ELIMINATING DISPARITIES IN CLINICAL TRIALS (EDICT) PROJECT*

INTERCULTURAL CANCER COUNCIL
BAYLOR COLLEGE OF MEDICINE

EXECUTIVE SUMMARY REPORT FROM EIGHT COMMUNITY DIALOGUE MEETINGS

Conducted
OCTOBER 2008 – JUNE 2009

EDICT Community Dialogue Meeting in San Francisco, June 2009

* The EDICT Project is funded by an unrestricted educational grant from Genentech, Inc.
1. Overview of Community Dialogue Meetings

Community meetings were held in one city selected from each of the eight regions of the ICC Network in the U.S. and its associated territories. Each meeting was a collaboration of the Eliminating Disparities in Clinical Trials (EDICT) Project and the Intercultural Cancer Council (ICC).

The overall objectives of the meetings were to:

1) bring the mission of EDICT and its specific policy recommendations to local community stakeholders, and
2) obtain feedback from communities related to their questions and concerns about clinical trials.

The meetings were held in New York City (Harlem), Cincinnati, San Juan/Cayey, Puerto Rico, Charleston, West Virginia, Honolulu, Tampa, Tucson/Phoenix, and San Francisco.

Methodology for Selecting Meeting Sites

The methodology for site selection explored several key cities in each region and evaluated potential sites by: underrepresented populations in the area; local experts in issues related to clinical trials disparities; clinical trial activity; local ICC and EDICT leadership; community-based partners; potential co-hosting institutions; and location of strategic academic or community programs. San Juan/Cayey, Puerto Rico, Honolulu, Hawaii, and Charleston, West Virginia represent three ICC regions that were iden-
MEETINGS AS A FEASIBILITY STUDY

The Community Dialogue Meetings were conducted to determine if EDICT could engage stakeholders in the discussion on disparities in clinical trials and assess whether there was sufficient interest in continuing and sustaining the EDICT work locally. The meetings were conducted with limited resources, but produced meaningful findings because our local collaborators and partners contributed significantly to meeting planning and implementation.

EDICT received a very positive response from communities and interest in continuing efforts to increase awareness of underrepresentation in clinical trials. There are plans to continue this dialogue with these communities and others in the future and to invest more resources in this worthwhile effort.

BACKGROUND ON THE EDICT PROJECT

In 2006-2008, the EDICT Project brought together over 300 national representative stakeholders from the public, private and non-profit sectors for a two-year collaboration resulting in the development of 33 policy recommendations in nine categories to address the problem of disparities in participation in clinical trials. (EDICT Policy Recommendations can be found at the following link: http://www.bcm.edu/edict/PDF/EDICT_Project_Booklet.pdf)

During the policy development process, a model was designed to identify key stakeholders involved in eliminating disparities in clinical trials. At the center of the model, are populations underrepresented in clinical trials. The next concentric circle identifies the three key “Participating Stakeholders” – communities, sponsors and researchers, who typically exert the most immediate influence on recruitment and retention of the underrepresented into clinical trials.

Our primary objective for each meeting was to bring the message of EDICT and its policy recommendations to individuals in the community and CBOs (community-based organizations), who are often overlooked in the clinical trials process. Another objective was to bring representatives of the local research institutions and teams in those communities to meet community leaders and hear from the community members. In many of the meetings, representatives of the government, industry or non-profits that sponsor the research, also attended in order to contribute to the discussion and obtain input from the community.
THREE TYPES OF MEETINGS WERE CONDUCTED

Each city’s meetings were a unique blend of community size, topics, and specific interests and level of involvement of local collaborators. However, each city’s meetings shared a basic framework:

1) **A community “town hall” meeting** – to present EDICT issues and receive feedback from community participants.

2) **One or more roundtable meetings** – of local participants (15-50) with expertise in an identified issue of particular relevance to underrepresentation in clinical trials.

