

Awareness and Education Survey, 2012

Education & Best Practices Committee

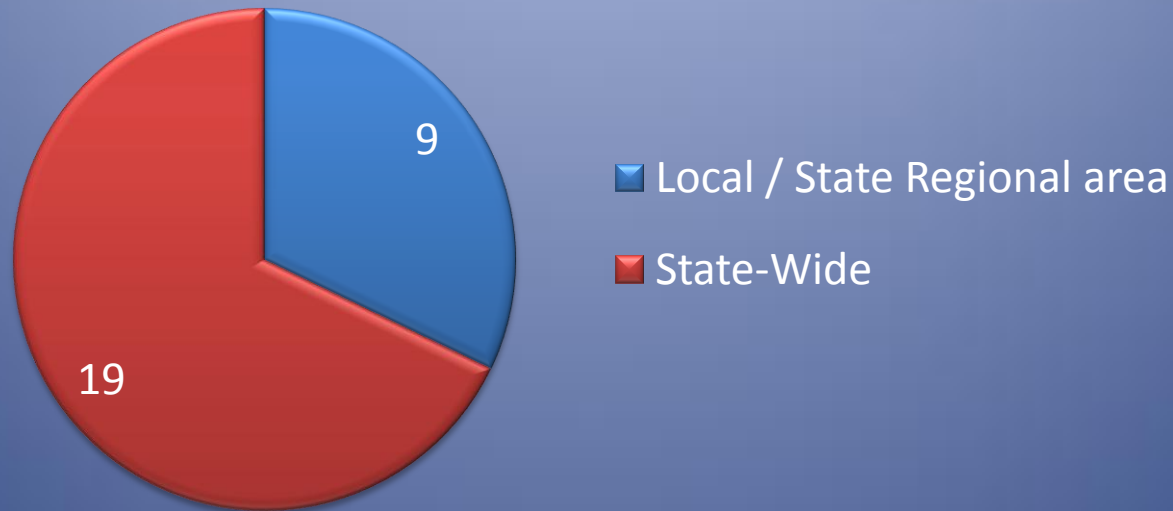
October 7, 2012

Wolfram Blattner
President, North Texas Prostate Cancer Coalition (NTxPCC)

Note: All of the Comments are my own and do not
necessarily reflect positions of NASPCC or NTxPCC

- This survey queries NASPCC State Prostate Cancer Organizations on the availability of prostate cancer awareness and survivor education within participating organizations.
- The following are data collected with the survey. Note that some of the responses may add to more than the number of participating States as some questions in the survey allowed for multiple answers. Data shown are for responses received as of August 4, 2012. (We received 28 responses from 40 organizations)

