

Cancer Health Disparities Summit 2007
***Catalyzing Transdisciplinary Regional Partnerships to
Eliminate Cancer Health Disparities***

Breakout Session Summaries

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Communications and Bioinformatics

Reliable and well-coordinated communications and bioinformatics resources are essential to the success of collaborative programs. Using advanced communication technologies (including e-mail, teleconferencing, telemedicine, and Web-based information dissemination and training) reduces the cost of project management and improves the timeliness of information sharing. Coordinated use of bioinformatics resources (including registries, clinical databases, and electronic health records) is necessary to support collaborative data collection, analysis, and evaluation.

Enhancing Communications and Bioinformatics Infrastructure to Support Interdisciplinary Research and Training

Community organizations often lack the Internet access and experience required to take advantage of the variety of communication resources available to and provided by their academic and institutional partners. Funding mechanisms that support collaborative research projects must include resources to provide community partners with hardware, software, and training needed to close the digital divide that prevents them from accessing up-to-date communications and bioinformatics resources. Collaborators may need to be persuaded that technology is an important component of community-based research. Institutional technical issues (e.g., existence of firewalls, use of proprietary software) must be addressed. IT personnel must be included in budget requests and the need for IT support must be explained in detail in the budget justification. Community partners may also need technical assistance in grant writing to obtain funding from additional sources to support infrastructure development and maintenance.

The program announcement for each collaborative research project must include a stipulation that standardized data from all partners will be compiled into a shared database. Partners should be funded to participate in shared data collection and storage based on the level of effort each is expected to contribute to system design and maintenance. Data gaps must be identified and strategies for filling them must be developed. Ownership issues must be resolved to ensure that all partners have equal access to project data. All partners who plan to use project data should be involved in designing the systems used to collect and manage data.

As caBIG (the cancer Biomedical Informatics Grid) evolves, it will become an essential tool for enhancing communication and bioinformatics infrastructure for collaborative research projects and the communities in which they operate. caBIG can offer free software, space for storage and manipulation of large data sets, technical assistance, and a forum for communication among partners. Researchers involved in collaborative research projects should become familiar with caBIG resources and let caBIG leadership know what their needs are. caBIG should expand its outreach beyond basic science to inform communities about the types of resources that can be made available to them. caBIG informatics architecture must be expanded to include psychosocial variables in addition to imaging, epidemiology, and genomics. A champion representing the needs of community-based participatory research is needed within caBIG.

Currently, information about the scope and breadth of cancer research and the variety of available resources is fragmented. The CRISP database can be used to search for information about active grants so that researchers can find people who are working on similar topics; the Cancer Research Portfolio provides similar data coded by research topics plus information on funding opportunities and research resources; and the Web sites of numerous NCI Divisions,

Centers, and Offices provide a wide variety of databases, bibliographies, statistics, and information about clinical trials. A user-friendly portal should be created (possibly by caBIG) to serve as a gateway to this array of information sources.

Researchers and service providers need improved access to standardized state-level hospital data. Development of a universal electronic health record system could result in standardized, real-time data collection to facilitate consultation between doctors. This would help clinicians see what is going on with cancer within state populations.

GMaP can play an important role in ensuring access to communications and bioinformatics resources within geographic regions. This initiative will help partners within communities identify resource disparities and develop collaborative approaches for sharing existing resources and obtaining funding to create new resources.

Consolidation of clinical data with personal health records over time, combined with biomedical advances using molecular technology, can lead to the development of personalized medicine, in which care is tailored to the specific biological, behavioral, and psychosocial factors that affect individual patients. However, privacy and ownership concerns constitute barriers to personalized medicine. All institutions involved in data sharing and consolidation must buy into the concept, and policy and administrative issues must be resolved to the satisfaction of all partners. A review of HIPAA (Health Insurance Portability and Accountability Act) regulations should be conducted to determine whether technological advances require policy revisions. Social science efforts will be needed to prepare communities for the advent of personalized medicine.

Evaluation plans must be tailored to anticipated project accomplishments and outcomes. These plans must be flexible because community-based participatory research strategies can change over time in response to changing or unanticipated conditions within the community.

Communicating the results of collaborative research to community members is not a high-tech problem. Instead, this effort requires identification of and access to communication channels that are already established and trusted within the community. Informing the community involves not only translating data into lay language, but also teaching community members about how to interpret research findings.

Supporting the Costs of Infrastructure Development and Maintenance

State and local governments must play an active role in bringing state-of-the-art communications and bioinformatics resources to rural and underserved areas. Agencies and institutions involved in the development and implementation of state cancer control plans should place strong emphasis on policies designed to provide infrastructure funding for all cancer-related research and service delivery programs, including specific strategies to support replacement costs as technologies evolve.

Multiple Federal agencies (e.g., NCI, CDC, IHS, AHRQ, HRSA) should share the costs of community infrastructure enhancement, since this effort will increase the capacity of community-based organizations to provide ongoing services to underserved populations after collaborative research projects have ended. Development of standardized data management systems and grantee reporting requirements for all federally funded research could reduce infrastructure costs.

Options exist for assisting community organizations without Federal funding. Surplus computers owned by academic centers should be made available to the community. Free or low-cost services for telecommunication (e.g., iChat, Skype) should be explored. Corporate sponsorship may be available for Web kiosks to provide public access to project information.

Program Examples

- caMATCH, a caBIG pilot research project, has developed an Internet-based, patient-centric clinical trial eligibility matching application designed to help cancer patients locate clinical trials and help principal investigators identify potential study participants.
<https://cabig.nci.nih.gov/tools/caMATCH>
- The National Library of Medicine's Go Local links on MedlinePlus health topic Web pages provide links to Web sites with information about health services in local geographic areas, such as hospitals, physicians, nursing homes, support groups, and health screening providers. <http://www.nlm.nih.gov/medlineplus/golocal/index.html>
- NCCR's IDEANet initiative is designed to broaden access to high-performance computational resources, tools, and training across participating states. As part of IDEANet, the Lariat program helps programs and research centers in six states engage in collaborations through connectivity to the NCCR Biomedical Informatics Research Network. <http://lariat-west.org/>
- The NIH Roadmap for Medical Research promotes and expands high-quality informatics networks. <http://nihroadmap.nih.gov/>
- One CDRP site involving community-based hospitals that treat minority populations has been provided with funding to create a high-tech Telesynergy system that includes microscope scanners and videoconferencing. The system allows grantees to work with mentors to learn how to set up clinical trial infrastructure. The system is being used to support physician and technical staff training. Some grantees are developing interactive Web-based modules for training. Some sites also use the system for patient examinations.
- Cancer Control P.L.A.N.E.T. is a Web portal and repository for evidence-based interventions that have been evaluated and proven. <http://cancercontrolplanet.cancer.gov/>

Community Engagement

Guiding Principles of Community-Based Participatory Research

Community-based participatory research (CBPR) is a nontraditional research approach in which the community takes an active role in planning and conducting research. Effective CBPR researchers are engaged in the community before, during, and after research takes place. The community is involved in driving the research agenda as well as making decisions about data collection, data analysis, program implementation, and program evaluation. CBPR recognizes the community as an equal partner in all phases of research, and equitably allocates funds to the various partners.

Barriers to CBPR and Possible Solutions

Barriers to Partnering

CBPR requires partnerships between various sectors, including academic researchers, community healthcare professionals, and the community. There are several social, cultural, and economic barriers that impede these partnerships and the practice of CBPR.