3) **Focus groups in six locations on “Clinical Trials Navigation”** – New York City (Harlem), Cayey, Puerto Rico, Honolulu, Phoenix/Tucson, San Francisco with an additional city added to the data – Houston, the home of the EDICT Project.

2. Role of Local Collaborators

One or more local collaborating partners were essential to the success of the meetings. They came from public, private and non-profit sectors and assisted with the development of agendas, identification of local speakers, invitation lists, and other meeting logistics. A brief overview of local collaborators and their roles in each of the sites are described below. (The meetings are presented in the order they were conducted.)

**New York City (Harlem)**

Harold P. Freeman, MD, President and Founder, Ralph Lauren Center for Cancer Care and Prevention and Harold P. Freeman Institute for Patient Navigation, was a collaborator for the roundtable discussions on Clinical Trials Navigation. Sylvia White, Chief of Staff at the Harlem Hospital, was instrumental in assisting EDICT in the organization of the community meeting at the hospital and inviting key community leaders and advocacy organizations from the five boroughs of New York. Numerous city, state and national political leaders attended as well as representatives of the minority media.

**Cincinnati**

Local collaborators included James Powell of the National Medical Association’s (NMA) Project IMPACT (Increasing Minority Awareness and Participation in Clinical Trials) and Dwight Tillery, CEO of The Center for Closing the Health Gap in Greater Cincinnati, a unique region-wide advocacy organization. Together they identified the key academic and research institutions as well as community representatives that...
were instrumental to the discussion of disparities in clinical trials.

The University of Cincinnati College of Medicine (UCCM) hosted a roundtable discussion of local experts on “The Role of Community Health Professionals in Eliminating Disparities in Clinical Trials” led by Dr. James Heubi, Associate Dean of Clinical Research. The community meeting was hosted by our collaborators and featured presentations by Dr. Dean Kereiakes from The Christ Hospital and Lindner Research Center and UCCM CTSA Associate Dean of Clinical and Translational Research, Dr. Joel Tsevat.

The roundtable meeting addressed “The Role of Community Health Professionals in Eliminating Disparities in Clinical Trials.”

Panel members included (l-r) Dr. Alfonso Alanis, Anaclim CRO, Patricia Milton, Avondale Community Council, John M. Isidor, Schulman Associates IRB, Dr. Frank Biro, UCCM, Dr. James Heubi, UCCM, Dr. Bradley Jackson, Premier Medical Group. Dr. James Powell, NMA, was co-moderator with Dr. Armin D. Weinberg, EDICT (not pictured).

Photo by Kelly Tarver

◆ San Juan/Cayey, Puerto Rico

Dr. Guillermo Tortolero-Luna, Director of Cancer Control and Population Sciences, University of Puerto Rico, and Marta Sanchez, Coastal Partnership Program Coordinator, National Cancer Institute, Cancer Information Service, University of Puerto Rico, incorporated the EDICT meeting as part of the 2009 Clinical Trials Workshop for the University of Puerto Rico and M.D. Anderson Cancer Center U-54 Partnership for Excellence in Cancer Research. Other roundtable meetings were conducted with local physicians, members of the Puerto Rico Medical Association and the Pharmaceutical Industry Association of Puerto Rico. A focus group was conducted in Cayey, a rural community, approximately 50 miles from San Juan.

◆ Charleston, West Virginia

The Mountains of Hope (MOH) West Virginia Cancer Coalition, consisting of more than 260 members and representing over 130 organizations, featured the EDICT Project as the program for the community and physician education meetings for the spring quarter. Both meetings focused on issues related to “Rural and Appalachian Populations in Clinical Trials.” MOH Executive Director Jim Keresz purity, and Pamela Brown from the University of West Virginia Mary Babb Randolph Cancer Center, acted as collaborators with the EDICT Team and identified outstanding panelists to kick-off the discussion in the sessions.