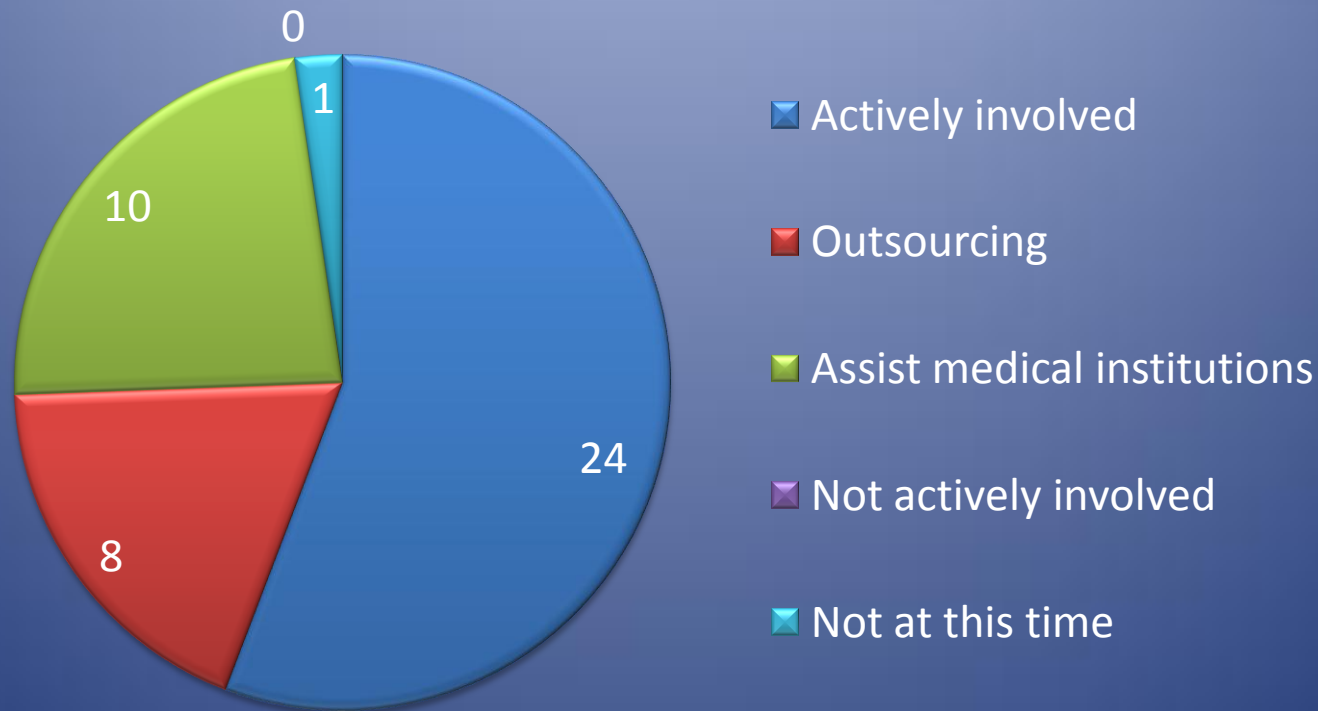
Your organizational setup



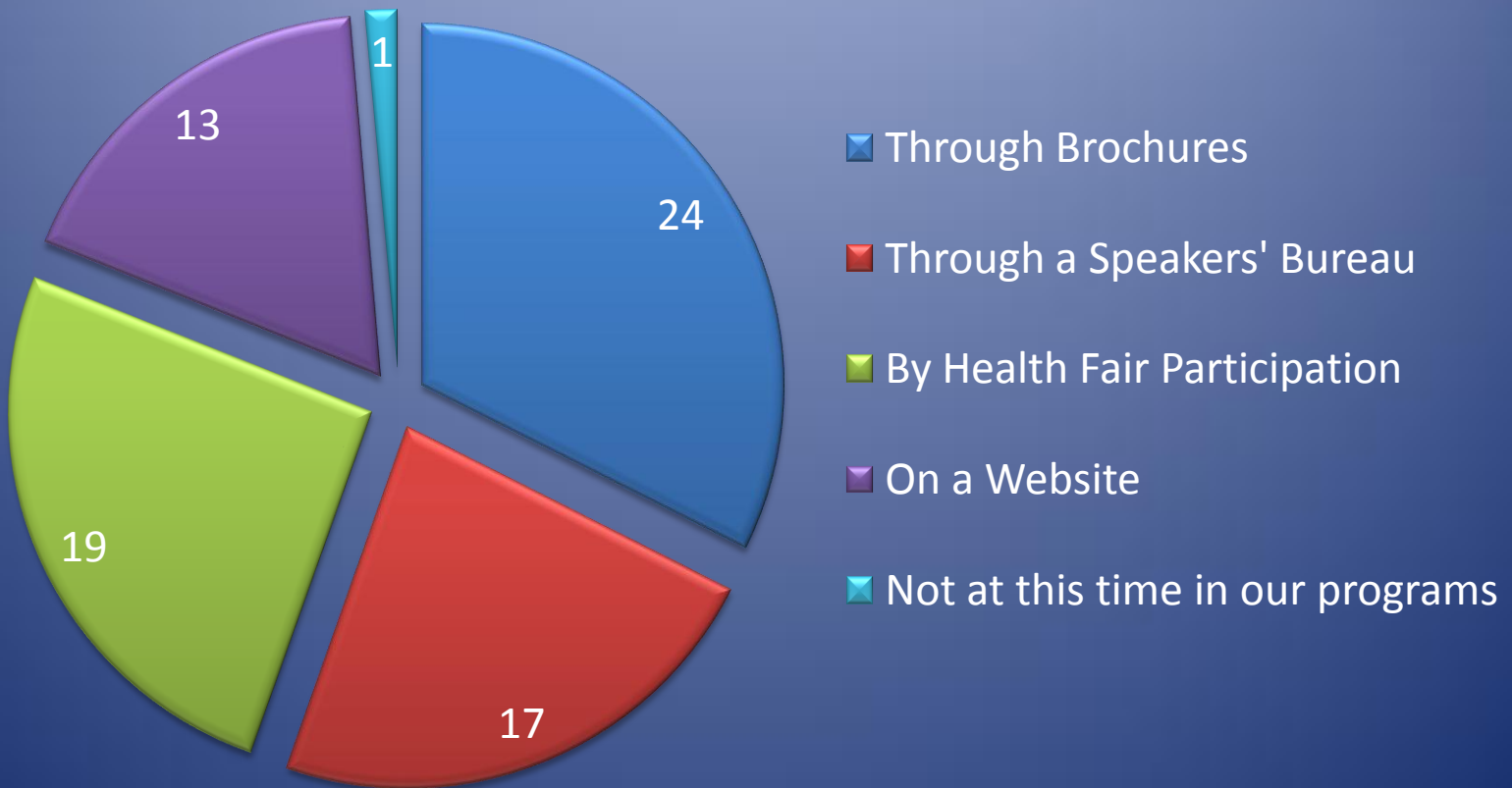
Local (9): CT, GA, KS, MI, MO, NV, N-TX, OH, PA