It is often difficult to identify and bring together all appropriate partners. Geographic separation sometimes keeps potential partners from working together. The significant amount of time it takes to build relationships, particularly with the community, can also be a barrier to partnerships.

Partnerships often suffer from lack of communication and failure to develop mutually beneficial relationships. Partners often have different goals, which may sometimes conflict (e.g., researchers want to publish papers and communities want to make sure there are long-term benefits for their community). Community members, community healthcare providers, and academic researchers need to find a common vocabulary with which to communicate and also need to be explicit with one another about their needs, expectations, and goals.

Partnerships that involve minority populations may be deterred by racism. Minority community members may feel disempowered if program administrators and leaders are from the majority population.

In addition to these barriers, there are also many cultural and social barriers that relate specifically to the different groups involved in CBPR partnerships.

Community

Community members often mistrust researchers and may not want to be involved with cancer research because of the negative connotation of the disease within the community. Furthermore, people in the community are less likely to be involved in research if they do not have access to standard health care. Researchers need to work with other service-providing agencies and organizations to ensure that the communities in which they are doing research have access to quality health care.

Community members sometimes do not understand research-related concepts or processes, such as IRB review. This can result in frustration and lead to a breakdown of partnerships. To avoid this, efforts should be made to educate the community about these issues.

Small community-based organizations may be hesitant about partnering with larger organizations and academic institutions because they may worry about losing control.

Community Healthcare Providers

Community healthcare providers may worry about the additional time they will need to spend with patients as part of a research project and the lack of reimbursement for this time. Additionally, many community healthcare providers do not understand or appreciate research.

Academic Institutions and Researchers

Academic institutions and researchers often have paternalistic attitudes toward the community. They often lack understanding of and respect for the culture of the community and the fact that communities have a wealth of knowledge and expertise. They are often unwilling to let communities share ownership of projects.

The academic research culture is generally unsupportive of CBPR. Universities expect faculty to perform research, not provide services that may be necessary for the community. The promotion and tenure system makes it difficult for junior investigators, who are under intense pressure to publish and may also have teaching obligations, to spend time building the relationships necessary for CBPR. University IRBs are often rigid about requirements that are not compatible with CBPR, and extensive “red tape” makes it difficult for funds to flow from the university to the community. To address some of these barriers, junior faculty should be credited for time spent conducting CBPR. Institutions should also create infrastructure to meet the needs of the community and provide support for researchers to build relationships before research projects are initiated. Finally, a comprehensive funding mechanism that requires community engagement for funding should be created to encourage academic institutions to become more involved with the community.

Inadequate Funding

Inadequate funding is a barrier to CBPR. It is often difficult for CBPR projects to obtain funding because CBPR is often undervalued by both academic institutions and review panels that do not understand the needs of the community. The NIH funding cycle also poses difficulties for CBPR. CBPR often does not progress at the same pace as other types of research. Traditional 5-year grants do not provide adequate time to build relationships between partners and move projects forward. Gaps in funding that occur when grants are being resubmitted are also detrimental to community-based programs. To address these barriers, community members should become more involved in review panels, and alternative funding structures should be explored (e.g., the NCRR funding model—2 years of planning plus 5 years of research). Programs should also seek multiple funding sources.

Enablers of CBPR

Strong commitment by all partners contributes to the success of CBPR, as does the recognition that all partners should be equal participants and mutually benefit from the relationship. If the community’s strengths, knowledge, and experience are recognized by other partners, the community will be more empowered and be a more active participant in the program.

CBPR benefits from time, mutual trust, and capacity building. Open communication and personal contact are also enablers, helping to bridge gaps between diverse partners.

Involving the right people from the community is critical for CBPR. Community advisory boards help researchers develop programs that are in alignment with the needs and interests of the community. Identifying community “gatekeepers” who are respected in the community is essential for gaining the support of the community. Researchers should consider identifying a community member to be a co-principal investigator on a grant; this will help ensure that knowledge remains in the community after funding has expired. Recruiting and retaining staff from the community will increase community buy-in and help the program better serve the needs of the community. Community representatives can also help disseminate research results in the community. It is also important to have a person who is experienced in the preparation of proposals for IRB consideration and understands feedback provided by the IRB.

Institutions with positive reputations and a history of collaboration will likely be more successful finding community partners. Institutions will be able to build stronger CBPR programs if they acknowledge the importance of CBPR, reward faculty for participating in CBPR, and exhibit cultural sensitivity. A flexible IRB that understands the needs of the community and can help resolve conflicts can also be an enabler of CBPR.

CBPR participants need to understand the culture and constraints of their partners. For example, the community needs to understand that academic institutions can share some, but not all resources.

Best Practices for CBPR

Several best practices have been identified for optimizing the effectiveness of CBPR. Of central importance is identifying a research question that is in alignment with the interests, needs, and strengths of the community. Approaches for identifying these interests, needs, and strengths include formal community assessments (e.g., Community Readiness Assessment Tool), focus groups, and interviews.

CBPR requires a transdisciplinary approach, with participation from several sectors. Regional collaborations can be particularly beneficial since populations within the same region often struggle with the same issues. Multiorganizational efforts are facilitated by use of a common IRB.

Funding agencies, including NCI, should make sure they understand the community before developing Requests for Funding (RFAs). RFAs should be developed with input from people familiar with CBPR and allow for flexibility in proposal preparation.

Researchers should build relationships with the community before they apply for funding, and the community should remain intimately involved throughout the project. Representatives from various parts of the community should be involved in strategic planning to ensure that the research is relevant to the community and sensitive to cultural attitudes and norms (e.g., community advisory boards); it may be necessary to reimburse community members for the time they spend on this process. The research agenda should be community driven, not researcher imposed.

All partners should be involved in identifying shared goals and shared rewards. It is a good idea to generate a Memorandum of Understanding to which all partners will adhere. Undergoing a consensus-building process can also be of use. Partnerships must be mutually beneficial. Importantly, maintaining equal footing requires ongoing communication and assessment of progress and future directions.

Transparency is important for CBPR. Researchers should fully disclose project details and budget issues to community partners. Researchers need to make sure that the community understands the goal of the research project and provide information on research progress and outcomes.

Funding should be distributed equitably among partners; this allows each partner to carry out their role and builds trust. The owner of data generated through the research should be established up front.

Researchers should be trained to better interpret CBPR data in a culturally sensitive fashion. It may also be helpful to involve community members in the interpretation of data to ensure that the community perspective is represented in this process.

Dissemination of Guidelines and Best Practices for CBPR

Guidelines and best practices for CBPR need to be captured in formats that are accessible to and understandable by other CBPR programs. Successful CBPR endeavors should be published in the journals that are read by CBPR researchers and organizations. Best practices should also be posted on the Web, using organizational Web sites and other resources such as Cancer Control PLANET (<http://cancercontrolplanet.cancer.gov/>). Other possible venues for sharing best practices include newsletters, meetings, and the Community Campus Partnerships for Health (<http://depts.washington.edu/ccph/index.html>).

Best practices are often discussed at site visits of NCI programs, but the notes from these meetings are confidential, making it impossible for other programs to benefit from them. NCI should consider allowing programs/investigators to make information from these site visits publicly available. Access to grants would also facilitate dissemination of best practices.

