Conceptual Framework and Interview Guide Development

Similar to the process we used for prior work,<sup>16</sup> our team used the TDF to inform the development of our interview guide ([Supplemental Appendix](#)). TDF domains are based on psychological behavior change theories and allow for characterization of determinants influencing physician practice change. The TDF can also be linked to the Behaviour Change Wheel's Capability, Opportunity, and Motivation (COM-B) model, which posits that behavior is influenced by various factors and that changes to behavior are brought about by modifying capability (C), opportunity (O), and motivation (M).<sup>17</sup> This linkage can inform intervention development to improve active surveillance care delivery through targeted selection of behavior change strategies.

Our interview guide assessed (1) knowledge about active surveillance, (2) factors influencing adherence to follow-up testing, and (3) preferences for team-based care delivery and roles among PCPs and urologists. We pilot tested and refined the interview guide with our study team, including a urologist (T.A.S.), a PCP (A.R.), an expert in cancer treatment decision making (S.T.H.), and 2 qualitative methodology experts (M.D.F. and D.A.W.). We conducted pilot tests with a urologist from the Michigan Urological Surgery Improvement Collaborative (MUSIC) and a PCP from our academic institution for further refinement.

### Participants

We recruited PCPs and urologists to participate in our study. All participants were offered a \$50 incentive to participate. We used multiple approaches to recruit PCPs. We e-mailed PCPs at our large academic institution in both the internal medicine and family medicine departments. To obtain a more representative sample of PCPs as themes emerged during our iterative coding analysis that required further exploration, we additionally conducted internet searches for primary care

practices in rural regions of Michigan. We excluded PCPs who did not have any experience providing care to men on active surveillance.

We partnered with MUSIC to recruit urologists. MUSIC is a statewide, physician-led quality improvement collaborative designed to evaluate and improve the quality of prostate cancer treatment, including active surveillance. With the support of MUSIC leadership, our study team e-mailed urologists to assess interest in participation.

Participant recruitment was stopped after we achieved thematic saturation.

### Data Collection and Analysis

Two members of the study team (A.R. and A.J.R.) conducted all individual, semistructured interviews. Because of the COVID-19 pandemic, all interviews were conducted virtually over Zoom (Zoom Video Communications, Inc); they lasted an average of 31 minutes (range, 19-47 minutes). All participants provided consent at the start of their interviews. Interviews were audio recorded and professionally transcribed.

We used NVivo 12 software (QSR International). All transcripts were deductively coded using the TDF domains, and constructs were organized in the COM-B model.<sup>18</sup> Two team members (A.J.R. and L.S.) independently mapped all interview content to a relevant TDF domain. This was done iteratively; after coding 5 transcripts, we met as a study team to review the coding scheme, refined definitions for codes, and resolved any coding disagreements. Then, as a study team (A.J.R., L.S., and A.R.), we mapped all TDF domain content to TDF constructs. All results were presented to the team members (S.T.H., M.D.F., and T.A.S.) to discuss code summaries and resolve any discrepancies. We adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.<sup>19</sup> This study was approved by our institutional review board.

## RESULTS

### Physician Characteristics

A total of 19 PCPs and 15 urologists participated in the study. PCPs were, on average, aged 48 years. The majority were male (53%) and White (79%; 16% Asian, 5% African American), and practiced in academic medical practices (79%; 16% in large medical groups). PCPs had generally provided care to 1 to 5 men on active surveillance in the past year. Urologists were, on average, aged 52 years. The majority were male (80%) and White (87%; 7% African American); 40% practiced in large medical groups (34% in private practices, 20% in academic medical centers).

### TDF Domains

Physicians most frequently identified 2 primary TDF domains as influencing the delivery of active surveillance care: (1) knowledge and (2) environmental context and resources

(Table 1). The former mapped onto the COM-B domain of capability, while the latter mapped onto the COM-B domain of opportunity. The physicians discussed knowledge as it related to patients (having knowledge about active surveillance, that is, being informed patients) and to physicians themselves (having knowledge about active surveillance care delivery, that is, procedural knowledge). They noted barriers to and facilitators of active surveillance (eg, patients becoming lost to follow-up) and the impact of the organizational culture/climate (eg, physician communication, PCP involvement). We discuss each domain and construct in more detail below.