State-Wide (19): AK, AR, CA, CO, DC, DE, HI, IN, KY, MD, ME, MN, NC, NM, NJ, NY, TN, VA, WY

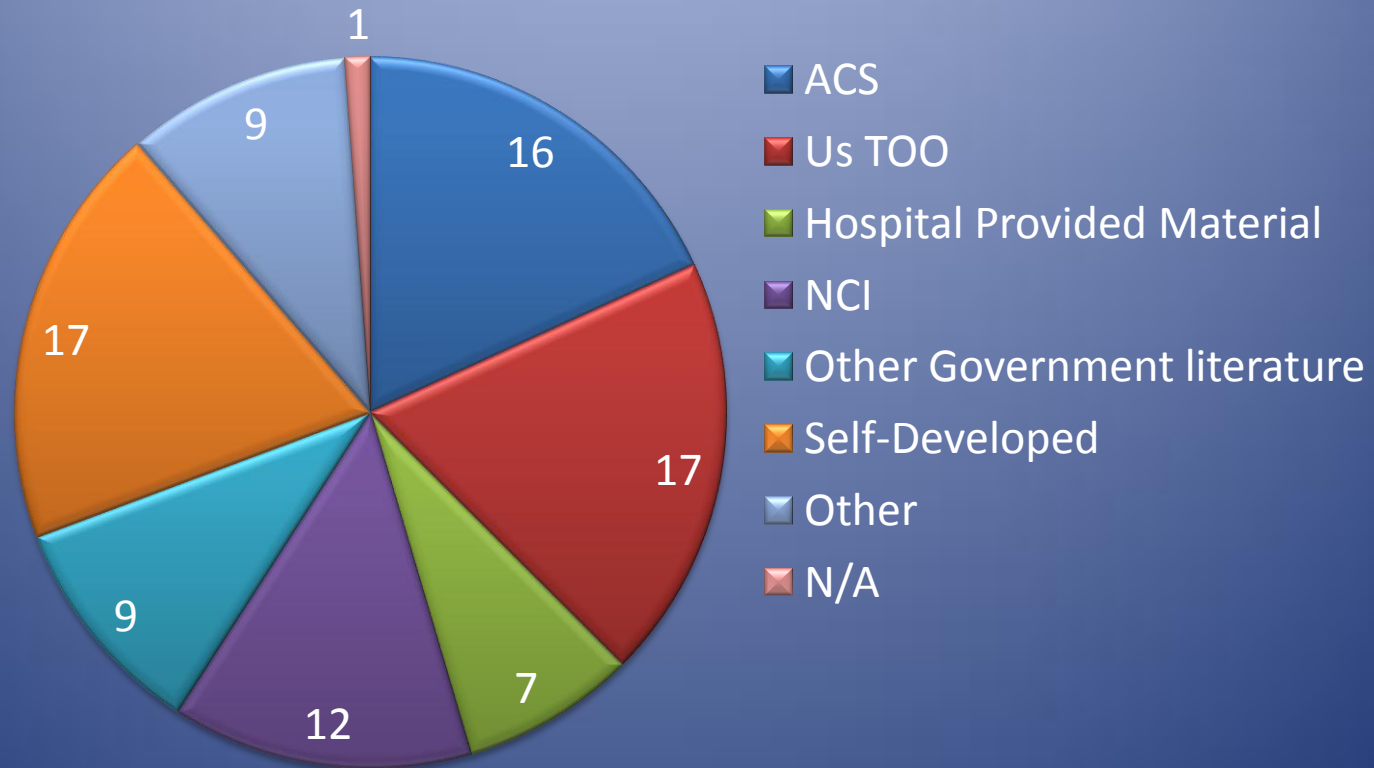
Is your organization involved in educating communities and survivors about prostate cancer? (check all that apply)



