

Researchers and Their Communities: The Challenge of Meaningful Community Engagement

Authors: The Clinical and Translational Science Award (CTSA) Consortium's Community Engagement Key Function Committee and the CTSA Community Engagement Workshop Planning Committee.

Abstract: A summary of the best practices emerging from a series of national and regional workshops on community engagement held in the following cities:

Bethesda, MD, May 15, 2007
Los Angeles, CA, September 14, 2007
Bethesda, MD, May 9, 2008
St. Louis, MO, September 5, 2008
Chicago, Ill, September 12, 2008
New York, NY, September 25, 2008
Philadelphia, PA, October 13 2008
Sacramento, CA, October 17, 2008

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Research Resources**

About the Authors:

A full membership listing of the Clinical and Translational Science Award (CTSA) Consortium's Community Engagement Key Function Committee can be found here: http://www.ctsaweb.org/index.cfm?fuseaction=committee.viewCommittee&com_ID=3&fullMembership=1

A listing of the CTSA Community Engagement Workshop Planning Committee can be found in Appendix A.

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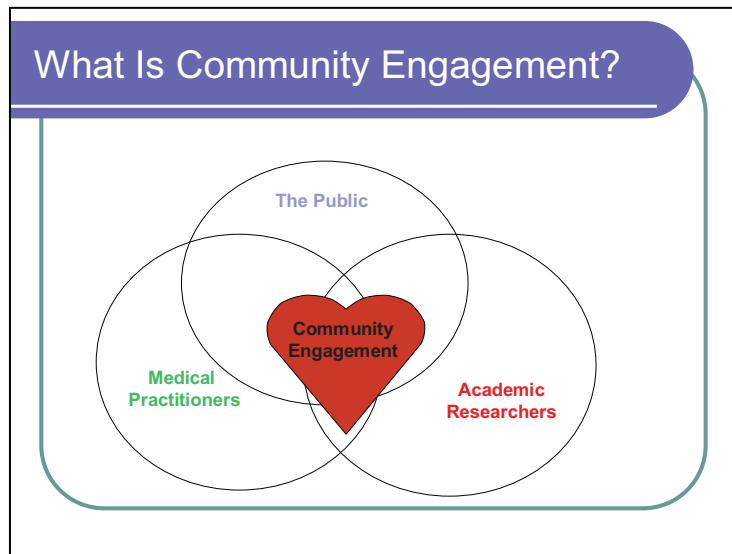
Introduction:

Sixty years ago, 5,029 men and women in the town of Framingham, Mass. forever changed the face of medicine and saved countless lives by participating in a longitudinal study on cardiovascular risk factors.¹ Framingham is one of many successful examples of how researchers, clinicians and communities can collectively work to improve health. But for many Americans – in particular those members of populations riddled with health disparities – the benefits of medical research findings have yet to improve their lives.^{2,3}

neighbors in behavior change, to community-based organizations and engaged citizenry who instigate political and policy change.

Too often, however, Academic Health Centers (AHCs) hinder rather than partner with communities to affect changes and improve outcomes. One crucial component of the Clinical Translation Science Award (CTSA) program⁴ is to enhance and nurture community engagement efforts.

Purposes & Objectives:



Successful translation of science into improved population health requires community support and involvement at every level – from volunteers who participate in clinical trials, to physicians and other health providers and community leaders who assist their

The CTSA program was born out of a frustration at multiple levels of society that the U.S. spends more money per capita on health care than any other nation for health outcomes that are similar or worse than peer nations. Four years ago, the National Institutes of Health (NIH) established a Common Fund which was enacted into law by Congress through the 2006 NIH Reform Act to support cross-cutting, trans-NIH programs.⁵ Out of

this shift in funding and priorities, the CTSA program was born.

Sponsored by and funded through the National Institutes of Health's National Center for Research Resources (NCRR), the CTSA program, which currently

includes 38 academic health centers in 23 states (see Appendix A), will ultimately link 60 institutions together at a total annual cost of \$500 million by FY 2012.⁶ Half the nation's medical schools – including institutions that do not belong to AHCs – will ultimately weave into the program.⁶

A community engagement key function committee with representatives from more than 40 medical schools and governmental agencies is currently working to knit together medical schools, health care providers, community-based agencies, and the community itself, to shape the definition and role of community engagement in clinical and translational research. (See <http://www.ctsaweb.org/index.cfm?fuseaction=committee.viewCommittee&committeeID=3&fullMembership=1> for a complete list of members.)

What Does Community Engagement Mean?

Community engagement can be difficult to define clearly, but at its heart, it is the intersection of the complementary efforts of members of the lay community, community non-profit organizations, health practitioners and medical and public health researchers to improve health.

While research advances drive advances in medical care, health care providers and patients often miss out on the benefits of research because they face significant barriers to participation and lack the means to readily translate research advances into everyday clinical practice.

Federal research agencies must work harder to cultivate and support strong collaborative partnerships, based on mutual understanding and trust, between communities and local academic institutions. This can only be achieved by 1) engaging communities as valued members of the research team and 2) by building stable infrastructure within communities not only to ensure their capacity to participate in research but also to implement new knowledge in ways that will lead to better health outcomes and sustainable community change.

