

ACCC's Prostate Cancer Projects

DEVELOPING TOOLS AND MEASURING EFFECTIVENESS

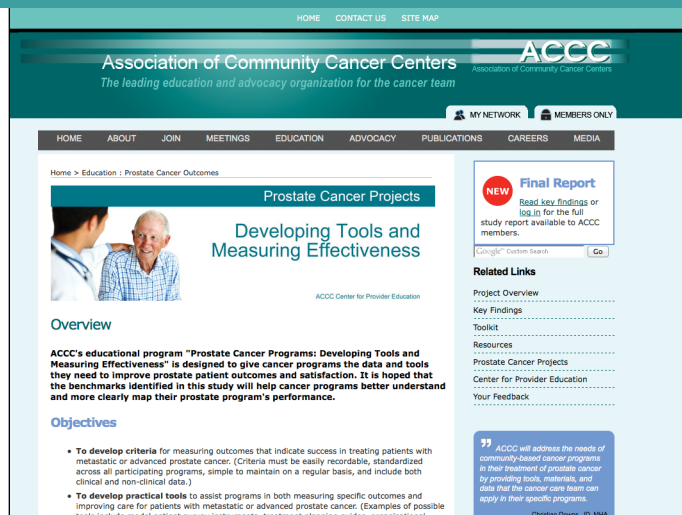
BY KIM LEMAITRE, MS

In 2010 the Association of Community Cancer Centers (ACCC), through its Center for Provider Education, launched the “Prostate Cancer Programs: Developing Tools and Measuring Effectiveness” education project to provide tools, materials, and data that cancer programs can apply in their specific programs to improve outcomes and satisfaction among their patients with metastatic or advanced prostate cancer. The two-phase project was developed with the following objectives:

- **To develop criteria** for measuring outcomes that indicate success in treating patients with metastatic or advanced prostate cancer.
- **To develop practical tools** to assist programs in both measuring specific outcomes and improving care for patients with metastatic or advanced prostate cancer.
- **To apply these criteria** and tools at cancer programs actively involved in treating patients with metastatic or advanced prostate cancer.
- **To determine and measure** which criteria and tools affect outcomes and increase success in treating patients with metastatic or advanced prostate cancer.
- **To share effective tools and report the study results** in a formal educational venue available to all providers.

Phase I of the project assessed core services, use of patient education materials and patient decision aids, outcomes data collection, and a number of other key variables in care of patients with metastatic or advanced prostate cancer.

Phase II of the project identified both clinical and non-clinical criteria for measuring outcomes and explored tools to assist programs in measuring specific outcomes and improving care. Nine cancer programs submitted outcomes data from their cancer registries for their patients with metastatic or advanced prostate cancer. These participating cancer programs then used specific “tools” designed to help their prostate cancer patients participate in decision-making about healthcare options. The core question was whether collection of outcomes data and use of patient decision aids can improve patient care processes.



The following nine cancer programs participated in this educational project:

1. Augusta Health Cancer Center, Fishersville, Va.
2. Bozeman Deaconess Cancer Center, Bozeman, Mont.
3. Ironwood Cancer and Research Centers, Mesa, Ariz.
4. Maine Medical Center Cancer Institute, Scarborough, Maine
5. Middlesex Hospital Cancer Center, Middletown, Conn.
6. Palo Alto Medical Foundation, Palo Alto, Calif.
7. Saint Joseph's Hospital of Atlanta, Atlanta, Ga.
8. Southside Regional Medical Center Cancer Center, Petersburg, Va.
9. West Georgia Health, Enoch Callaway Cancer Clinic, La-Grange, Ga.

These sites used a Prostate Cancer Toolkit (see below) to help their prostate cancer patients participate in decision-making about healthcare options.

For this study, ACCC examined a number of patient education materials and decision-making tools to assess their usefulness during treatment of metastatic or advanced prostate cancer. Patient decision tools provide information on the treatment options and help patients clarify and communicate the personal value they associate with different features of the options.