CBPR programs and researchers need to take the initiative to search the literature and talk to other programs to learn about best practices. The NCI Cancer Information Service (CIS) “Using What Works” program offers guidance on how to adapt evidence-based approaches for new programs (http://cancercontrol.cancer.gov/use_what_works/start.htm).

Best Practices for Clinical Trials Recruitment and Retention

Several steps can be taken to increase the participation of minority and underserved populations on clinical trials. The public, particularly members of minority and underserved populations, need to be told about the importance of clinical trials. Also, patients need to be given the opportunity to participate on a trial; many healthcare providers and researchers assume that minority/underserved patients will not want to participate, but at least one study has shown that African Americans and Hispanics are likely to participate if they are asked. In general, the referral system for clinical trials should be streamlined.

People in the community may be hesitant to participate in trials because of fear or mistrust of research/researchers. Also, many patients do not like the connotation associated with the term “subjects” and would rather be called “participants.”

Building relationships with key people in the community, including community health workers, can aid in recruitment. People will be more likely to participate if they hear about a clinical trial from a trusted source. Partnering with churches or targeting local media can help inform the

community. Educating clinic staff (e.g., nurses, receptionists) to talk to patients about clinical trials is also helpful.

The strict eligibility criteria of many trials preclude participation of minority and underserved populations. It may be easier to recruit and retain participants if inclusion criteria were made less restrictive. Researchers should consider using geographers to identify populations that may be eligible for trials and target these populations for recruitment efforts.

Researchers should be flexible about their clinical trial design. They may be able to attract trial participants if they add an arm to the trial that directly addresses community interests.

Researchers should adopt verbal or implied consent whenever possible so participants are not burdened with a lengthy consent process. It is also important to be open with participants and potential participants about the clinical trials process.

Training

All sectors participating in CBPR need to be trained. Academic researchers need to be trained about how to interact with the community in a culturally competent way and learn about their audience. One approach to help researchers and physicians learn about CBPR is to have community members talk to medical students about this topic.

Community-based organizations also need training. Researchers could provide a “walk-through” of an ongoing community-based study to help community members understand how research studies function. The community also needs to be trained to increase their self-reliance.

Community members can be trained to do surveys and taught basic computer skills that will help them access a number of resources. Training in grant writing would also benefit community-based organizations; universities should set aside funds so they can actually provide funding to some participants in grant-writing courses.

NCI has a number of training resources. Several services provided by CIS, including grant-writing support and technical assistance, are widely underutilized. The “Using What Works” program helps programs adapt evidence-based interventions for their purposes (http://cancercontrol.cancer.gov/use_what_works/start.htm); these types of “train the trainer” approaches have been very effective. The CARRA (Consumer Advocates in Research and Related Activities) program provides training for patient advocates interested in being involved in the research review process (<http://carra.cancer.gov/>). There are also online trainings about clinical trials designed for patients and healthcare professionals.

There is a need to train medical interpreters. Many minorities and underserved populations do not speak English as their first language, which can be a barrier to accessing healthcare and participating in research.

Infrastructure

Infrastructure is needed to support and promote CBPR. Basic healthcare facilities are a necessity, but may not be present in some rural communities or other remote areas (e.g., Guam). Data management systems and biostatistics core facilities are also important for research.

In many cases, existing infrastructure can be used to support CBPR. Existing offices within academic institutions could be asked to manage CBPR and maintain relationships with the

community. Programs should seek to use existing Web-based infrastructure to exchange information; the Intercultural Cancer Council was mentioned as a good resource in this regard (<http://iccnetwork.org/>).

Programs also require technical assistance to allow them to take advantage of existing resources, particularly Web-based resources. There are programs available to help identify resources. For example, the Office of Minority Health Resource Center (<http://www.omhrc.gov/>) subscribes to a foundation database and a database of people interested in volunteering. Programs can request that the Office perform specific searches and provide them with the results.

Collaborations and Partnerships

Benefits of Collaborations and Partnership

Collaborations and partnerships are essential for cancer health disparities research. They help make more efficient use of resources and avoid duplication of effort. They also make it more likely that underserved populations will benefit from research.

Collaborations among Researchers

Health disparities research requires an interdisciplinary, team-based approach that includes social scientists as well as geneticists and others. Collaboration among researchers focused on different diseases can also be beneficial. A diverse research team also ensures that different perspectives are represented, which should enhance the quality of the science being done. Researchers benefit in many ways by collaborating with other researchers. They may gain access to new data or information. They may also expand the population with which they work, which can help strengthen or validate research findings. Collaboration also encourages dissemination of successful approaches and best practices. Research partners may also facilitate networking with new partners and new communities. By working together, researchers expand their capacity and may increase their likelihood of receiving funding.

Collaborations with the Community

Establishing collaborations and partnerships with the community increases trust and community support. Partnerships among different community organizations will help leverage resources. The community is essential for identifying problems within the community that contribute to health disparities. Furthermore, the community involvement contributes to sustainability and is necessary for disseminating positive research results to the community.

Selecting Partners and Building Partnerships

Partnerships must be built on common goals and benefit all participants. Organizations and programs should perform self-evaluations to identify their needs and strengths before seeking out partners. They should then find partners and communities with similar goals and complementary strengths and needs. While it is important to understand differences in goals and priorities, partners should focus on commonalities.

Identifying Community Partners

When partnership with the community is desired, it is important to go to places where the community congregates (e.g., barber shops, churches, sororities/fraternities, community events). Building relationships with community leaders and opinion leaders is also important; these can include local elected officials, religious leaders, educators, and others. Community advisory boards and community coalitions can also provide venues through which to initiate interaction with the community. Conference calls can be held with community organizations to explore whether there are opportunities for collaboration.

Researchers should engage the community beyond any single research project. They should volunteer for efforts unrelated to their research and serve on community boards. This will help them learn about and become invested in the community. It will also build the trust of the

community. Long-term relationships can also be built when researchers begin by providing services to and developing a relationship with the community through a gradual process. Researchers also need to involve the community in the development of community-based research projects instead of waiting until it is time for implementation.

Researchers can also reach the community by engaging organizations or other researchers already embedded in the community. Existing infrastructure (e.g., community-based organizations, professional societies, physician organizations, churches, state cancer consortia, local Cancer Information Service) may help researchers network with potential partners and interface with the community. Researchers should also consider expanding existing partnerships to meet new needs.

Building and Sustaining Community Partnerships

Once a partnership is forged, those involved must work to ensure that it is sustained and productive. At the onset, it is important that the goals of the partnership are defined and that participants understand and agree to their roles. However, since change is inevitable, flexibility is also critical. Partners should discuss upfront how they will address changes as they arise. They must also be committed to working together despite challenges.

Many communities and community members will be more amenable to working with researchers if the researchers provide a service to the community. It is important that the community benefits from the partnership.

Continuous bidirectional communication is essential to success. Researchers need to listen to the needs and ideas of the community; they must involve the community in decision-making and not simply tell it what to do. It is important that researchers use language and terminology that is meaningful to and appropriate for the community (e.g., black versus African American; not all couples will be man-woman). Effective communication will empower the community, build group cohesion, and prevent conflict. In order to reach out to the community, it may be necessary for researchers to work evenings or weekends when community members are available. Communication will be facilitated if researchers hire staff members who are from the community. Researchers should also engage lay community health workers who may be able to help them interact with community members. Communication can take place via a range of mechanisms, including email, phone calls, and in-person meetings.