◆ Honolulu

JoAnn Tsark, Project Director of `Imi Hale – Native Hawaiian Cancer Network solicited the participation of The Queen’s Medical Center to provide the facility and support to conduct the roundtable discussions, and the Hawaii Comprehensive Cancer Control Coalition (CCCC) to convene the forum for the community meeting. State Senator Rosalyn Baker, Chair of CCCC, presided over the community meeting. The NCI’s Cancer Information Service, Pacific
Region, with support from the Cancer Research Center of Hawaii developed and printed a report of the results. Staff from each program joined ‘Imi Hale staff to serve on the planning committee. JoAnn Tsark, the collaborator and active participant in the ICC, designed detailed roundtable meetings with a variety of community stakeholders to systematically evaluate the selected EDICT policies and their application to Hawaii and the state cancer plan. An extensive report of the proceedings is available at this link: http://www.bcm.edu/edict/PDF/EDICT_Hawaii_Regional_Meeting_Report.pdf

**Tampa**

The Tampa Bay Community Cancer Network at Moffitt Cancer Center served as the host for this meeting. Dr. Lodovico Balducci, Division Chief, Senior Adult Oncology, Moffitt Cancer Center helped coordinate a roundtable panel on issues related to “Older Americans in Clinical Trials” that included four national experts. Dr. Cathy Meade, Director, Cancer, Culture and Literacy Institute, Moffitt Cancer Center, developed a roundtable on “Cultural Competency and Literacy Issues in Clinical Trials” with experts from the Cancer Center, the Cancer Information Service and the University of South Florida. All panelists were contributors to the Community Meeting that followed, held at Morsani Center at the University of South Florida.

**Tucson/Phoenix**

Sharon Jaycox, Liaison to Special Populations at the Arizona Department of Health Services, was the local coordinator for the Arizona EDICT meetings. Dr. Jesse Nodora from the University of Arizona Cancer Center at Tucson, coordinated a roundtable discussion on “American Indians in Clinical Trials” with representation from a variety of tribal and other community organizations from the area.

Dr. Robert Valdez, Director of the Robert Wood Johnson Foundation Center for Health Policy, University of New Mexico, facilitated a roundtable on “Insurance Coverage Issues in Clinical Trials” in Phoenix. All collaborators participated in the Phoenix community meeting that featured a panel of area experts from four underrepresented populations – Latino/Hispanic, American Indian, Asian and African American. The EDICT Team also met with leaders of the Inter-Tribal Council while in Phoenix.
Dr. Dan Dohan of the University of California San Francisco, Philip R. Lee Institute for Health Policy Studies, helped coordinate and identify local experts for the roundtable discussions on “Health Systems and Clinical Trials”. Angela Sun, from the Chinese Hospital, helped develop a roundtable conversation with medical staff of the Chinese Hospital on “Asian Americans in Clinical Trials.”

Active ICC members Susan M. Shinagawa and Jennie Cook as well as Lisa Tealer, Senior Diversity Manager at Genentech, Inc., worked with EDICT to develop a very well attended community meeting with representation from many of the area's underrepresented communities. In addition, the EDICT Team attended the board meeting of the advocacy group, AANCART (Asian American Network for Cancer Awareness, Research and Training).

The following panelists answered questions from the San Francisco Community Meeting participants:

(I-r) Lisa Tealer, Sr. Diversity Manager, Genentech, Dr. Daniel Dohan, UCSF (not visible), Dr. James Powell, National Medical Association, Dr. Ho Tran, Asian Pacific Islander Health Forum, Dr. Armin D. Weinberg, EDICT, and (not pictured) Susan M. Shinagawa, Asian & Pacific Islander National Cancer Survivors Network.