### Knowledge Domain

**Patient: the informed patient.** PCPs and urologists alike discussed the importance of a patient who was knowledgeable about active surveillance (ie, an informed patient) as a management strategy. They noted that patient education was critical to this knowledge and should ideally start at the time of prostate cancer screening. It should involve shared decision making on whether to initiate screening and a discussion of treatment options available, including active surveillance, and what each would entail.

When physicians discussed how to improve active surveillance care delivery, having an informed patient was perceived as important for the initial choice of active surveillance and subsequent adherence. PCPs specifically noted how confusing terminology could be for patients and the importance of spending time explaining the differences relative to other management strategies. Both physician groups also discussed how patients' understanding of what active surveillance is helps facilitate their receipt of recommended follow-up.

**Physician: the physician's procedural knowledge.** Urologists were viewed as the experts in active surveillance and the most knowledgeable on this strategy. They educated their patients on active surveillance, thereby ensuring patients were informed. PCPs sometimes referred to uncertainty when explaining active surveillance to patients. This uncertainty included a lack of general knowledge about active surveillance and specific knowledge about follow-up protocols and interpreting results.

Interviewer: "Could you walk me through how you describe [active surveillance] to [patients]?"

PCP: "Not really. So, I was a little reticent to participate because I think I don't know as much as I should know about this."

PCPs noted deferring to urologists, and when involved in their patient's active surveillance care, wanted explicit guidance from urologists regarding follow-up. For example, PCPs wanted to know what an acceptable rise in PSA level would be. A few, however, did note that in their role as a PCP, they review what the urologist discussed with the patient and help explain and/or clarify any issues during their visits.

### Environmental Context and Resources Domain

**Barrier: becoming lost to follow-up.** PCPs and urologists alike identified patient loss to follow-up as a barrier to active surveillance care delivery. They discussed patients becoming lost in the health care system, but also misunderstanding active surveillance and what it required. For example, several urologists discussed keeping personal lists of patients on active surveillance to ensure they received the recommended follow-up. The physicians also noted that patients may believe that because of the low-risk nature of their prostate cancer, they do not need the level of monitoring required by active surveillance.

**Facilitator: communication and organizational culture.** PCPs and urologists discussed the importance of communication between clinicians. Most often, physicians communicated electronically through the electronic health record, routing clinic visit notes or using portals to send messages. Both physician groups noted, however, that telephone calls were a better way to communicate. One urologist reported calling a PCP when a patient possibly needed extra guidance or assurance about his treatment choice, and the urologist wanted the PCP to provide that. One PCP commented on how telephone calls better facilitated their involvement in providing follow-up care.

"I think if there's any sort of handoff decision...don't just put it in a letter. Call us up...I'd be happy to talk with you...I really detest paper handoffs. You get a letter, and it's just like 1 line in there. You're like, 'Oh, thanks.'" – PCP

Several PCPs also commented on how working in a smaller practice or health care system allowed them to get to know urologists (through repeated clinical experiences), facilitated having a professional relationship, and made communication easier.

**Barrier and facilitator: PCP involvement in active surveillance care delivery (shared care).** PCPs and urologists alike viewed the PCP role in active surveillance to be mainly supportive. PCPs noted that during their visits with patients, they discuss the patient's medical issues, review specialist visits, and provide education. This was important to their role as the patient's primary physician and was how they contributed to ensuring an informed patient. They also talked about how patients have trust in them and view them as a source of information and a source for guidance about management.

Similarly, urologists wanted PCPs to reiterate their plan of care to the patient. Urologists hesitated when it came to PCPs doing any of the active surveillance follow-up themselves. They questioned whether PCPs were knowledgeable enough about the details of active surveillance to be responsible for its management.