Community partners should be trained so they can contribute to research projects in meaningful ways. This will also build community capacity that outlasts a particular project, empowering communities to do their own research. One effective approach is to have “train the trainer” programs so that information is disseminated to the community by community members. One area in which community members need training is grant writing and submission.

Accountability is very important for maintaining partnerships. Program evaluations should take place to determine whether key objectives are being met. All partners should be held accountable for their work.

Other Partners

Community-based researchers should seek a variety of partners. Groups of researchers working within a community should form loose coalitions so they can benefit from one another. Local media outlets should also be viewed as potentially beneficial partners, as should the home

institutions of researchers. Funding agencies, particularly local organizations that provide funding for community research, should be approached as partners.

Establishing Diverse Leadership

Representatives from all components of a partnership should play leadership roles. Members of the community, particularly cancer survivors, should be given the opportunity to fill these roles. Training may be needed to help community members be effective leaders in the context of a research project.

Barriers

There are many barriers to forming collaborations and partnerships. The competing agendas and priorities of different partners can interfere with productive interaction. The priorities of researchers will not always be the priorities of the community. Some community members feel that researchers need to be willing to address the needs and priorities of the communities in which they want to work, even if these needs do not match research goals; however, some researchers feel they are unequipped or unable to provide for some of the needs of the community (e.g., jobs).

Many communities are skeptical and distrustful of researchers, which can be a barrier to forming partnerships. This can be alleviated somewhat if a new investigator is introduced to the community by a researcher who is already embedded in and well trusted by the community. Some researchers also have an unconscious bias about the abilities of community partners, which degrades trust and leads to uneven partnerships. Trust can be maintained by defining clear roles at the onset of a partnership.

Lack of communication is another barrier that can lead to mistrust and misunderstanding. Both researchers and community members must operate as transparently as possible so that all members of the partnership are aware of progress and the status of funding. Researchers should appoint a public liaison to keep the community informed; regularly scheduled conference calls are another way to ensure that communication routes are kept open. Language barriers can also contribute to communication failure. Translators must be employed when necessary, and everyone involved needs to accept that meetings with translators will be longer than usual.

Building effective partnerships requires a significant time commitment, which can be a barrier. Partnering with the community can be particularly time consuming. Sometimes funding opportunities can pass by because it takes too long to build the necessary relationships with the community. Administrative issues can also be time consuming, taking time away from research activities.

The existing tenure policies of academic institutions also pose a barrier to community-based participatory research. The criteria for tenure, including the need for large numbers of publications, is inconsistent with the time commitment needed for working with the community.

Lack of funding is also a barrier to collaboration; it is often difficult to maintain funding, even for programs that are shown to be effective, particularly if they are not viewed as innovative. Other barriers include geographical distance, turnover of staff within community coalitions, and the need to obtain approval from multiple Institutional Review Boards (IRBs).

Balancing Scientific Rigor and Community Involvement

Community involvement should not be equated with lack of scientific rigor; however, it is recognized that tension sometimes exists between the scientific and community aspects of a partnership. Improved communication and education can alleviate some of this tension.

Community members and community-based practitioners are not opposed to scientific rigor but are sometimes suspicious of the motives of researchers. Researchers need to be honest with the community about what it will and will not get out of a research project. Researchers also need to be open to working with community members, and both sides must be willing to compromise in order to design a project that will be both scientifically rigorous and acceptable within the community. One way to accomplish this would be to have the community advisory board and the scientific advisory board meet.

Community members often become frustrated with review processes. Researchers should take the time to educate the community about what research is, how study sections work, and the role of IRBs. This will help community members understand the value of and time required for the scientific review processes. Involving community members on study sections and IRBs will improve understanding of these processes and also help review panels understand the perspective of the community. Study sections and IRBs need to be educated about community-based participatory research and the differences between this and other types of research.

Some groups have found creative ways to increase community benefit while maintaining high standards of scientific rigor. Centers can be involved in research projects as control groups; this will allow more centers to benefit from the resources made available through research projects. Another approach is to make resources available for patients who participate in a study investigating patient navigation.

Needs

All sectors involved in cancer health disparities research need training to help them understand and collaborate with others. Researchers need training about how to work in interdisciplinary teams and how to engage the community. Community members need training about research and grant review processes. Review panels, including both study sections and IRBs, need training about community-based participatory research.

Policy changes may be necessary to encourage researchers to collaborate with each other. NCI and other agencies that issue Requests for Applications should make funding contingent on the formation of partnerships.

Technology

Technology can be used to enhance partnerships, in part by facilitating communication. Teleconferencing and videoconferences can help groups that are geographically separated stay in touch. Web-based portals that allow document sharing are also useful, as are Web-based resources for designing and performing surveys. Although there are numerous technologies available, many groups do not use them. Some groups are not aware they exist, while others lack adequate funding to access cutting-edge technologies; funding is needed for infrastructure, training, and technical assistance. Some communities can access these resources through partnerships, including with the Cancer Information Service. Other technological resources needed are core facilities dedicated to biostatistics and bioinformatics.

Program Examples

- An academic institution helped a church in St. Louis secure a partnership with Pepsico so that the church could conduct a program. Because of this, the church was more open to working with researchers from the academic institution.
- NCI worked with the Lance Armstrong Foundation, the American Society of Clinical Oncology, and Northwestern University on the EPEC (Education in Palliative and End-of-life Care) Project, which involved development of a train-the-trainer curriculum for addressing end-of-life issues. Other partners are being engaged to disseminate the curriculum.
<http://www.livestrong.org/site/c.khLXK1PxHmF/b.2662073/k.BF0D/EPECO.htm>
- The Dana-Farber Cancer Institute holds media workshops. Invited members of the media come to discuss health disparities.
- One group sent physicians to provide treatment to an American Indian tribe in Montana. The group began to work with the Indian Health Service, earned support from the community, and then went to the Tribal Council. The process was slow, and the group was always conscious of cultural differences.
- The Dana-Farber Cancer Institute, Harvard University, and the University of Massachusetts-Boston worked together on a project collecting data from unauthorized Dominican and Brazilian immigrants in the Boston area. The project involved innovative data collection methods and all interviewers were born in the same country as the participants. The project gathered information about access to care, cancer screening, and other issues.
- The NCI Cancer Disparities Research Partnership Program provides grantees with the Telesynergy program, which links mentoring cancer centers with mentees. Telesynergy provides support for training, data management, and collaboration.
<http://www3.cancer.gov/rrp/cdrp/index.html>
- The Carolina Cancer Control Network (www.carolinacommunitynetwork.org) and the University of South Carolina worked with the Women's Auxiliary to perform outreach at a convention of 1,700 Baptist churches. "Cancer 101" training sessions were held for church representatives from each region of the state and each region identified projects or programs in which they were interested.

Managing and Sustaining Programs

Challenges

Lack of funding is a common challenge for managing and sustaining cancer health disparities programs. Programs need to adapt to shrinking budgets, which often make planning and prioritization more difficult and optimal use of assets even more important. At the same time, programs must maintain and/or increase their capacity to serve the uninsured and underinsured. Obtaining adequate funding is challenging for disparities programs in part because research grants cover only research and do not provide support for services, which are often needed in the community.

The traditional schedule for program funding is also a challenge; creating behavior change often takes much longer than the funding period of grants. Other challenges include lack of an organized system for sharing information about Minority-Based CCOPs and HIPAA regulations.