Photo by Susan M. Shinagawa

3. Matrix of Roundtable Topics and Key Feedback from Roundtable and Community Meetings

<table>
<thead>
<tr>
<th>City</th>
<th>Roundtable Topics</th>
<th>Outcome/Feedback: Community Meetings/Roundtables</th>
</tr>
</thead>
<tbody>
<tr>
<td>New York City (Harlen)</td>
<td>• Clinical Trials Navigation</td>
<td>• Fear and mistrust of medical research is still a major barrier in the African American community.</td>
</tr>
<tr>
<td></td>
<td>• African Americans in Clinical Trials</td>
<td>• Community leaders emphasized the need to understand the lessons of Tuskegee, but keep minds open to the importance of trials to communities with the burden of disease.</td>
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<td></td>
<td></td>
<td>• Great need exists for culturally competent community-based education and outreach to gain community’s trust.</td>
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<td>• Navigation is needed to help individuals to access and overcome barriers to participate in trials.</td>
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<tr>
<td>Cincinnati</td>
<td>• Role of Community Health Professionals in Clinical Trials</td>
<td>Future of clinical research demands partnering with communities to understand unique cultural issues as a first step to establishing trustworthiness of research.</td>
</tr>
<tr>
<td></td>
<td>• African Americans in Clinical Trials</td>
<td>• Education about trials and disparities is needed at all levels – sponsors, professionals, IRBs, as well as patients and public.</td>
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<tr>
<td></td>
<td></td>
<td>• More minority physicians are needed as clinical trial investigators, as they are an important source of racial and ethnic minority participants.</td>
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<tr>
<td></td>
<td></td>
<td>• All physicians should be educated about clinical research in order to advise patients about appropriate research participation.</td>
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<tr>
<td>Cayey/San Juan, Puerto Rico</td>
<td>• Latino/Hispanics in Clinical Trials</td>
<td>Underrepresentation and abuse occurs in trials here. More emphasis exists on financial rewards of recruiting patients, rather than benefits to patients.</td>
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<tr>
<td></td>
<td>• Pharmaceutical Industry/Community Physician Perspective</td>
<td>• As a result, much mistrust exists - communities want trials that are relevant to them, transparency from researchers, and results to be shared.</td>
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<td></td>
<td></td>
<td>• There is no centralized system for citizens to find trials.</td>
</tr>
<tr>
<td>City</td>
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<tr>
<td>Charleston, WV</td>
<td>• Appalachian Populations in Clinical Trials</td>
<td>• Rural and Appalachian populations are also underrepresented groups in clinical trials – but are often overlooked.</td>
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<tr>
<td></td>
<td>• Rural Populations in Clinical Trials</td>
<td>• Clinical trial networks are needed to facilitate collaboration and provide more trials in rural, underserved areas.</td>
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<td></td>
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<td>• WV state cancer coalition is addressing disparities in cancer trials by setting up a clinical trials network through a state oncology association and state cancer plan.</td>
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<tr>
<td>Honolulu</td>
<td>• Native Hawaiians and Pacific Islanders in Clinical Trials</td>
<td>• EDICT policies are relevant to Hawaii and should be added to the state cancer plan.</td>
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<tr>
<td></td>
<td>• Application of EDICT Policies to Hawaii and State Cancer Plan</td>
<td>• More community involvement is needed in entire trials process, since all aspects of trials are designed on U.S. Mainland.</td>
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<tr>
<td></td>
<td></td>
<td>• Physicians are key in promoting trials – and can be better supported through education, expanding coverage, training navigators and other “physician extenders” to address clinical trials with patients.</td>
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<td>• Research institutions should revisit the IRB’s role in ensuring equity in representation in trials.</td>
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<tr>
<td>Tampa</td>
<td>• Older Americans in Clinical Trials</td>
<td>• Without appropriate age representation in trials, you do not have evidence-based medicine.</td>
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<tr>
<td></td>
<td>• Cultural Competency and Health Literacy Issues in Clinical Trials</td>
<td>• More information needed on participants with co-morbidities for trial outcomes to be relevant to the elderly.</td>
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<td></td>
<td></td>
<td>• Age of potential participants should be assessed physiologically, not chronologically.</td>
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<td></td>
<td>• Recruitment plans must include information and resources on how to reach people you want involved in a trial -- including consideration for tailored communications for different groups according to culture, literacy, and disease type.</td>
</tr>
<tr>
<td>Tucson/Phoenix</td>
<td>• American Indians in Clinical Trials</td>
<td>• Major barrier to clinical trial participation includes the many diverse tribes and tribal laws that demand review of trials in addition to usual IRB review.</td>
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<td></td>
<td>• Coverage Issues in Clinical Trials</td>
<td>• American Indians have the historical experience of being misused in clinical trials and many see no benefit in participation.</td>
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<td>• Complexity of the Indian Health Service makes it difficult to go out of the system for trials – the unfamiliarity with traditional system could be facilitated by navigation.</td>
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<tr>
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<td></td>
<td>• Much confusion exists regarding both public and private insurance coverage of clinical trials in all sectors of the population.</td>
</tr>
<tr>
<td>San Francisco</td>
<td>• Health Systems and Clinical Trials</td>
<td>• Lesbian/Gay/Bisexual/Transgender populations are underrepresented in clinical trials.</td>
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<tr>
<td></td>
<td>• Asian Americans in Clinical Trials</td>
<td>• Community participation needs to be a prerequisite to clinical trial planning.</td>
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<td></td>
<td>• Health professionals here from immigrant populations are an untapped resource to educate their underrepresented patients about trials.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• More resources needed for community groups to conduct effective outreach to underrepresented communities.</td>
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<tr>
<td></td>
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<td>• How did we get today’s standard of care without representation of all groups in clinical trials?</td>
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</tbody>
</table>
4. Overall Findings from Community and Roundtable Meetings