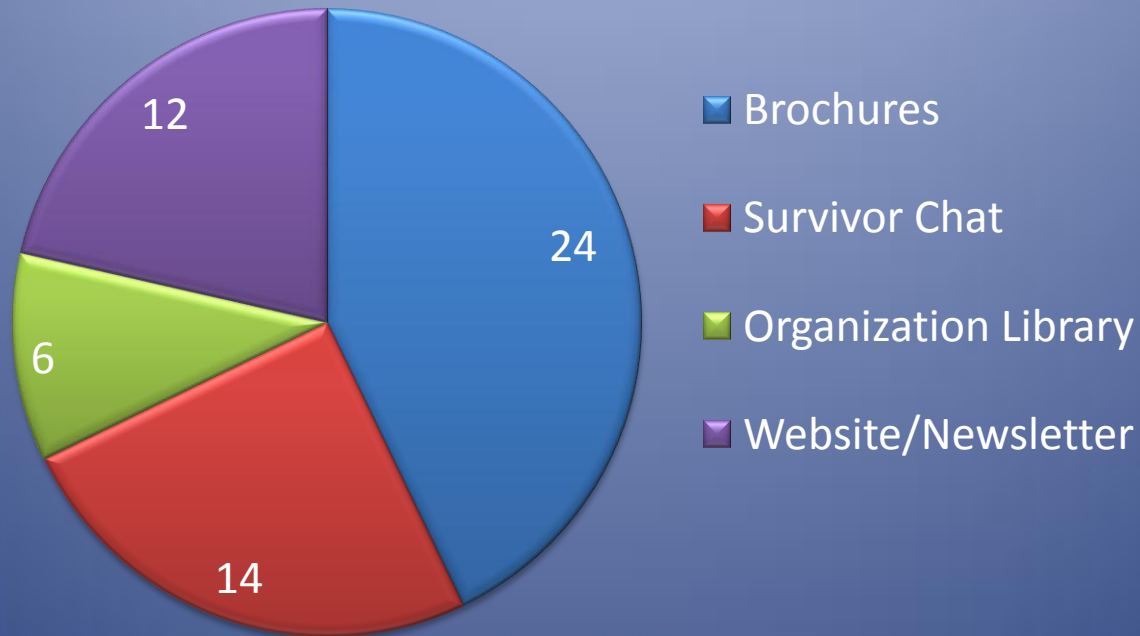
Are you disseminating basic information about prostate cancer ? (Check all that apply)



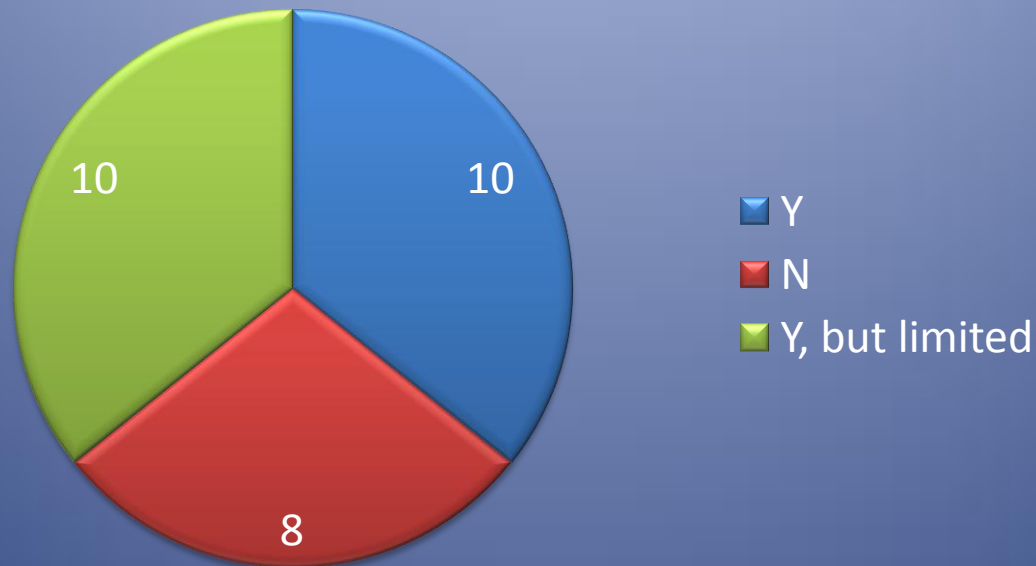
What resources are you using for Awareness Brochures? (check all that apply)



Are you providing information for newly diagnosed?