Strategies

Programs can employ a number of strategies to successfully manage and sustain themselves in times of budget constraint. Programs should constantly evaluate themselves in order to identify opportunities for improvement and help them demonstrate their value to others (e.g., possible funders). Programs should also find ways to contribute to other institutions/organizations (e.g., hospitals). They should seek to engage healthcare professionals, who can be excellent advocates. Community-based organizations should also seek out mentors in government and academia who can help them understand evidence-based science and access the scientific community.

Cancer health disparities programs should be conscious that the health issues they are dealing with often stem from economic problems. The best way to bring about sustainable changes in health disparities is to address the problem of poverty in America.

Funding

In order to sustain themselves, programs must aggressively pursue funding from a number of sources. Because of the competitive funding environment, it is even more important for programs to clearly describe their goals and the value of their work. It is equally important to understand the agencies/people from which funding is being requested so that requests can be tailored. Several types of funding sources should be pursued.

Community, Foundations, and Other Nonprofit Organizations

Programs should hold fundraising events to help raise money within the community. People will be more likely to contribute if they are told about personal stories that illustrate the importance of the work of the program. One possible approach is to partner with other community organizations for fundraising events.

Support can also be sought from nonprofit organizations (e.g., Komen, Avon), particularly those that have local chapters. Endowments represent one way for individuals and organizations to support the work of a program.

Government

Local, state, and Federal government agencies are sources for cancer health disparities funding. Programs should reach out to state legislators and get to know the government program offices that manage their grants. One source of funding that is not widely utilized is the Small Business Innovation Research Program.

Other possible approaches to increase awareness of cancer health disparities and raise funds for research include working with the U.S. Postal Service to produce special stamps and working with state governments to create vanity license plates that promote a particular area of research (e.g., breast cancer).

Institutions

Institutional funds can sometimes be secured to support programs. Some institutions will agree to use indirect costs to increase funding for a program.

Small community-based organizations should try to partner with larger institutions, which may agree to provide matching funds to support a program or a particular aspect of a program (e.g., training).

Businesses and Corporations

The business community is another possible source for funding. Many large corporations are required to donate money to philanthropic causes and are looking for venues to do this. Local businesses may also be willing to support programs that will help the community.

Infrastructure

Infrastructure is an important part of health disparities programs. NCI has recognized that community-based organizations often do not have the same infrastructure in place as academic institutions and have provided funding for infrastructure through the CDRP.

Although infrastructure is important, it is not efficient for all programs to build new infrastructure. Programs should more actively look for existing resources and partners that may be able to serve their needs without investing in extensive new infrastructure.

For community-based organizations, infrastructure often needs to be flexible. It may be necessary to hire personnel who are able to perform multiple types of tasks. It may also be necessary to redirect funds from one area to another.

Partnerships

Engaging in partnerships is one way that programs can help sustain themselves. Effective partnerships can help programs increase capacity in spite of budget constraints. Partners can exchange in-kind services to make efficient use of scarce resources. Potential partners include community and government councils, cancer centers, patient advocacy groups, industry, insurance companies, and academic institutions.

Programs should be willing to assist other organizations/programs even if they do not immediately receive compensation; building the relationship may lead to opportunities in the future. Programs and organizations should develop Memoranda of Understanding (MOU) for

partnerships in which they become involved. MOUs help define roles and responsibilities of all partners.

Translation and Dissemination of Evidence-Based Research

Translating research that is conducted under structured conditions into practical and effective change in the community is challenging. Many different approaches can be used to disseminate information, including press releases, radio, newsletters, television, the Internet, schools, physicians' offices, train-the-trainer programs, and informational sessions with community advisory boards or others in the community. For effective dissemination, information must be presented in culturally appropriate ways and adapted for the audience. Stories may be a powerful way to communicate with the community, while physicians may be receptive to other forms of information.

There are several existing tools to aid in dissemination. Cancer Control PLANET provides information on evidence-based programs. Organizations/researchers are able to post programs and invite evaluation. A new feature of Cancer Control PLANET called PRIME (Program Resources for Implementation, Management, and Evaluation), which is being co-sponsored by the Lance Armstrong Foundation and the American Legacy Foundation, will help organizations access funding to implement evidence-based programs. The NCI Cancer Information Service Using What Works program helps organizations adapt evidence-based programs for their own needs. Advocacy organizations (e.g., Robert Wood Johnson Foundation) can also be helpful partners in dissemination.

Physicians are often slow to adopt evidence-based approaches. They often do not have the time or resources to learn about emerging best practices. Electronic medical records and other electronic media may help them better implement effective intervention approaches. Patients should be empowered to bring information to their healthcare providers. Some programs have developed clever ways to inform physicians about evidence-based research. One program faxes questions to provider offices and provides free snacks or lunch if the providers can correctly answer the questions.

Researchers should be thinking about translation and dissemination from the onset of their projects. This will help speed these processes. Funding mechanisms should be modified to require and support translation and dissemination.

Health Policy and Legislation

Strategies for Influencing Policy

Health policy and legislation can be powerful tools for addressing public health issues and sustaining health disparities programs. It is important that programs and researchers stay informed on policy issues that could influence their work; larger organizations and institutions should create health policy departments or task forces to perform this function. Researchers and community members should also make sure they are registered voters and build relationships with elected officials and their staff and other policymakers.

Individuals and organizations (e.g., healthcare providers, funding organizations, universities) with similar goals and interests should join together to advocate for particular policies.

Policymakers are more likely to respond if they know a large and diverse constituency supports a policy.

Policies that support public health are not limited to the government. Institutions and companies also have policies that may influence the health of their employees or surrounding communities. For example, cancer centers can require their oncologists to perform at least some clinical research and companies can implement smoke-free policies.

Partnerships

Some institutions and organizations have limitations on lobbying and advocacy efforts. Additionally, many smaller organizations do not have the expertise or resources to launch large-scale policy-related efforts on their own. These organizations should partner with other groups to increase their influence on public policy and legislation.

Many professional societies and large advocacy organizations have policy branches and/or strong connections to local, state, and Federal legislatures. For example, the American Cancer Society Cancer Action Network polls candidates about their views on cancer issues and disseminates the results to voters. The National Breast Cancer Coalition has an effective advocacy training program. Partnerships with these organizations can help smaller organizations make a larger impact on policy. Organizations should use the Internet and other tools to seek out potential partners.

Monitoring and Evaluating the Effects of Policy

An inventory of existing policies can help identify areas of need. It is important to evaluate public policies so that effective policies are maintained and ineffective policies are modified or eliminated. Both qualitative and quantitative evaluation is needed. The CDC Behavioral Risk Factor Surveillance System has county-level health survey data that can be used as a reference or for baseline assessments.

Evaluation requires specific skills and dedicated time. Outside contractors can be hired to perform evaluations. Alternatively, graduate students or schools of public health may be able to assist in evaluation.

Interacting with Policymakers

Influencing policy requires interaction with policymakers at all levels; face-to-face meetings are often the most effective, but phone calls, electronic communications, and briefing documents can also be useful. Personal stories will resonate with people; people who have been affected by cancer or by a particular program should be enlisted to advocate for policies.

It is important to know as much as possible about the background of the policymakers with whom you will be interacting. Efforts should be made to identify policymakers willing to champion a particular policy or issue; policymakers who have had a personal experience with cancer may be more likely to do this.

Public media can be used to attract the attention of policymakers. Coverage of cancer health disparities by the media provides a window of opportunity for talking to legislators and other policymakers about these issues.