By listening to participants of the EDICT Regional Dialogue Meetings, we noted several recurring themes in the discussions. These themes are consistent with the EDICT policy recommendation categories and are applicable to local communities including:

- Enhancing Public Education about Clinical Trials in Communities
- Enhancing Professional Education – Researchers, Healthcare Professionals and IRBs
- Fostering Community Involvement in Clinical Trials
- Navigation and Support of Individuals in Clinical Trials
- Health Care Coverage for Costs Associated with Clinical Trials

SUMMARY OF FINDINGS

THE NEED FOR EDUCATION ABOUT CLINICAL TRIALS AND DISPARITIES IN CLINICAL TRIALS – the EDICT Project Team repeatedly heard the need voiced for education across the board: in the community, for health care professionals, research institutions, research sponsors and IRB members:

- Communities – there is limited knowledge about what clinical trials are and where they are available. Misconceptions and myths abound, and citizens need to be enlightened – and not for the first time when they are diagnosed with a serious illness. Citizens also must be aware of the importance to them personally and to their communities for adequate representation of all groups. Culturally and linguistically proficient strategies and materials for different communities, as well as attention to literary and health literacy are needed for successful community outcomes.
- Health Care Professionals – there is a lack of knowledge and understanding of the research process as well as the specific manifestations of disparities in clinical trials among many health care professionals. Health care professionals are the key to educating and referring patients to trials and should be able to advise their patients about participation in trials.
- Researchers, Research Institutions, Sponsors – often may also lack training on the issue of disparities in clinical trials and do not consider this issue when designing and conducting trials.
- IRB Members – also may lack the training to recognize disparities in protocols. IRB members do not regard eliminating disparities in clinical trials as part of their mandate, and see their primary focus as ensuring the safety of participants.

MISTRUST – Since all meetings were conducted with a primary or secondary focus on a specific underrepresented population, the issue of mistrust of medical research as a major barrier to participation by underrepresented groups was routinely an issue of discussion among meetings addressing African Americans, Latino/Hispanics, American Indians, Asian Americans and Pacific Islanders, rural/Appalachian populations and older Americans. In several communities, community groups were able to cite specific examples of trials in their community that had created the mistrust.
ROLE OF COMMUNITY INVOLVEMENT IN CLINICAL TRIALS PROCESS/IMPORTANCE OF BUILDING COMMUNITY RELATIONSHIPS – Community members and advocates recommended that better ties be established between communities and research institutions. Research must be relevant to the communities and communities must be part of the process for designing and implementing trials. Communities requested feedback about results of research and that sponsors of trials ensure that this is an integral part of planning their research.