To help advance these goals NCRR launched a series of regional workshops focusing on community engagement in research. Beginning in 2007, the first two workshops were held in Bethesda, MD, and Los Angeles, CA, and titled Fostering Collaborative Community-Based Clinical and Translational Research. The initial two workshops brought together more than 200



Steve Woolf, MD, MPH, professor of Family Medicine, Epidemiology and Community Health, Virginia Commonwealth University, presents at the May 9th National Conference

participants from academic institutions, community health care providers and payers, civic organizations and advocacy groups, other NIH Institutes and Centers, and other agencies within the U.S. Department of Health and Human Services (DHHS). Participants discussed barriers to and enablers of effective academic-community partnerships, and set the stage for future national and regional workshops around the country.

In 2008, the CTSA Community Engagement Key Function Committee and NCCR, with funding provided by the Association for Prevention Teaching and Research (APTR) and the Centers for Disease Control and Prevention



Griffin Rogers, MD, MACP, Director, National Institute of Diabetes and Digestive and Kidney Diseases, presents at May 9th national workshop

(CDC) sponsored one national meeting and five regional workshops on community engagement within the CTSA program in 2008 to bring together key stakeholders such as researchers at CTSA sites, community partners and health practitioners. A list of members of the sub-committee that planned the workshops can be found in Appendix B.

The national workshop, “Accelerating the Dissemination and Translation of Clinical Research into Practice” held May 9 in 2008, brought researchers and clinicians together to discuss how best to translate research findings into improved health for all Americans. Over 400 participants from 34 states, 2 Canadian provinces, and South Korea attended the workshop which addressed topics such as defining translational medicine, public-private collaboration, the importance of addressing health disparities, and the role of information technology.

Other workshops were held in St. Louis, MO, Chicago, IL, New York, NY, Philadelphia, PA, and Sacramento, CA during September and October 2008 (See Appendix C).

Each of the 5 regions worked collaboratively to identify a workshop format that best met the needs of their sites and community partners (See Appendix D). Four sites employed a mix of panelist/ podium sessions and breakout groups. The western region used “open space technology” which allowed workshop attendees to determine the agenda for the day when they arrived.⁷

Over the course of these workshops, CTSA sites, aspiring CTSA sites, community partners and collaborators, and national thought leaders collectively worked to define community engagement, articulate challenges and identify potential best practices. While regions vary considerably in the types of populations they serve, their political contexts and the culture of their academic institutions, many common themes emerged that can serve as a

pathway to larger, national improvement of health outcomes.

The main questions to emerge from these discussions across the nation centered on the same theme: How do we conceptualize clinical translation and community engagement? For some in the research community, the question simply involves increasing the pool of participants recruited for clinical trials. For others, it means including their communities into the research agenda. Multiple participants at events remarked that our nation's bookshelves are much healthier than our people as study after study is published but never translated into every day practice.

While everyone agrees that accomplishing better translation of research into health requires a multi-level approach, thought leaders across the nation have conceptualized this

process in different ways.⁸⁻¹² Steve Woolf, MD, MPH, Professor of Family Medicine, Epidemiology and Community Health, Virginia Commonwealth University, spoke at the national conference and likened translational medicine to “blind men feeling an elephant – it means different things to different people.” Over the course of the workshops, it became clear that definitions encompassing all views are broad. Griffin P. Rodgers, MD, MACP, Director, National Institute of Diabetes and Digestive and Kidney Diseases, discussed during his presentation the importance of multi-disciplinary teamwork in prevention research translation. Similarly, community engagement ultimately means linking the work of everyone – at multiple levels of research, medicine, public health and communities – to the goal of improved population health outcomes.

Outcomes:

Over the course of the six community engagement workshops across the country, several commonalities emerged at each meeting that might assist CTSA sites in deepening and strengthening their work in community engagement (see Appendix E). While this list is by no means comprehensive, it is a starting point that incorporates the thinking of researchers and community partners across the nation. Broadly, these practices include: “Changing the Frame,” “Defining Community Broadly,” “Attracting Partners,” “Interacting Successfully with Community Partners,” “Developing a Common Language for Community Engagement,” “Identifying Fundable Roles for Community Partners in Research Grants,” “Developing New Relationships with Data,” “Working with Practice Based Research Networks,” “Integrating Community Involvement into Decision-Making Processes,” “Dissemination: Evolving Beyond Publishing,” and “Building a Pipeline of Community Engaged Researchers.”