Legislators should also be invited to attend local meetings to help them understand ongoing research and outreach efforts. Special events tailored for policymakers can also be held (e.g.,

legislative breakfasts), or opportunities for policymakers to participate in a program can be identified.

People interacting with policymakers cannot be afraid to be strong advocates for their cause. Establishing a “give-and-take” process will help build long-term relationships with policymakers, who appreciate having reliable sources of information about and insight into problems facing the community.

Providing Information to Policymakers

Legislators and other policymakers need information on which to base their decisions. Cancer health disparities programs should provide policymakers with convincing information about the reality of health disparities and ways to address these disparities.

Policymakers should have information about health demographics (e.g., diseases that commonly afflict their communities, insurance status), and should be told how their district or state compares to other districts/states on particular issues. The SEER database (<http://seer.cancer.gov/>) and caBIG Web site (<https://cabig.nci.nih.gov/>) are sources for this type of information.

Elected officials are also particularly interested in the opinions of their constituencies. The American Cancer Society collects some data on public opinion regarding topics such as smoking legislation. Legislators are also interested in personal stories that illustrate the struggles or successes of people in their communities. Survivor testimony can be particularly effective.

Policymakers need information about the effectiveness of programs. They are particularly interested in the cost-effectiveness of programs and potential economic impact (e.g., effects on jobs or productivity). Policymakers need to be educated about public health, health disparities, and factors that contribute to health disparities (e.g., racism). They also need to be made aware of how particular programs successfully address disparities. Researchers should be asked to talk to legislators when appropriate. NCI should consider providing time at next year’s Summit for programs to share success stories that may be used to educate policymakers.

It is a good idea to ask policymakers what other information they need to make a decision or convince them to support a particular policy.

Information provided to legislators and other policymakers should be made as simple as possible; clarity and brevity are highly valued by policymakers. Groups should work together to ensure that policymakers are provided with consistent messages.

Training and Tools

Community members, healthcare providers, researchers, advocacy groups, and businesses should all be educated about health policy and how to influence it. Community members need to be appraised of their power to influence policy. Researchers must understand that they have a responsibility to advocate for public policy that will support research.

Several advocacy organizations and pharmaceutical companies have formal training programs that teach individuals and organizations about the legislative process and how to interact with legislators (e.g., AstraZeneca Hot Seat Advocacy program). Skills taught include how to frame stories and identify key decision-makers. Some organizations plan a lobby day on Capitol Hill following the training.

The right tools and resources can facilitate activity related to health policy. Some state cancer partnerships have newsletters that are disseminated to legislators to inform them about important issues. Legislators can be asked to sign a document indicating support for a particular policy, and a list of supporters/nonsupporters can be made public to hold the elected officials accountable. Action alerts that inform the community about important pending legislation can also be helpful; these are most effective when they are accompanied by simple instructions informing people exactly what to do to support or oppose legislation. It would be useful to add a policy component to Cancer Control PLANET to inform people about evidence-based practices related to health policy.

Examples of Health-Policy-Related Activities

- A program in Connecticut was provided government funding. A portion of the funding was used to hire an outside evaluator to determine the effectiveness of the program and generate a report for the legislature. The program and evaluator are currently working to identify metrics of success.
- A Boston-based program has conducted surveys and focus groups to determine public understanding of the healthcare reform plan in Massachusetts. Based on their findings, the group will generate recommendations to the legislature about how to improve understanding and implementation of the plan. Funding for the project was provided by multiple sources.
- Patient navigation programs are currently undergoing evaluation. At least one program is attempting to document the financial implications of patient navigation in order to request a change in Medicare reimbursement.
- A Boston-based group packaged stories of cancer survivors and provided them to policymakers.
- Arkansas uses tobacco taxes to fund breast cancer research and delivery of care.
- Health Care for All, a Massachusetts group, has a program that funds advocacy training for physicians. It also presented pilot work on patient navigation to the Massachusetts legislature, which resulted in dedicated money for patient navigation.
- Community groups in Allegheny County worked to get legislation for smoke-free workplaces. The policy was overturned, but because the groups also educated restaurant owners and other employers, many businesses decided to go smoke-free anyway.
- In Connecticut, \$7 million of the tobacco Master Settlement Agreement was used to support tobacco cessation, breast cancer screening, and pilot colorectal cancer screening programs.
- In Colorado, 85 cents from every pack of cigarettes goes into a fund that supports health- and tobacco-related activities.
- In Massachusetts, tobacco settlement money was initially spent on anti-tobacco activities, but has since been redirected. Subsequent changes in smoking rates have been observed.
- There is legislation pending in Pennsylvania to mandate insurance coverage for colorectal cancer screening. Groups in Pennsylvania have been learning from the experiences of New York, which recently implemented similar legislation.

- Louisiana was the fifth state to enact a law mandating that insurance companies provide coverage for participation in clinical trials. However, the law has some loopholes that allow large corporations to get away with not providing this type of coverage.
- Policies regarding school nutrition have been established in many locations.
- In Delaware, legislation in the 1990s provided funding for PSA testing. Similar legislation was passed to pay for pap smears; however, pelvic exams were not covered by the policy so many women were still unable to be screened for cervical cancer. Additional lobbying was required to secure funding for pelvic exams.

Training

Distinctive Challenges

There are several distinctive challenges associated with training and career development in health disparities research, particularly community-based participatory health disparities research. The community wants to establish long-term relationships with researchers, which is not always compatible with traditional short-term training programs. However, this barrier can be overcome if trainees are introduced to the community by trusted senior researchers who have been embedded in the community for a long time.

Because it is often difficult to establish causation through community-based research, community-based participatory research is often not highly respected. This makes it difficult to attract funding for training and education. This perception also makes career development difficult for junior investigators interested in community-based participatory research. Community-based participatory research necessitates investment in community engagement and relationship building, but young investigators are under pressure to generate publications in order to receive tenure. This issue needs to be addressed from an institutional perspective.

Universities interested in recruiting community-based participatory researchers may have difficulty doing so. Individuals with expertise in community-based participatory research may not have the educational background or administrative skills necessary to hold an academic position. It may also be difficult to identify the best place for community-based participatory researchers because existing departments may not have similar focus or expertise.

Needs

Expand the Pipeline

In order to build up a workforce of minority and underserved investigators to conduct cancer health disparities research, it is necessary to enhance the pipeline at every juncture. Attention must also be given to career transitions to ensure that researchers progress to becoming established, independent researchers.

Pre-College

The current approach to teaching science in elementary, middle, and high schools should be changed. Facts and figures need to be put into context so students can recognize the relevance of science to their communities. Students should be told if their community experiences health disparities; this personal connection will spur interest in health disparities research. Science teachers should be linked with cancer research centers to ensure that they have accurate and relevant information. Students could also be exposed to science through science camps and other hands-on activities. There is often state and Federal funding available to support public health education programs, particularly those targeted to children.

Students should be told about potential careers in science and research. This can be done through career days or career fairs. Universities should send representatives to participate in the career day activities of local schools, particularly in minority neighborhoods. Importantly, students should be told what they could accomplish as researchers. High school students could also be

exposed to the medical field and community-based participatory research through job shadowing or internships.

College

Efforts are needed to augment the interest of college students in cancer health disparities research. Students with interest in research should be recruited to work in research labs. In order to do this, it may be necessary to link students who attend non research-intensive institutions with investigators at research-intensive institutions. Some colleges have a person or department to help students identify potential research experiences, but others lack this resource.