CLINICAL TRIALS NAVIGATION – Participants at most community meetings mentioned the need for assisting the underserved who are not familiar with research and the complex healthcare system in the process of locating and negotiating the barriers to participating in trials – the concept that EDICT and others have labeled “Clinical Trials Navigation.”

LACK OF KNOWLEDGE REGARDING INSURANCE COVERAGE – The fact that routine care associated with clinical trials is frequently not covered under the variety of insurance products was identified early on in the EDICT process as a barrier to participation and an area in need of policy change. In addition, this barrier includes lack of knowledge of whether clinical trials are covered under a particular insurance product. We found this echoed in the community meetings, and that most individuals have no idea whether clinical trials are included as part of their public or private health insurance plan.

ROUNDTABLE MEETING ON CORE COMPETENCIES FOR CLINICAL TRIALS NAVIGATORS (CTN)

Two roundtable meetings were held in New York City to identify the core competencies needed for training Clinical Trials Navigators. Hosted by Dr. Harold Freeman, “Father of Patient Navigation,” attendees included individuals from entities that fund navigation programs, such as Health Research and Services Administration (HRSA), Susan G. Komen for the Cure, American Cancer Society, National Cancer Institute, Lance Armstrong Foundation, American Heart Association, The Leukemia & Lymphoma Society, and others research institutions.

There was agreement among participants that there is an increasing necessity for navigation for the special needs of participants in clinical trials. Clinical Trials Navigators provide a crucial liaison between investigators, subjects and communities. Clinical Trials Navigators may be healthcare professionals, social workers, cancer survivors or other lay persons from the community. Because of the diverse background of those entering this work, there is a need to
institute basic training to establish the core knowledge and skills needed.

Patient Navigation specialists advocated that Clinical Trials Navigation be widely adopted as the accepted standard of practice for research institutions and together outlined the core competencies needed when navigators work with patients. These competencies include having up-to-date information on national and state insurance requirements, knowledge of what community resources are available and how to access them for patients, formal training in navigation, and having access to culturally and linguistically proficient community education materials provided in languages for non-English and limited English speaking populations.

**Focus Groups to Further Explore Clinical Trials Navigation for Underrepresented Groups**

Focus groups were coordinated by Venus Gines, EDICT Project staff member, in conjunction with the Community Meetings in five sites, with Houston as an added sixth site. The objective of the focus groups was to obtain input regarding clinical trials navigation training from those representing different underrepresented populations. Focus group participants consisted of individuals working or volunteering in the capacity of Community Health Workers, Patient Navigator, Nurse Navigator, Social Worker and Promotoras (Spanish-speaking community health educators/advocates) with an emphasis on a different population in each area:

- New York City (Harlem) – African Americans
- Cayey, Puerto Rico – Puerto Ricans/Cubans/Dominicans
- Honolulu – Native Hawaiians/Pacific Islanders
- Tucson/Phoenix – American Indians
- San Francisco – Asian American and Pacific Islanders
- Houston – Mexican Americans/Central Americans

The following questions were asked of focus group participants:

**What cultural, socio-economic and practical barriers are encountered by the specific populations you serve?**

Most frequently cited responses were:
1. Mistrust, lack of information, and cultural barriers
2. Low literacy, fear of the healthcare system and research
3. Access to healthcare resources, cost of health service/lack of insurance and language barriers

**What are barriers to you as a Patient Navigator?**

Most frequently cited responses were:
1. Lack of provider/investigator understanding of navigator role
2. Lack of financial support for the navigator services
3. Lack of information on trials in general, and specifically culturally and linguistically tailored information
4. Lack of training/certification for navigators.

**What recommendations do you have on the development of a Clinical Trial Navigation curriculum?**

The most cited recommendation for training was that other members of the clinical trials team, including investigators and sponsors, also be trained in trial navigation concepts in order to better understand the role of a navigator, particularly from the community health worker’s perspective. Also mentioned frequently were identification of culturally and linguistically tailored resources for education and location of trials.