## DISCUSSION

In this study, we used a behavioral framework to identify barriers to and facilitators of optimal active surveillance

for low-risk prostate cancer care. Knowledge (having an informed patient and a knowledgeable PCP) and environmental context and resources (having good communication between physicians and optimizing the PCP role in shared care) were identified by both PCPs and urologists as most relevant to active surveillance care delivery. With an increasing

number of men choosing active surveillance for low-risk prostate cancer, ensuring these men receive the recommended follow-up care and appropriately remain on active surveillance for their management is important. Within the context of national calls for team-based cancer care, our study uniquely presents the perspectives of both physician groups on their

**Table 1. Summary of Most-Referenced TDF Domains and Constructs for Active Surveillance of Low-Risk Prostate Cancer**

TDF Domain and Construct <sup>a</sup>	PCP	
	Summary	Example Quote
<b>Knowledge (awareness of the existence of something)</b>		
Patient: the informed patient	<p>Active surveillance can be confusing (ie, terminology, difference from watchful waiting).</p> <p>Patients need to understand what active surveillance is and, ideally, education should start at the time of prostate cancer screening.</p>	<p>"The first thing I try to make sure that they know about is that it's different than just waiting. It's not just watchful waiting because they get confused about what they hear on the news and on the internet. And so I walk them through that active surveillance is actually sort of very close monitoring ... there's very specific laboratory tests, biopsy schedules are anticipated, imaging, and then this is done in collaboration with the urologist..."</p> <p>"...I think they're [patient] more likely to follow the active surveillance if they understand the what and the why about it."</p>
Physician: procedural knowledge	<p>PCPs lack knowledge about active surveillance and need more education.</p> <p>For PCPs to be involved effectively, they need explicit guidance on active surveillance follow-up.</p>	<p>"Better education for the PCP I think. I can't say in my residency I had, and even in my boards, that question doesn't really come up very often. Even though... in clinical practice, [active surveillance] does come up ... how often and what is concerning, what is less concerning. I don't think we have that nuance at all."</p> <p>"I think for some of these patients on active surveillance, it would be helpful if not only just routing the auto note, but like making it clear what they're [urologists] looking for, especially if we're going to follow them in the future, or making it clear what we're looking for that would trigger the next step ..."</p>
<b>Environmental context and resources (any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behavior)</b>		
Barrier: becoming lost to follow-up	Patient lack of understanding about active surveillance can lead to not receiving follow-up.	"I think the problem with active surveillance, you know where they're checking something every 6 months to a year, they can get this false sense of security after a couple of years that it's not changing, I don't really need to do that."
Facilitator: communication and organizational culture	Although EHRs facilitate effective communication between physicians, collegial relationships (from working in smaller practices, proximity) with specialists makes communication easier.	"The nonencounter message system inside MyChart is really important for this function for me because I feel like I can just tap the specialist on the shoulder and say, 'Hey, what about this?' ... But I think my trigger is a little easier to start a conversation if I just know it's just going to be like just bumping into somebody in the hallway."
Barrier and facilitator: PCP involvement in active surveillance care delivery (ie, shared care)	<p>PCPs can collaboratively work with urologists to support patient management (eg, review specialist visits with patients and reiterate information).</p> <p>Patients trust their PCP and turn to them for guidance.</p>	"But I think having a good relationship with your primary care and having an investment in your primary care relationship, both from the physician side and the patient side is key ... if I have a man who I have a lot of touch points with because I'm also seeing him for like his diabetes and hypertension and COPD ... I'm apt to see him more in clinic, and be like hey, 'I've noticed you haven't had your surveillance for your prostate cancer and it looks like you were supposed to see so-and-so 6 months ago and you didn't'..."

COM-B = Behavior Change Wheel's Capability, Opportunity, and Motivation; COPD = chronic obstructive pulmonary disease; EHR = electronic health record; PCP = primary care physician; TDF = Theoretical Domains Framework.