Changing the Frame

Traditional biomedical research necessitates planning and controlling for all possibilities from the beginning to the end of a study. True community engagement, however, is an iterative process where both parties negotiate continuously. This shift in the thinking can be radical for researchers both in medicine and public health. Best practices include:

- **Expanding Types of Research Methods.**
Many community partners spoke of the need for medical research to expand beyond the strict randomized control models that often leave the community feeling as if they receive little benefit. Russell Glasgow proposed that research methods evolve to address four key issues: 1) studies should include representative patients rather than the easiest, least complicated patients 2) interventions should be tested in multiple settings, not just AMCs 3) comparison conditions should also offer a treatment, rather than a placebo or no treatment and 4) studies should measure multiple outcomes that matter to clinicians, decisions makers, and community members such as feasibility, implementation, range of applicability, impact on quality of life or benefit relative to existing treatments.¹³ Community members over the course of the workshops also echoed this vision.
- **Community Engagement is an Art and Science.**
Researchers should use skills that are needed for any social interaction and recognize that partnerships and coalitions that help mobilize resources and influence systems, policies, programs and even practices should be guided by real principles and strategies. Letting go of the ability to plan everything and instead

participate in a more iterative process may seem “sloppy” but researchers must overcome this perception.

- **Move from an “Us” to a “We” Orientation.”**

Researchers and community partners should move away from an “us and them” orientation and instead find common goals. If the approach to community engagement always starts with a “research-centric” model, little progress will occur.

- **Community First.**

Too often researchers turn to the community when they find they are having difficulty recruiting people for a trial. Community engagement is the opposite of this approach – it puts the community and its priorities first, not last.

The Importance of Defining Community Broadly

One main set of practices identified was defining exactly who we mean by “community.” There are multiple layers of community partners to work with, including community health practitioners and clinicians, governmental agencies, non-profits, advocacy organizations, schools, religious organizations, jails, neighborhood leaders, etc. The list goes on and on. The consensus at each workshop was that it is crucial to clinical translation that the definition of community be defined broadly:


- **Understand the multiple memberships of a community member.**

Community is a fluid concept, in which membership can be by choice or by innate trait such as gender, race, and sexual orientation. People hold multiple memberships in

communities and researchers should view communities as systems composed of individuals and sectors. For example, if you are partnering with a church– be aware that members intersect with many other areas of the community such as schools,

workplaces, senior centers and governmental agencies. Also, communities are living organisms and not fixed in time. Do not make assumptions that all members of a community will be familiar with and affected by particular events. For example, a protest or collective action during the civil rights era by one group

Understand “Multiple Memberships”



A Community Member Almost Always is a member of several groups. For example, one person might identify as being:

- *a resident of a neighborhood*
- *a member of a religious organization*
- *a member of a racial or ethnic group*
- *an alumni or student of a school*
- *part of an age cohort (ie, young adult, senior citizen)*

in a community that is vitally important might be scarcely noticed by other members.

- **Work with Clinicians Outside of the AHC.**

The majority of care delivered in this country is delivered in private physician's offices, community, homeless, migrant, and school-based health centers, free clinics, and other settings outside of academic centers. Partnering with these professionals – doctors, nurses, physician's assistants, dentists, social workers – in crafting a research agenda and in disseminating results is crucial to the CTSA program's success.

- **Partner with Public Health Departments.**

Both AHCs and Public Health Departments imagine themselves as being “the front line” of health care. They're both right and they both need to work together. Public health departments already have access to epidemiological data, partnerships, funds, and the capability to affect large environmental changes. Challenges to working with this community include the idea that “research is a dirty word,” program evaluation is rarely resourced, as well as fiscal and bureaucratic barriers.

- **Working with children can impact the whole community.**

Attendees talked about the importance of including children in the entire research process – from programs that encourage youth to be interested in science and research to interventions aimed at changing children's behavior. Often, children have a large impact on their entire community – from school staff to parents and grandparents in the community. Adults will rally around policies that help protect kids from behaviors such as smoking – policies that can in turn affect their own behavior. One example offered was a program that addressed the needs of the elderly and children through a school-based program which paired elderly volunteers with schools in need. Volunteers participating showed improved health outcomes; schools appreciated the involvement.

- **Remember that political support begins with community engagement.**

Funding and support at the local, state and national level is influenced by what is perceived to be the needs of the community. Empowered research communities will become empowered health advocates. The greater the number of people included in the process, the greater the number of people who are advocating for better outcomes.

- **Understand the power of community normalization.**

Despair and bad health can become the expected “norm” of a community. For example, a 25-year old patient with obesity and diabetes might tell her physician, “I'm going to end up on dialysis anyway, why bother?” Understanding, questioning and changing community norms is a tremendous challenge in translating science into community gains. But it's wise to remember that what happens in the community is as important as what happens in the doctor's office.

Attracting Partners to the Research Enterprise

One of the largest challenges facing CTSA sites is breaking out of the mindset that community engagement is about attracting partners to studies. True community engagement means drawing more members of the community into the research process and moving beyond transactional, one-way models of recruitment for studies and onto more expansive definitions of partnership. Best practices include:

- **Be aware of the community’s perception.** There is often a long list of perceived benefits of community engagement to researchers but from the community’s perspective, research typically means “guinea pig.” To get to “Yes” researchers need to be honest and clear about the purpose and goal of research; to do homework about the community’s demographics and economics; and to be helpful and humble. The community has the right to self-determination and to decline researchers’ views.
- **Ask the community what it wants.** Invest the time in taking part in community organizing activities and dig deep to find those who typically are underrepresented in research. One approach is to conduct focus groups with underserved populations. Often, researchers will find that the biggest issues are needs not traditionally addressed in the research agenda: mental health, violence and trauma, illicit drugs, depression, stress, and suicide. Many communities, when asked, will express concern with social determinants of health such as poverty, stigma, discrimination, and social exclusion of underserved communities based on historical experiences with government agencies (police, courts, education and social services.)
- **Help to provide expansion and closer coordination of services.** Many sites are working closely with community health centers and primary care providers outside of the AHC to coordinate and improve clinical care. One approach is to include offering technical assistance service to community organizations looking to improve their services. Starting relationships at this point – working to better provide services rather than merely recruiting for studies – provides a solid foundation for partnerships.
- **Host community events.** Another idea is to take the research process out into the community to create spaces where bidirectional exchanges can take place such as “town hall meetings” where AHCs can present their research agenda and structured “speed dating” events in which researchers and community groups seeking research assistance can meet.
- **Identify long-term community leaders.** Instead of thinking in terms of recruitment for single studies, find long-term partners such as neighborhood leaders or clergy members who want to work together on larger outcomes and broader ideas.
- **Creatively use media.** Don’t rely just on bulletin boards, flyers and newsletters for recruitment and dissemination – be creative! Learn how to work with media outlets such as radio, TV and the Internet. Remember that not all community partners have affordable and easy access to the internet. Think about high and low tech ways to

communicate. Also, partner with artists, musicians and playwrights in the community who might have effective non-traditional ways of communicating.

- **Identify and address barriers.**

Numerous barriers exist in community engagement and research including establishing trust, a lack of understanding of research, the researcher's communication style. It is important to identify these barriers and think carefully and collaboratively about how to overcome them.

- **Acknowledge historical mistakes.**

There is a long legacy of historical wrongs in research. Being open about the past and explaining how and why IRBs work to protect the rights of subjects is a better strategy than trying to brush away historical concerns.

- **Raise the prestige of participating in research.**

When you compare research participation to donating blood to the Red Cross, you see that blood donors are often given time off from work to donate and receive buttons, stickers and numerous small 'Thank you' messages. Research participants are not recognized the same way. Researchers should find creative ways of thanking and recognizing research participants.

- **Find ways to reward community engagement within the AHC.**


While most of the best practices in community engagement center on attracting partners outside the AHC, it is also difficult to recruit partners within the AHC. In academia, researchers are rewarded for grant money and publications. AHCs need to expand assumptions about what constitutes success to include community engagement. Faculty should be encouraged and rewarded to work on community engagement.

Learning How to Interact Successfully with Community Partners

Community partners and CTSA researchers attending the workshops had many

Relationship Building in Community Engagement

Key factors for building bridges to community partners



<u>Relationship Building Tools</u>	<u>Relationship Building Plans</u>
<ul style="list-style-type: none">• Time investment• Appropriate <i>listening</i> skills• Appropriate <i>communication</i> skills• <i>Equitable treatment</i> of community and research skills sets	<ul style="list-style-type: none">• Engagement goal setting• Task identification, task assignment, and project monitoring• Small steps approach to creating a research agenda

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conversations regarding cultural "dos and don'ts" and common rules of etiquette when working with community partners. Most attendees agreed that the cultural norms and expectations or academic institutions are often wildly different than the culture of community partners. There is no one clear set of rules given that working with a large corporate partner will be very

different than working with a neighborhood organization, school or physician group. However, there are some general themes that are helpful.

- **Make the time to build un-funded connections.**

Often, building connections when there is not a specific project or grant is the best time to do so. Eliminating the restrictions inherent in having to answer to funding organizations can allow for more creativity and flexibility. For example, many researchers reported joining or forming local health coalitions and groups even though they weren't funded to do so. Forging relationships in these groups without a specific project or agenda in mind both builds trust and enables true partnership when applying for funding.

- **Bi-directional approaches are crucial.**

Top-down and bottom-up approaches to research rarely work. True partnerships involve both partners identifying and formulating the questions.

- **Understand the various meanings of "Power."**

Researchers may assume that education equals "power," yet in some communities power may be based on respect or standing within the community. Researchers need to be aware of different meanings and how communities conceptualize the varieties of power. Open and respectful discussion of power issues can enable people to examine the power dynamics which exist in a community and in a partnership. Sometimes identifying issues and discussing their history can make partners more comfortable talking about such sensitive issues.

- **Sharing power involves respecting what all groups bring to the endeavor.**

Partnerships can be equitable and based on what each organization is able to contribute. Partners can acknowledge each others' contributions by encouraging all to participate in discussions and in making decisions. Participants at workshops emphasized the importance of sensitivity to how groups show respect. Academics rely on listing degrees earned and positions held to communicate power and importance. Partnerships may consider listing members' non-academic degrees and honors, such as positions held in religious organizations or local groups. Omitting everyone's credentials may or may not be appropriate depending on the group. Similarly, the use of first names only instead of "Dr." and "Ms." may or may not be appropriate depending on the group.