*Clinical Trials Navigation focus group participants in Harlem led by Venus Gines (center, front).*
6. Activity in Eight Communities Since EDICT Meetings

Examples of activity in the eight communities since the EDICT meetings include:

- One of San Francisco’s collaborators, Susan M. Shinagawa, has participated in: 1) eight meetings in northern and southern California, and 2) cancer conferences at six California universities where she presented or shared EDICT information to a variety of Asian and Pacific Islander organizations.

- Sharon Jaycox, Phoenix collaborator, and other Arizona Cancer Coalition Members have continued to address implementation of the EDICT policies and incorporation into the state cancer plan since the EDICT June meetings. In addition, a survey was conducted for EDICT of community oncology physicians in rural Arizona in collaboration with the Arizona Cancer Coalition Research Committee – to obtain insights into the experiences of community based oncology practices and clinical trials, particularly related to collaboration and awareness among sites and to assess special needs of rural and ethnic/minority patients.

- The ‘Imi Hale Native Hawaiian Cancer Network, completed a report on the Hawaii Regional EDICT meetings and distributed e-copies to all attendees and 300 printed copies to state stakeholders. The report summarized meeting discussions on the relevancy of the EDICT recommendations to Hawaii and Hawaii specific strategies. A formal report on the Hawaii Regional EDICT meetings was made by Amanda Allison, at the Hawaii Comprehensive Cancer Control Program Meeting ‘Imi Hale Native Hawaiian Cancer Network. ‘Imi Hale Project Director, JoAnn Tsark, presented highlights of the Hawaii Regional EDICT meetings at the Hawaii Society of Clinical Oncology in November, 2009.


- Cincinnati and Tampa reported they are laying the groundwork for the next steps, as there remains great interest in their communities.

- Two publications are in development by Martha Romney, an EDICT Fellow, from the proceedings of the Tampa roundtable on “Issues Related to Participation by Older Adults in Clinical Trials.”

- EDICT has been asked to collaborate on grant proposals to build upon the EDICT policy recommendations in several communities who participated in the Community Dialogue Meetings.

7. Conclusion

The EDICT Community Dialogue Meetings have laid the necessary groundwork for further engagement and capacity-building with communities whose trust and participation in clinical trials is necessary to producing high quality scientific evidence. Communities have responded to the EDICT Project’s insistence on including community representation throughout the life of the Project, and have requested more and varied communications with the EDICT Team following the Community Meetings.

EDICT anticipates holding additional community and roundtable meetings patterned after EDICT’s success with the first eight, and in addition, is planning to facilitate community engagement by way of state clinical trial networks, state cancer control and state health plans, and local advocacy training and guidance.
EDICT thanks the following individuals in the eight communities who contributed to the organization and/or implementation of the EDICT Community Dialogue Meetings:

**New York City (Harlem)**

*Hosts and Collaborators:*

Harold P. Freeman, MD – President and Founder
Ralph Lauren Center for Cancer Care and Prevention
Harold P. Freeman Institute for Patient Navigation

Sylvia White
Chief of Staff
Harlem Hospital

John M. Palmer, PhD – Executive Director
Harlem Hospital Center

Margo Michaels, MPH
Executive Director
ENACCT

Al Blixt
Sylvia James
Dannemiller Tyson Associates

*ICC Representatives:*

Patricia K. Bradley, PhD, RN
Villanova University

Linda Fleisher, MPH
Fox Chase Cancer Center

Selma Morris, MEd
International Health Consultant

**Cincinnati**

*Hosts and Collaborators:*

James H. Powell, MD
National Medical Association

Dwight Tillery, CEO
Closing the Healthcare Gap of Greater Cincinnati

Renee Mahaffey Harris
Executive Director
Closing the Healthcare Gap of Greater Cincinnati

Kelly Tarver
Communication Specialist
Closing the Healthcare Gap of Greater Cincinnati

Tiffany McDowell, PhD
Assistant Director of Research and Programs
Closing the Healthcare Gap of Greater Cincinnati