The project's Advisory Board reviewed an annotated bibliography developed for this educational program, and identified a broad range of specific patient tools, which were then categorized into measurement tools, patient decision aids, or clinical decision support tools. These tools assessed a wide variety of factors, including quality of care, quality of life, patient satisfaction, decision-making, treatment choice, supportive care, economics and cost, anxiety, decisional conflict, and decisional regret, for example. The Advisory Board chose to focus on tools that best facilitate decision-making and to pilot-test those tools at the participating sites. Select tools were used to create a Prostate Cancer Toolkit that includes patient education materials and decision-making tools, such as the EPIC-16 CP tool, to measure specific outcomes and patient satisfaction. The Toolkit, available at www.accc-cancer.org.

org/prostateinfo, includes the following resources:

- Expanded Prostate Index Composite-16 for Clinical Practice (EPIC-16 CP) (www.accc-cancer.org/education/pdf/PCP-EPIC.pdf)
- *Us TOO! Advanced Prostate Cancer Resource Kit*, educational materials and resources (www.ustoo.org/Advanced_Disease.asp)
- *Ottawa Personal Decision Guide* (www.accc-cancer.org/education/pdf/PCP-OPDGuide.pdf), a general patient treatment decision-making tool to help patients evaluate, clarify, and communicate their preferences based on their values
- *Ottawa Family Decision Guide* (www.accc-cancer.org/education/pdf/PCP-OFDGuide-Sample.pdf), a two-page guide to assist families facing tough health and social decisions
- *Ottawa Decision Support Tutorial* (<https://decisionaid.ohri.ca/ODST/>), a self-paced, free online tutorial to help cancer program staff increase their skills in providing patient treatment decision-making support.

Key Findings

Study findings were presented at ACCC's 29th National Oncology Conference in fall 2012. The study's full final report is available on the ACCC members-only website at www.accc-cancer.org. Key study findings include:


1. Cancer programs in this study used a number of different education materials for patients with advanced prostate disease. Education efforts were generally not coordinated among members of the multidisciplinary team.
2. Cancer programs differed in the degree to which patients had input into their own treatment decisions. In some programs the urologist made treatment decisions largely without patient input, while in other programs the patient had access to multiple specialists who worked with the patient to determine the best treatment option based on patient feedback.
3. Most cancer programs were not using patient decision-making tools, which provide information on the options and help patients clarify and communicate the personal value they associate with different features of the options.
4. Through ACCC's educational project, participating cancer programs implemented the EPIC-16 CP, a patient decision-making tool designed to evaluate patient function and quality of life after prostate cancer treatment. While urologists most often used the tool, a wide variety of other healthcare professionals involved in advanced prostate cancer patient care also successfully implemented the tool. Users overwhelmingly found the tool to be practical, efficient, and easy to implement in clinical practice with little to no adaptation. The tool provided useful information about prostate cancer patients' quality of life that could be evaluated and meaningfully contribute to treatment decision-making for this population. Some sites found additional tools useful, such as prostate cancer educational materials and decision guides, in conjunction with the

EPIC-16 CP to facilitate patient understanding and treatment decision-making processes.

5. All cancer programs in the study followed clinical guidelines for diagnosis and treatment of prostate cancer. Most programs based treatment decisions on National Comprehensive Cancer Network (NCCN) guidelines. Still, staff education about clinical guidelines was inconsistent across cancer programs.
6. Use of patient navigation services and the role of the patient navigator varied across all cancer programs. Few cancer programs had a patient navigator designated specifically to prostate cancer patients. Instead, programs used GU, general, and/or urology navigators. Navigators addressed psychosocial needs, referred patients to community resources, provided education, coordinated services and schedules, and assisted with patient decision-making. Social workers and nutrition professionals assisted the navigator.
7. Use of patient navigation services and financial counseling, as well as referrals to social services, rehabilitation, nutrition counseling, and support groups were surprisingly low for all patients in the study and may reflect inadequate processes for tracking the use of these services.
8. Many cancer programs were not collecting sufficient outcomes data to assess the quality of the care they provide to patients with metastatic or advanced prostate cancer.
9. Coordination of care among members of the multidisciplinary team appeared to be best if all members used the same electronic medical record (EMR). Most cancer programs, however, did not coordinate care for their patients with advanced prostate disease.

During the course of the project, study leaders encouraged participating sites to examine their EMR systems and processes for data capture and look for ways to improve intake of information from referral sources. Project resources including, study highlights, the annotated bibliography, and the "Prostate Cancer Toolkit" are available at: www.accc-cancer.org/prostateinfo.

Next Steps

ACCC plans to collect data at additional cancer programs, conduct training at participating sites on strategies to enhance data collection for supportive services, and continue its efforts to educate the oncology community about decision-making tools for patients with advanced prostate disease. ACCC will continue to broaden understanding of whether collection of outcomes data and use of patient decision-making aids can improve patient care processes. 

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