Minority college students may need help navigating the system. Minority college students often need financial support for college; Federal support is available for undergraduate students, and some of these programs provide support specifically for minorities (e.g., NIH, NSF). Efforts could be made to help minority undergraduates interested in research careers prepare for the GRE. It may also be of use to identify students at 2-year colleges who are interested in research careers and help them transition into 4-year institutions.

Professional, Graduate, and Postgraduate

NIH/NCI provides a number of training and career development grants for graduate, postgraduate, and professional students. NIH/NCI should consider mandating that a portion of these grants be awarded to researchers from minority/underserved populations or those interested in health disparities. NCI should offer fellowships in community-based participatory research to help create a national pool of researchers trained in this area. It is also important to track trainees to increase understanding of what works and identify areas for improvement.

There is a dearth of degree programs and courses focused on community-based participatory research and health disparities. These types of programs would help define the term “disparities,” identify causes of health disparities, and help fit research into the framework of the community.

Doctoral students and postdoctoral fellows should engage in career development activities. These could include presenting research at seminars or scientific meetings and receiving feedback from mentors and peers. Students could also be involved in grant preparation, or participate in mock grant preparation/review sessions to become familiar with the process.

It seems that many African Americans elect to take jobs in the nonprofit sector rather than pursuing university careers after earning their Ph.D. These students should be tracked to see why they are making this decision; it may be that they feel they can do more for their community through nonprofit work than through academia. This may be compounded by the fact that it is difficult for interested Ph.D.-level scientists to transition into community-based participatory research. There are very few postdoctoral programs across the country focused on this area (e.g., North Carolina, Johns Hopkins University, University of Michigan). Others may be dissuaded from pursuing an academic career because the culture is very competitive and tenure is difficult to earn. Also, the relatively low salaries of researchers may deter young people from choosing this career path.

Many health care professionals may be interested in cancer health disparities, but are not trained to conduct research. Training programs should be made available for interested health care professionals—including physicians, nurses, and others—to help them acquire the necessary skills to do health disparities research. This may be challenging for professionals in rural areas.

Junior Investigators

Junior investigators who are from minority/underserved populations or are working in the area of cancer health disparities need extensive support and mentoring and should receive this from their institutions as well as from NIH/NCI. The activities and progress of junior investigators should be tracked at the institution level; for example, institutions should keep track of grants written and received by the investigator as well as mentoring activities. The possibility of using indirect grant costs to support junior researchers should be explored.

Junior investigators should attend professional meetings and sign up for professional society listservs to begin interfacing with the research community. Conferences, including the Summit, should design breakout sessions and tracks for junior investigators. This would allow sessions to address issues important to junior investigators and provide an opportunity for networking.

It is also important that the time of junior investigators be protected. They should not be involved in too many activities and should be allowed time to focus on their research. Junior investigators should be given the opportunity to learn about different areas of research, possibly by shadowing other researchers. Junior researchers should be encouraged develop competitive research programs based on funding trends.

Community

Training is also needed for community members and other nonresearchers who are involved in or want to become involved in community-based participatory research. Mini-courses can be used to teach them the basics about research. General community education programs should also be made available and their availability communicated to the public. One way to do this would be to integrate these programs at the national level.

Funding

Lack of funding is a major barrier for training and career development. More funds are needed for tuition assistantships and stipend support. Funds are also needed to support predoctoral research; many students who cannot do fellowships need support while they are writing their dissertations. Students also need more opportunities to interact with students and educators in other disciplines; funds to send trainees to other sites would promote regional collaboration.

Awareness

Efforts must be undertaken to ensure that individuals and institutions are aware of programs available to support training. NCI should be proactive, informing grantees about how to apply for minority supplements and career development awards and asking them if there is anyone at their institutions who may be eligible for these programs. There is information on the Web about many programs and training support, which is helpful. However, many of the Web sites are difficult to navigate. Also, funding organizations should ensure that their application deadlines are realistic; some organizations have deadlines that are too early or coincide with busy times of the school-year calendar. It would be helpful to have a Web-based repository of all training opportunities available, perhaps organized by age group (e.g., high school, college).

Mentoring

Mentorship is a critical component of training and career development. Mentorship is needed in a number of areas, and trainees benefit from having several mentors. Senior investigators can help trainees identify and develop relevant and meaningful projects on which to work. They can also help trainees and junior investigators determine whether their institution is providing an environment conducive to advancement of their research program. Mentors should also help junior investigators write and submit grants as well as navigate through institutional processes. They should also teach young researchers how to interact with multidisciplinary teams and the community. Mentorship should not be limited to research, but should also provide support for other aspects of trainees' lives.

The most effective mentors are those who are passionate about their work and mentoring. Senior investigators need to recognize that they have an obligation to mentor younger researchers; this is how their research will be carried forward. It is important to provide training for mentors to help them mentor to the best of their ability. Institutional support for mentorship is also crucial.

Trainees and junior researchers should actively seek out mentors. Trainees should not feel confined to a small pool of potential mentors, but should seek mentors from outside their departments and institutions. Effective approaches include contacting potential mentors via email or in person, or asking a mutual acquaintance to make an introduction. It is important that trainees select mentors who are committed to mentorship and understand their goals. Trainees should feel comfortable "interviewing" potential mentors, particularly if they are considering entering a formal training program. Trainees should also evaluate existing mentoring relationships to determine whether they are in alignment with their needs.

There are, however, challenges to identifying effective mentors. It is often difficult for community-based participatory researchers to find mentors with expertise in this area. There is also a dearth of mentors from minority/underserved populations, making it necessary for young researchers from these populations to seek out other types of mentors. This can result in issues related to cultural sensitivity and cultural competency. To address this, efforts should be made to link trainees with appropriate mentors. One possible approach would be to develop a database of mentors and/or mentoring programs. Professional societies could also help connect mentors and mentees, as could the Intercultural Cancer Council. The availability of funds to support regional mentorship programs would also be beneficial.

Knowledge and Skills Gaps

Grant Preparation and Review

Success in the proposal preparation and review process is critical for building a strong research career. However, many trainees need improvement in this area. In addition to learning how to write grants, trainees and junior investigators need to be taught the importance of selecting an appropriate study section and tailoring proposals to the expertise of the potential reviewers. Researchers also need to understand the importance of building relationships with funding agencies and program directors. This will help researchers plan projects that are in alignment with what funding agencies are looking for.

Junior investigators should seek mentorship from established researchers when preparing their grant applications. They should also consider working with senior researchers as co-Principal Investigators.

Grant writing workshops help trainees and junior investigators hone their grant preparation skills (e.g., week-long local/regional workshops). Access to examples of successful grants would also be beneficial. Institutional grants management offices will often help junior investigators improve their proposals by pointing out strengths and weaknesses and correcting language.

Mock study sections can help students and junior investigators learn more about the process of grant review. Academic centers and agencies should hold mock study sections so that trainees can actively participate in the process. Also, NIH has videos of mock review panels for different types of grants.

Trainees and junior investigators should also observe real review processes. Training grants could be modified to require trainees to participate in the review process in some way. The NIH Center for Scientific Review (CSR) should create an observer role so that students can see how study sections operate (confidentiality issues would need to be taken into consideration). Trainees and junior investigators should also take advantage of the fact that institutional protocol review meetings and institutional review board meetings are often open to the public. Insights gained from observing these review committees will help with preparation of future proposals.