- **Include partners in planning.**

It can't be emphasized enough that the planning process should include community partners. Before writing research grants it's important to include community partners in defining the research agenda and in planning new projects. One idea is to develop mission statements with partners. Writing down who will be

**Work Yourself Out of a Job.....But
Leave a Trace....**



Ideally, how do you want a community to remember you were there?

- Improved Health Knowledge & Skills?
- Greater Access to Care?
- Infrastructure or technology such as electronic medical records?

responsible for what part of a project can be a useful tool for forging shared understandings. As partners work on a memorandum of understanding (MOU) they will clarify terminology, expectations and timelines. These MOUs may be revised and renegotiated. Extensive planning processes with communities might include focus groups with the underserved.

- **Pay Community Partners Fairly.**

Community partners should not be expected to volunteer. Find funding roles and mechanisms to make sure people are compensated for their efforts. On the other hand, it's important for AHCs to not "poach" by hiring away employees working for community organizations and offering salaries much higher than community organizations can afford to pay.

- **Food, parking, and parties.**

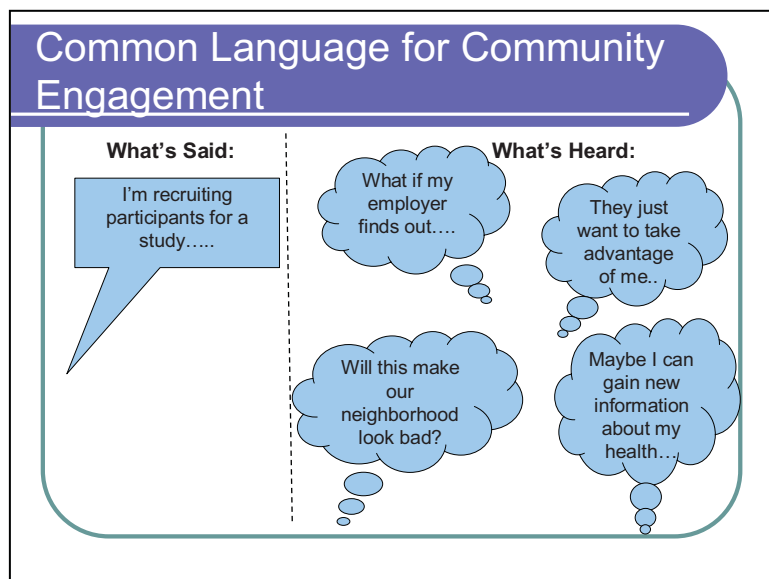
There are a number of tactics that researchers may not think of that are very important to community partners such as holding meetings in settings where it is easy for partners to park or are close to mass transit; providing food and beverages at meetings; offering child care; and remembering to celebrate successes together. Several CTSA sites discussed hosting "appreciation" events for research participants after studies where they can interact with researchers and receive information about the study, and, if applicable, their own disease.

- **Ideally, work yourself out of a job but "leave a trace."**

The goal of community engagement should be empowering the community to take leadership in the betterment of its own health. Instead of swooping in and out of a community like a helicopter, the process of research should always leave behind infrastructure in terms of technology, knowledge and skills in the community. Good research also should leave good outcomes such as improved health or a strengthened sense of trust and connection.

Developing a Common Language for Community Engagement

Finding a way to define community engagement is one of the most pressing challenges facing CTSA grantees as they try to work both with each other and within in their communities. For example, working with each other, we are still trying to collaboratively define levels of translational research that lie beyond bench to bedside (ie, T3, T4).^{8-10, 14} At the community level, we need to bridge the language of research with the language of community partners. Some of the best practices discussed, included:



- **Understand and navigate the differences between multilateral and bilateral communication.** It can be especially

difficult to facilitate meetings with multiple community partners such as local policemen, CEOs and executives and school teachers. Each group has different social norms in how they communicate with each other. To meld multiple cultures it is important to have a conversation at the beginning of meetings about norms, group guidelines, and processes.

- **Listen!**

At every workshop researchers and community partners emphasized the importance of communication and advised listening for a long time to understand what partners want; informing partners when they ask for information. Only after these two steps are complete should researcher try to educate and engage.

- **Don't get lost in translation.**

Workshop participants pointed out that too often grant money is tied to using certain “magic” words that work for grants. It is important to not lose sight of the end goal of population health when “wordsmithing” grants.

Identifying Fundable Roles for Community Partners in Research Grants:

Community partners—whether they are a physician group, a non-profit neighborhood improvement organization or a public health clinic—are often skeptical of partnerships with academic institutions that expect engagement without compensation. Partnership involves sharing resources and AHCs should not expect participation without compensation. But sorting out the accounting hassles of sharing grant money is challenging. Best practices discussed include:

- **Consider sub-contracts to and from partners.**

When writing grants and working with foundations, work with the community in planning and establish ways to share money. If partners haven't been identified in this stage, write in salary support for a consultant. Establish upfront guidelines for sub-contracts such as how to track spending and activities, how to document receipts, etc.