<sup>a</sup> The TDF knowledge domain mapped onto the COM-B model capability domain. The TDF environmental context and resources domain mapped onto the COM-B opportunity domain.



ability to effectively care for men with prostate cancer on active surveillance, with insights into supportive interventions for optimal active surveillance.<sup>20</sup>

PCPs and urologists most frequently referenced the capability of patients and physicians as influencing active surveillance care delivery. Physicians believed that if patients

understood active surveillance (were informed patients) and what active surveillance entails from the time they decided on it, they would be more likely to adhere. Organizations, including the American Urological Association, encourage physicians to engage in shared decision making with patients about their low-risk prostate cancer treatment.<sup>1</sup> Essential to

this process is physicians having sufficient knowledge about active surveillance to educate patients on factors to consider (eg, life expectancy) and details about the treatment itself (eg, immediate and long-term adverse effects). Whereas urologists felt confident in having the procedural knowledge to discuss active surveillance and manage men opting for this strategy, PCPs did not. This is not surprising because PCPs have previously reported having insufficient knowledge to participate in the delivery of cancer care, such as survivorship care.<sup>13</sup>

How best to support cancer-related education for PCPs so they are capable of engaging in active surveillance remains a challenge. Education of PCPs about active surveillance is key for their effective participation; for example, knowledgeable PCPs could help ensure that their patients on active surveillance understand what the recommended follow-up is and receive it. Although there are many resources for PCPs pertaining to cancer screening, fewer are available regarding cancer treatment and survivorship. Training options for PCPs include continuing medical education conferences; when led by urologists, this education also facilitates familiarity between the physicians, which our participants noted was important to having productive interspecialty interactions. Another option includes PCP-focused guidelines. For example, the American Cancer Society prostate cancer survivorship guidelines have a section dedicated to care coordination and practice implications that recommends specific responsibilities for PCPs in survivorship care.<sup>21</sup> PCPs in our study endorsed the need for something similar for active surveillance management. These guidelines will need to be specific to PCP roles and responsibilities in active surveillance (eg, when should the PCP order a PSA level, what change in PSA level should prompt a return visit to the urologist), targeted

<b>Urologist</b>	
Summary	Example Quote
Patients need education about active surveillance, such as what it is and what to expect, which will help promote adherence.	"Like everything else, it's just education and educating them that it is important ... well, that active surveillance is different than, for example, observation, that the patient ultimately may require treatment, that the cancer can change over time. It can become more aggressive and it can grow to a point where the patient does need active treatment ..."
Urologists are very knowledgeable about active surveillance and can educate patients.	"First we determine their overall health, and we estimate what their life expectancy is. Then we look at their tumor characteristics and ... we also talk about their concerns in terms of quality of life issues, in terms of urinary function, sexual function, and then using those parameters we come up with a potential plan."
Lack of structured database (eg, those integrated into the EHR) can lead to not receiving follow-up.	"I know some people have the infrastructure to keep all these patient names in a database, and if they don't follow up, they can call them and things like that, and I just don't have that."
Although EHRs facilitate effective communication between physicians, collegial relationships (from working in smaller practices, proximity) with specialists makes communication easier.	"Communication is mostly through notes. Occasionally, I may pick up a phone but I mean, nobody talks on phones anymore, so we're messaging. In [name of city], it was a smaller community, so it was a lot more picking up the phone and talking to people."
PCPs' primary role in active surveillance should involve working collaboratively with urologists to support patient management.	"... a few times a year I'll say [to the patient], 'You should go talk to your primary care [doctor] and talk to them.' And if I don't know where [PCP] stands, or if I really feel strongly that this guy's like looking to get out of treatment and needs it or looking to have treatment when he shouldn't have it, I'll actually just call the primary [care physician] and I'll say, 'Listen, this guy needs X or this guy needs Y, and here's why I think so. So do you mind reaching out to him or if he reaches out to you, just confirming that you agree?'"

to the PCP audience (by publishing in primary care journals), and easily accessible (ie, at the point of care delivery).

