

1. What did your institution/organization do to support SPN activities?

- Institutions helped leverage grants
- Institutions provided support while allowing SPNs to have autonomy
- Created collaborative partnerships and enhanced continuity of these partnerships
- Workforce diversification and study population diversification

1a. How has this benefited the institution and community?

- Created more community-based grantees
- Provided for more community-based employment and investment; money stays in community
- Community feels ownership of SPN process
- Opened lines of communication and increased trust between community and universities

1b. What evidence shows these benefits?

- Greater use of SPN; SPN is seen clearly as a resource in the community
- Increase in cancer screening and participation in/access to clinical trials
- Career development is “just happening” – awards, publications, and minority supplements

2. What lessons have been learned?

- Having multilingual opportunities has opened opportunities
- Leveraging resources is key
- Defining role of partners and providing early education is key
- Inform all members of research study, especially of time commitment:
Time management for partners has been a barrier
- Knowing and learning about culture of community
- Develop effective communication structure to keep sites in the loop
- Understand importance of peer-review process in pilot study – don't have same person review your work the whole time
- Consider examining statistics on gift cards and other gifts
- Problem with giving money because it requires SSN
- Develop MOUs—Memoranda of Understanding

3. What happened that was not expected, and how did your SPN respond?

- Difficulty in finding minority researchers for pilot projects.
- Difference in priorities between SPN and community—e.g., clinical trials and accruals **Response:** Educate the community about clinical trials
- Lack of access to treatment facility (esp. in Guam after hurricane) **Response:** Rely on prevention, not treatment
- Misdirection of tobacco dollars (Colorado); state legislature used funds on roads, etc. **Response:** SPN instead looked for other sources of funding
- University hospitals not welcomed in community by local hospitals to provide services **Response:** Both parties at table to find out how to best serve community needs

4. What are your SPN's best practices/accomplishments?

4a. What would you replicate or do again?

- Develop culturally sensitive materials
- Continue to form community networks
- The staff should reflect the community that is served
- Offer incentives to participants (snacks, prizes, etc.)
- Utilization of community health model
- Use NCI/CIS train-the-trainer programs for clinical trials
- Use pre- and post-testing to assess behavioral change
- Use faith-based institutions for cancer prevention efforts
- Engage HBCUs to train undergrads to do behavioral research addressing cancer issues; provide opportunities for interns
- Have grad schools and medical centers develop programs to increase minority researchers
- Use modular mammography to bring screening into community

4b. What would you not do again?

- Too much “handholding”
- Fail to gain input from community before planning programs
- Fail to provide for evaluation from beginning
- Fail to obtain provider input when designing a patient-generated screening questionnaire
- Make assumptions about the population
- Assume staff members will always be available or willing to work on other projects
- Accept interns without proper screening for language fluency
- Demand a more stringent selection process for leaders
- Try to train staff in too short a timeframe

5. How does the community perceive your SPN and your institution/organization?

POSITIVE:

- Increase in request from community for access to SPNs
- Increase in number of screens and repeat screens
- Increase in requests from policy makers for opinions on minority health
- Ease of recruiting volunteers for clinical and prevention trials
- Increase of feeling of community ownership through existence of coalitions and community councils
- Number of letters of support for recompetitions
- SPNs being asked to represent communities in state cancer plan

5. How does the community perceive your SPN and your institution/organization? (cont'd)

NEGATIVE

- Sometimes people did not want to participate in certain events because of a negative perception of the hospital or university
- Participants may be uncomfortable giving out personal information
- Language and culture can be a hurdle
- Community welcomes the idea of research but may be too busy, not understand projects, or physicians may worry about providing care in the clinic
- SPN plans may go against university or hospital regulations
- Community may not be aware of SPN
- A Patient Navigator would make things easier for the patient to schedule screenings, etc.