- **Provide and encourage “how-to” training in your institution.**

Participants in workshops suggested offering training to accounting staff within the AHC on reporting rules for FTEs and financial requirements. It is also often necessary to provide community partners with similar training and technical assistance for their accounting staff as well.

- **Consider a variety of structures.**

Fundable roles for community partners are not “one size fits all” solutions and

Share Funds with Partners

Sharing Resources and Funds Requires Creativity and Diligence!

- Provide training for accounting staff within the institution
- Provide technical assistance to partner organizations
- Consider pilot projects



each situation will vary. What works for a physician group will not work for a non-profit activist group. Be flexible.

- **Pilot Projects.**

Provide funding for community partners to design their own pilot projects. Sponsoring these projects allows community partners to identify their own research agenda and methods but couples their efforts with funding and technical assistance at the institutional level. While not all of these projects will work, this laboratory approach is likely to yield bottom-up ideas that can truly affect overall outcomes at the community level.



Developing New Relationships with Data

When community partners work with AHCs on research, who owns the data? Traditional research takes a sort of “mining” view of data in which information provided by the community gathered is the property of researchers. Community partners, however, might feel resentful that they don’t have access to this information. For example, people who are HIV-positive and participating in a study might express frustration when they feel like they literally gave up “their blood, sweat and tears” and then are left without the cutting-edge information they are eager to receive. Best practices discussed include:

- **Customize research in a way that works for the community.**

Sometimes evidence-based recommendations will not fit the needs of specific communities. For example, Native Alaskans contract a much deadlier strain of pneumonia than the general population and are better served to get vaccines more often than other groups. The Indian Health Service (IHS) was able, using data, to recognize this and customize recommendations for this specific community.

New Relationships with Data

<u>Old Model:</u>	<u>New Model:</u>
<ul style="list-style-type: none">•Data is the sole property of the researcher•Dissemination is through academic journals•Privacy and proprietary concerns trump sharing	<ul style="list-style-type: none">• Data is the shared property of the community•Dissemination is provided with or without journal-worthy results•Privacy is protected, academic proprietary needs are addressed AND data is freely shared.
	

- **Use**

- measurement to change practice.**

Although intimate partner violence in IHS communities has been prevalent for years, it was difficult to persuade physicians to screen patients for it. By measuring whether or not physicians were asking patients about violence, screening rates went

from 1% in 2004 to 80% in 2007. Workshop participants working with practice-based research networks also discussed the need to focus data on what will help rather than hinder how clinicians provide care.

- **Remember that the primary goal of data collection is to help the community.**

In the IHS system, data is the property of the people who contribute to it and is used to help improve their lives. While data exists in the IHS system, patients own it. If any member of the community asks for data, IHS runs the report. Other participants, particularly community partners, talked about the need for greater data sharing with members of the community. Privacy concerns and proprietary rules often prevent this sharing, but it is important to find compromises.

- **Build in Plans for Null or Negative Results.**

Too often null or negative results from a study will never get published or disseminated. However, this information might be of great use to community partners who would like to further the study. Build in contingency plans for this scenario into the IRB and study protocol.

Working with Practice-Based Research Networks (PBRNs)

Physicians and other health care providers working outside of the AHC are often the keystone to effecting a true change in outcomes. PBRNs are uniquely equipped to both help define the research agenda, participate in research and translate findings quickly into practice. Each workshop featured PBRN speakers and attendees who were knowledgeable about the importance of working with these groups. Best practices included:


- **When working with PBRNs understand what doctors need and want.**

PBRN projects must be a two-way street. Bottom-up approaches rarely work and top-down approaches only work in a fee-based model such as pharmaceutical trials. True success comes only with partnership. Research that has the most impact 1) asks the questions physicians want answered 2) allows flexibility and physician involvement 3) leaves behind paths for physicians to change practice (technology, information, etc).

Work with the Entire Practice

The extra burdens of research do not solely affect the physician. Remember to work with everyone in a practice:

- Nurses & PAs
- Administrative Assistants and Schedulers
- Pharmacists
- Lab technicians
- Social workers
- Dietitians



- **Primary care physicians are looking for root causes.**

Primary care physicians, who see ever rising rates of chronic illness, want help in finding ways to prevent illness. Research agendas need to reflect helping physicians to work with their patients to prevent illness.

- **Remember to work with an entire practice not just individual physicians.**

Working with a physician researcher also involves working with that doctor's nurses, physician assistants, administrative assistants, billing clerks and other staff. Build in the time to explain studies to everyone in the practice. This will not only help to smoothly facilitate the process, but also will help to more quickly disseminate findings and change practice.

- **Partner with Health Center Controlled Networks**

Networks of health centers exist in most states and are increasingly interested in participating in research. These groups are coalitions of health centers which work together to implement health information technology and many are funded by HRSA. Although these networks are controlled by health centers, they often involve other providers, such as hospitals, health departments, and specialty care providers, in order to assure the continuity of care for health center patients. Their data collecting ability and community connections make them ideal partners to consider. Most of these networks are not practice-based research networks, but would be good partners for PBRNs.