Opportunities for trainees and minority researchers to participate on review panels should be expanded. Participation on review panels holds a number of advantages: investigators will increase their knowledge of the review process, build relationships with other researchers, and get ideas for their own research. CSR could consider including postdoctoral fellows as third reviewers for grant proposals. Efforts should also be made to recruit minority researchers as formal members of study sections. Scientific review administrators should ask current reviewers and/or university offices of diversity affairs to help identify qualified minority researchers. Also, minority investigators should be proactive, asking for the opportunity to serve on review panels, including study sections and institutional review boards.

It is also important that community members are invited to participate in the review process at the local, state, and Federal levels.

Publication

Cancer health disparities researchers also need knowledge about how to publish their research results. To be successful, they need to publish early and often. Mentors should engage trainees in the manuscript review process and help junior investigators develop publications.

Collaborations and Cross Talk

Researchers and the Community

The community should be intimately involved in establishing the agenda for community-based research and should not be placed in a subservient role to researchers. Researchers need to become intimately involved in the community; engaging highly respected community members can help researchers make inroads into the community.

Regional Collaboration

Regional collaborations can be mutually beneficial. Regional newsletters and institutional Web sites can also be used to share relevant information about projects with potential partners. The GMaP program may be useful for identifying regional collaborators for training or other purposes.

Transdisciplinary Collaboration

Researchers from a variety of backgrounds and disciplines should work together to address cancer health disparities. Currently, there are not enough nurses involved in cancer health disparities research; they should be more involved and encouraged to play leadership roles. Researchers in other areas who have established community trust should be approached about collaborating on a cancer health disparities project; it may be useful to create a database of researchers who have gained respect within the community. The Summit could also be expanded to allow cancer health disparities researchers to access the experiences of other researchers. Importantly, standardized data collection is necessary if data collected by different groups is going to be combined.

Model Programs and Best Practices

- Provide summer internship opportunities for students in grades 10-12.
- One program has a mobile science lab built on a school bus that is used to promote awareness about cancer research among students.
- The American College of Surgeons invites in-state high school students and some college students to attend their meeting each year and pays for their travel and expenses. This helps expose these students to science. Follow-up is performed on students who participate in this program.
- The Chi Eta Phi sorority has the Chi Teen program, which provides health education sessions for middle and high school students, and the Future Nurses Club, which promotes the interest of potential students in a career in nursing. Chi Eta Phi also provides financial and tutorial services for members serving as mentors.
<http://www.chietaphi.com/2006/programs/index.html#teen>
- The Leaders in New Knowledge (LINK) program at Moffitt Cancer Center provides minority high school and undergraduate students the opportunity to be mentored by Moffitt investigators. Students get hands-on experience in research and participate in conferences. Students can participate in the program for 2-5 years, which allows them to become integrated into the research environment in a meaningful way.
<http://www.moffitt.org/Site.aspx?spid=EB532E3CD72F462A8F409E477F268BD7>
- Xavier University and Tulane University have several partnerships that provide the opportunity for training.
 - The Minority Access to Research Careers (MARC) program at Xavier University includes cancer research opportunities. Through this program, three students from Xavier are working in cancer research labs at Tulane University.
<http://www.xula.edu/MORE/marc.html>

- High school juniors and seniors in a charter school have the opportunity to do cancer research in a laboratory at Tulane University. The program includes a competitive poster session at the end of the summer.
- The Universities recently developed a joint course in cancer biology that can be taken by students at either institution for either undergraduate or graduate credit. Faculty for the course are from both institutions.
- The Meharry-Vanderbilt Alliance, which is funded by a U54 grant, supports a number of training opportunities. The priorities of the Alliance are research, training, and outreach. <http://www.meharry-vanderbilt.org/>
 - Meharry Medical College students between their first and second years are given the opportunity to pair with a mentor at Vanderbilt University Medical Center and conduct a research project in the laboratory of the mentor.
 - The Alliance supports recruitment of junior faculty and has a mentoring program with advisors from both schools to assist junior faculty.
- The Moffitt Cancer Center Cancer, Culture, and Literacy Institute is a year-long program that includes a 5-day intensive course, Web-based seminars, and mentoring. Sixty percent of participants are from minority populations.
- The Minority Training Program in Cancer Control Research, a joint program of the University of California-San Francisco Comprehensive Cancer Center and the University of California-Los Angeles School of Public Health, encourages master's students to earn doctoral degrees that focus on cancer research. <http://www.ph.ucla.edu/mtpccr/>
- Wayne State University has a fellowship program for junior investigators through the Institute of Gerontology that focuses on health disparities.
- The Peer-Onsite-Distance (POD) program developed at the University of Arkansas is a three-tiered program that targets interns, fellows, and junior faculty. Peer mentors of the same ethnicity provide the mentees direction on issues they may not be comfortable asking other mentors about. The onsite mentor, who is a high-level professor, provides mentoring on research and career development. The distance mentor facilitates learning sessions regarding broad issues. Mentors and mentees are matched based on complementary skills and needs. Because mentors are part of a mentoring team, less time commitment is required from each mentor.
- The Mellon Mays Foundation Mellon Mays Undergraduate Fellowship is focused on increasing the number of minority students who pursue Ph.D.s in the arts and sciences. The program tracks its students to see how their careers progress. Fellows receive extensive mentoring and practical guidance. <http://www.mmuf.org/>
- The Carolina Community Network partners with the Kellogg Scholars Program to link postdoctoral fellows with appropriate local organizations.
- The Texas A&M University Project EXPORT center sends graduate students into local high schools to give presentations about careers in research and health disparities.
- The Kellogg Health Scholars Program has 25 community health scholars, six of whom focus on cancer.

- The American Public Health Association has the Black Caucus of Health Workers, which can be helpful for networking.
- Emerging Scholars Interdisciplinary Network is a network of early-career scholars of color, which promotes networking and career development. <http://www.emergingscholars.net/>
- The University of the District of Columbia and Georgetown University initiated a master's degree program in cancer biology, prevention, and control in 2004.
- There are several effective programs for training community members about research, including the Native American Cancer Research Program "Genetic Education for Native Americans," Spirit of EAGLES cancer resource center, and Education Networks to Enhance Cancer Clinical Trials (ENACCT).
- NIH has several programs and resources to support training.
 - High school and college students can participate in research-based internships.
 - Grant supplements are available for predoctoral and postdoctoral fellows from underrepresented populations.
 - Training grants are available for predoctoral students.
 - Mentored career development awards are available for postdoctoral fellows.
 - The NCI Consumer Advocates in Research and Related Activities (CARRA) program trains advocates and community members to participate in the peer-review process.
 - The NCI Careers in Cancer PowerPoint presentation includes talking points and graphics related to careers in cancer research.
 - NCRR Science Education Partnership Awards (SEPA) are designed to bring together biomedical and behavioral researchers, educators, community groups, and other interested organizations in partnerships to create and disseminate programs that give K-12 students and teachers and the general public a better understanding of life sciences.
 - The Postbaccalaureate Research Education Program (PREP) Awards provide support for underrepresented minorities who have recently graduated from college. These students work in research laboratories and participate in development and education activities. The program is designed to strengthen research skills to make participants more competitive for graduate programs and stimulate interest in health disparities.
 - The Bridges to the Future Program facilitates the transition of minority students from associate to baccalaureate degree-granting institutions and from master's to doctoral degree-granting institutions.