James E. Heubi, MD
University of Cincinnati College of Medicine

Sue Swearingen
University of Cincinnati College of Medicine

Joel Tsevat, MD, PhD
University of Cincinnati College of Medicine

Dean Kereiakes, MD
Medical Director, Christ Hospital and Lindner Center for Research

*Panelists:*

James E. Heubi, MD
University of Cincinnati College of Medicine

Bradley S. Jackson, MD
Premier Medical Group, Inc
Mason, Ohio

Frank M. Biro, MD
Cincinnati Children's Hospital Medical Center

Alfonso J. Alanis, MD
Anaclim Contract Research Organization
Indianapolis

John M. Isidor, JD
Schulman Associates IRB

Patricia Milton
Avondale Community Council

*ICC Representatives:*

Jaci Holland, RNC, CRNP
Ohio State University

A reception was held before the Cincinnati Community Meeting at The Christ Hospital.
Photo by Kelly Tarver
Charleston, West Virginia

*Hosts and Collaborators:*

Pamela K. Brown, MPA
Mary Babb Randolph Cancer Center
University of West Virginia

James A. Keresztyr, ACSW, MBA
Director, Mountains of Hope Cancer Coalition

Jenny Ostien, MS
Program Manager
Mountains of Hope Cancer Coalition

Joe Barker, MPA
Director, West Virginia Bureau for Public Health Office of Epidemiology & Health Promotion

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Honolulu

*Hosts and Collaborators:*

JoAnn Tsark, MPH
Research Director, Papa Ola Lokahi and Project Director - ‘Imi Hale - Native Hawaiian Cancer Network

Dileep Bal, MD, MS, MPH
Hawaii Department of Health District Health Officer, Kauai District Health Office

Amanda Allison
‘Imi Hale - Native Hawaiian Cancer Network

*Panelists:*

Dr. Kathryn Braun
Research Director
‘Imi Hale – Native Hawaiian Cancer Network
Professor of Public Health, University of Hawaii

Kevin Cassel, MPH
Cancer Information Service

Jonathan K. Cho, MD
Cancer Research Center of Hawaii’s Prevention and Control Program

Dr. Clayton D.K. Chong
Principal Investigator, ‘Imi Hale – Native Hawaiian Network

Dorothy Coleman, MS, RN
University of Hawaii Minority –Based Community Clinical Oncology Program

Paul T. Morris, MD, FACS
University of Hawaii John A. Burns School of Medicine

Randal K. Wada, MD
Cancer Research Center and John A. Burns School of Medicine
University of Hawaii

*ICC Representatives:*

Reggie Ho, MD
Clinical Professor of Medicine
John A. Burns School of Medicine
University of Hawaii

Neal A. Palafax, MD, MPH
Professor and Chair
Department of Family Practice and Community Health
John A. Burns School of Medicine
University of Hawaii

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*Panelists:*

Patti Davis
Hampshire County Cancer Coalition

Sara Jane Gainor, MBA
Director, Mid-Atlantic Cancer Information Service Partnership

Leslie Lassiter
Roane Cancer Education Coalition

Patti Fogg, MS
American Cancer Society

B. Dan Lucas, Jr., PharmD
CMAS Health Education and Research Institute

Jame Abraham, MD, FACP
Mary Babb Randolph Cancer Center

Wade G. Douglas, MD
Edwards Comprehensive Cancer Center

*ICC Representatives:*

Sharon Barrett, MS
Columbia, Maryland
Tampa

**Hosts and Collaborators:**

**Lodovico Balducci, MD**  
Chief of Geriatric Oncology, Moffitt Cancer Center

**Cathy Meade, PhD**  
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**William E. Haley, PhD**  
Professor of Aging Studies, University of South Florida

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**Arthur Meltzer, PhD**  
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**Julie Kornfeld, PhD**  
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**Clement Gwede, PhD**  
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Acting Director, Center of Excellence  
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**Doug Hirano, MPH**  
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**James H. Powell, MD**
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