Integrating Community Involvement Into Decision-Making and Review Processes

To truly include community partners in setting and carrying out the nation's research agenda, partners should be represented at every level of decision-making, including institutional review boards (IRBs). Inclusion at this level is complex and participants emphasized that there are no easy answers in this area. Best practices identified include:

- **Address barriers to including community members on the IRBs.**
A number of questions need to be posed and answered when trying to incorporate community members into IRBs. For example, should institutions work with communities to set up their own community-run IRBs or include community members on their AHC IRBs? What constitutes a "community member"? Whose role is it to educate the IRB about community concerns? Who is accountable if a study goes wrong?
- **Provide training for community members.**
Offer community members training on how the IRB process works. Remember that community members do not have the "soft perks" for participating in an IRB that faculty members do to make up for lack of compensation of time. Training should be convenient and accessible to community members
- **Get Help!**
There are a number of resources and expertise available to institutions wanting to include community perspective in their IRB process. NIH sponsors conferences on alternative IRB models. Find institutions that have overcome barriers and

exchange best practices. Provide training on community-based participatory research for IRB members or recruit IRB members who have that training.

- **Consider Giving Decision-Making Control to Community for Funding**

Some sites are setting up External Review Committees that give community representatives decision-making control over funding priorities and create incentives to address community-driven research priorities.

Dissemination: Evolving Beyond Publishing

To truly include community partners in setting and carrying out the nation’s research agenda, dissemination plans and strategies need to evolve beyond traditional medical journals. While AHCs reward researchers for how often they publish, journal articles do not always trickle down to the community level. Instead researchers must work with their partners to creatively push their information in a variety of ways. Best practices in dissemination include:

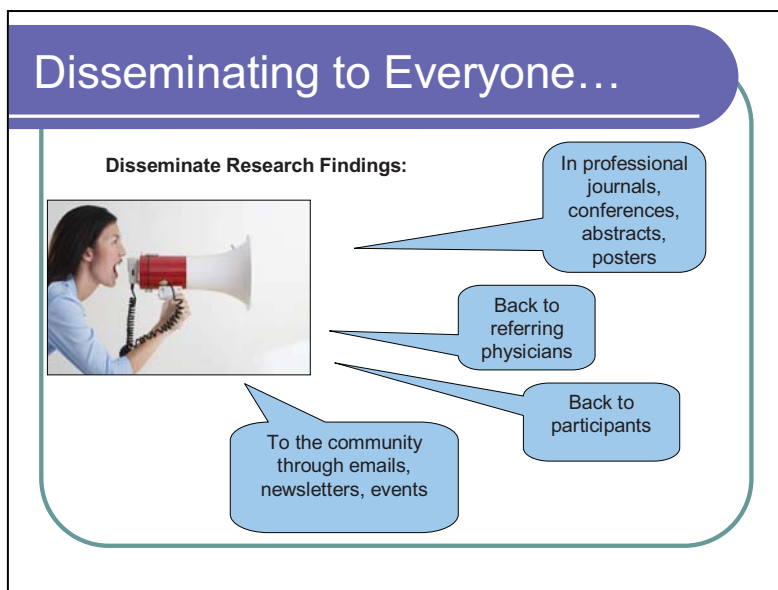
- **Dissemination plans should be part of the grant application process.**

Planning for dissemination at the beginning stages of a study – thinking through privacy and ethical concerns or reporting back results, best modes of communication for the intended audience, and how to time when information is released – is crucial. But rarely are researchers encouraged or rewarded for this effort. Participants recommended that funding organizations require and reward dissemination plans when scoring grant applications. In addition, funds should also be allocated for dissemination.

- **Start at the IRB Level.**

IRB considerations sometimes prohibit researchers from contacting research participants directly without their consent. Consider “opt-in” provisions in IRBs (“Is it OK to contact you with results?”) to encourage more participants to receive information. Work with IRBs at the beginning stages of a project to address this.

- **Disseminate information/outcomes back to the community throughout a study**



One challenge of research is giving community members information in a timely and useful way so that they get knowledge out of the experience. Too often, waiting until the end of a study to report outcomes will be too late to keep

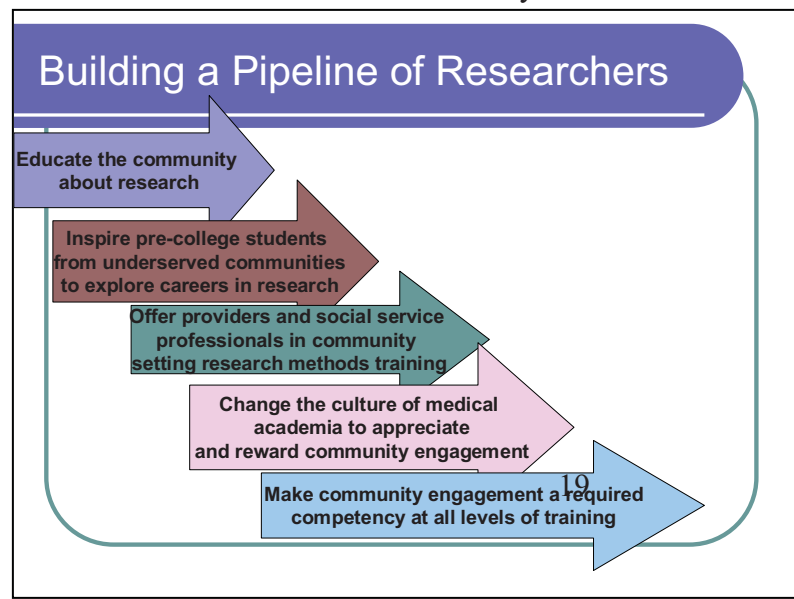
participants engaged. Find ways to keep partners updated throughout the process.