Does your organization provide information to rural areas (check one)



Note: tough thing to do; we should follow up with these 10 States to see how they accomplish this effort

Any particularly outstanding material used for educational information? Please describe (Optional)

- We have a joined brochure with Us TOO (North TX)
- We have two brochures for women only that have been successful (ME)
- Our newly diagnosed tutorial is very popular. The tool can be accessed from this page: <http://www.pccnc.org/navigation.shtml> (NC)

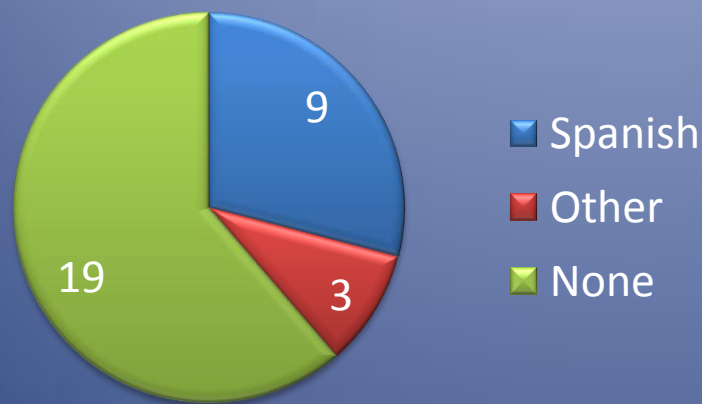
Note: Suggest to contact these three organizations if you are interested about details

Any particularly outstanding material used for educational information? Please describe (Optional)

General -

- Us TOO website material, Info Link which is excellent
- Malecare brochures and books
- ACS, PCEC
- Produced several PowerPoint presentations; initiated a "speaker's bureau", but without too much success.
- PCEC material
- AUA brochures
- Us TOO
- NCCN Guidelines for Patients

Is your written material available in languages other than English? Please specify



Comments: - “Other” includes French, Arabic
- Apparently we are lacking Spanish material

Are you providing information for advanced prostate cancer? Please specify

- Pamphlets (WY)
- We use a brochure directed at advanced stage PCa (NM)
- We have materials for advanced prostate cancer (IN)
- We have brochures devoted to advanced PCa (ME)

Note: Suggest to contact these four organizations if you are interested about details

Are you providing information for advanced prostate cancer? - Continued

- Malecare, NCI information
- Us TOO Material
- NCCN Guidelines
- PCRI
- Speakers

Information for Advanced PC (interpretation, WB)



What additional information would be helpful to YOU? (Optional)

- Culturally diverse material
- PSA's and Gleason at diagnosis.
- Time from diagnosis to treatment
- Different languages
- More material in Spanish and Asian languages
- Ways to get Funding
- How to engage local government
- Advanced PCa
- Successful efforts to reach men in rural areas

Final Comments

- Outreach in NM is difficult because the state's population centers are far apart. We do not reach rural areas nor are we in constant contact with our many Native American pueblos since leadership changes each year.
- Looking forward to establishing a permanent coalition for the State of Missouri
- Coordinating with State cancer group to begin offering activities state-wide (GA)
- The Delaware Prostate Cancer Coalition was just organized a few months ago and in the process of getting things in place
- We're just starting out so we hope to get more involved later this year (MN)

Final Comments - Continued



- We are working on a simplified independent web-site to enable local users information on resources. Our current information is tied to the NASPCC website.
- We are working with several organizations at this time to educate the public.
- We do much more than just education
- We feel that we have been very proactive in many areas. We have received a \$10,000 grant to help deal with the emotional journey of pc
- A Survivor Chat set up for face to face meetings, "Let's Talk on Tuesday ... About Prostate Cancer" session, has proven to be very successful (NTxPCC)
- Would like to find material that uses NASPCC guidelines for screening.

Concluding Comments - WB



- Advanced cancer material is constantly changing; even survivors with advanced PCa have limited knowledge about their own or other treatments
- Nobody mentioned Imaging. Imaging is not only important for initial treatment options, but also for possible locations of recurring PCa (before metastasizing).
- The coverage of rural areas is an enormous problem in all States.
- We are lacking material in Spanish.
- This survey was about Awareness & Education, not about overall capabilities.

Additional Data



- No information received from: AZ, FL, IL, MA, NH, OR, RI, SC, TX (Houston), UT, WA, WV
- Information available on PC Systems (Windows 7, XP, Vista, MAC, IOS) and Browsers (Internet Explorer, Firefox, Chrome, Safari, Flock)

Adding New Data



- Organizations that have not yet completed the survey are encouraged to do so.
- Information may also be updated by simply completing the survey again.
- Use the following link to submit:

http://www.instant.ly/s/JibAZZ9KAAA?source_type=email&source_type=email