Physicians described an opportunity to optimize active surveillance management for both PCPs and urologists. The lack of patient awareness of what active surveillance follow-up should entail was discussed as a barrier (eg, as it might contribute to being lost to follow-up). In fact, this lack of awareness has also been reported by patients themselves as being important.<sup>22</sup> In a systematic review of factors exploring active surveillance adherence, patients discussed needing support from their physicians, including continued education and self-management techniques for anxiety.<sup>23</sup> PCPs are in the ideal position to address these needs and provide psychosocial support, capitalizing on their longitudinal and trusting relationships with their patients.

In general, physicians thought that primary care clinicians should support urologists in active surveillance across the continuum, from the time of choosing active surveillance to the time of active surveillance implementation, ensuring men receive the recommended follow-up. Integral to shared care, though, was effective communication between physicians, and PCPs' receipt of explicit guidance from urologists on what they should do in caring for the shared patient. Often a lack of clarity in physician roles is cited as a barrier to effective team-based cancer care delivery. For example, we conducted a national PCP survey regarding their participation in low-risk prostate cancer decision making, and found that about one-third of PCPs reported uncertainty about their role.<sup>24</sup>

Fortunately, there are several facilitators to improving communication and thereby optimizing PCP involvement in active surveillance care delivery. As highlighted by physicians in our study, these include having shared electronic health records with clinician portals to send messages (such as questions) and building collegiality through increased interactions (such as telephone calls instead of routing clinic notes). Resource and time limitations may prevent use of these facilitators, however. At a minimum, therefore, a clinic note from the urologist to the PCP clearly stating the follow-up a patient needs and what the PCP's responsibilities are (eg, ordering a PSA test, reminding the patient to return for urologist visits) is needed.

Multilevel interventions may hold promise for optimizing active surveillance care delivery. For example, Connected-CancerCare is a multilevel intervention (website) targeting women with early-stage breast cancer and their physicians.<sup>25</sup> It includes patient education around survivorship and physician roles in team-based care (to improve knowledge) and a summary letter to oncologists and PCPs highlighting key patient-reported information (eg, physician role preferences in survivorship) to improve communication. Similarly, for active surveillance care delivery, a multilevel intervention that supports optimal team-based active surveillance care could target patients to improve their knowledge, provide PCPs with clinical guidance that enables their involvement without

adding to their workloads, and leverage the electronic health record to remind patients and physicians of active surveillance follow-up.

Although our study provides rich data characterizing physician perspectives on determinants that can be tapped to optimize active surveillance care delivery, there are some limitations. First, the TDF may not capture all the relevant domains. For example, communication between physicians was coded within the environmental context and resources domain, reflecting the organizational culture/climate (construct), whereas a more appropriate code might be communication. The rigorous development of the TDF and its evidence-based linkage to the COM-B model, however, facilitate the development of robust interventions to target physician behavior change. Second, given the nature of qualitative research, potential biases may exist (eg, a PCP conducting the interviews may have induced social desirability bias in participant responses); however, we followed rigorous processes, as outlined in the Methods section, to ensure reliability and validity. Third, we interviewed physicians who practiced primarily at academic centers (PCPs) or participated in MUSIC (urologists), which may limit generalizability. In particular, MUSIC focuses on quality improvement, and participating urologists may be more motivated to improve active surveillance care. MUSIC includes urologists from statewide and diverse clinical practices, however, and we purposefully recruited 4 additional PCPs from rural Michigan.

Having informed team members (educated patients and PCPs) and having good communication between physician team members (PCPs and urologists) were identified by physicians in our study as important to ensuring that men receive the appropriate testing and remain on active surveillance as long as it is appropriate. Although we used prostate cancer as our case study to explore active surveillance adherence, active surveillance is also being increasingly considered in other low-risk cancers such as breast and thyroid. With our use of the TDF, our findings lay the foundation in identifying key domains important to achieving successful active surveillance for men with low-risk prostate cancer. Future studies will need to focus on the design and implementation of multilevel interventions to improve active surveillance care delivery across the primary care and specialist interface.



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**Key words:** behavior change; implementation; primary health care; prostatic neoplasms; urologists; surveillance; interdisciplinary communication; patient care team; continuity of care; coordination of care; qualitative research

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 [Supplemental materials](#)

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