- **Don't Forget Referring Physicians**
Community physicians are often overlooked at the end of studies. If they aren't highly motivated to do research, they might be unlikely to refer patients for further studies if they are never informed of study outcomes. Do not forget referring physicians in dissemination strategies as they are vitally important to 1) translating findings into improved care 2) referring future patients for future studies.
- **Provide information to the community outside of studies.**
CTSA sites are trying to engage the community in the research process through list-servs, regular emails, newsletters, "open mic" nights and other venues that highlight a variety of research findings, instead of using a "study-to-study" approach. One idea is to explore using social media marketing (not to share confidential info) but to reach larger audiences – especially youth. It's important to think carefully about the best modes of communication and take into consideration the sensitivity of the information, the literacy levels and access to technology of the audience and interest of the audience.
- **Study dissemination strategies**
Participants at workshops discussed the need for more information about dissemination. For many researchers this is uncharted territory. While marketing, journalism, public relations and other disciplines can help, AHCs should start evaluating their own best dissemination practices and sharing with each other.

Build a pipeline of community-engaged researchers

Long-term, committed partnerships between communities and research institutions requires building a training pipeline that sparks interest in research in pre-college students, makes community engagement a required competency for doctoral and medical student, and rewards researchers for community-engaged projects that lead to improved outcomes. Best practices include:

- **Partner with educational organizations in the community.**
Work with museums, zoos, aquariums, libraries, schools, arts organizations and schools to host events, lecture series, health fairs, symposiums etc. and educate the community about health research. Do this both to educate the community at-large about research in a fun and recreational way, as well as to encourage young people (particularly those from communities underrepresented in medical research) to consider careers in health care research.
- **Work with Area Health Education Centers (AHEC)**
The Health Resources and Service



Administration (HRSA) funds 53 AHECs programs and 221 affiliated AHEC Centers in 45 states and the District of Columbia. These centers offer key links to educating health providers who might not typically be engaged in the research process.

- **Provide incentives for researchers to do community- engaged work.**

Workshops attendees lamented the barriers within their own academic institutions to community-engaged research. As discussed in this monograph, true community engagement takes time, money and patience. Its benefits are often not seen for years and making the case to decision makers at AHCs is not easy. But changing the culture of academia is essential. AHCs must be creative in how they measure success (ie, dissemination strategies that reach the community vs. number of journal articles published) of young faculty and how they compensate work.

- **Make community engagement a competency at all levels of training.**

Provide training for all university students/researchers doing community engagement through required coursework, self-paced modules and certification. Work to train IRB administrators and clinical researchers used to traditional research terminology in the language of community engagement. For example, resistance to using “participant” instead of “subject” requires discussions of the changing relationships among researchers, community organizations, and agencies and marginalized groups.

- **Provide research training for community members.**

Train researchers about community engagement, but also train community members to do research. One example is to offer a community-based research traineeship to develop the research capacity of medical and social service professionals who service underserved neighborhoods but have limited research experience.

Discussion:

In October 2008, the CTSA Steering Committee through a strategic planning process realigned the overall consortium into four main goals.

1. Enhancing National Clinical and Translational Research Capability
2. Enhancing the Training and Career Development of Clinical and Translational Scientists
3. Enhancing Consortium-Wide Collaborations
4. Enhancing the Health of Our Communities and the Nation

Of the four goals identified, Goal 4 is the main focus of the Community Engagement Key Function Committee (KFC). At a Face-to-Face community engagement KFC meeting held Oct. 24th, 2008, participants discussed this goal's two main components: 1) Developing a National Model for Community Engagement and 2) Informing Public Health Policy through Research. Over the coming year, Community Engagement KFC members (See Appendix B) will work to coordinate efforts for this goal and its elements.

Community engagement and advocating for larger policy changes at the structural level is new territory for many researchers. Throughout the workshops, attendees suggested that tackling these larger goals requires that CTSA look to organizations outside of academia that are highly successful in community engagement and translation of research.

Many speakers discussed the drug detailing model in the pharmaceutical industry and challenged attendees to

think of ways that academia can be as successful in disseminating health research information to physicians and the general public as the pharmaceutical industry. How can the research community establish itself as “honest brokers” that successfully bridge clinical research to clinical practice and improved population outcomes?

Other attendees, particularly those from

CTSA Strategic Goals

- **Goal 1:** Enhancing National Clinical and Translational Research Capability
- **Goal 2:** Enhancing the Training and Career Development of Clinical and Translational Scientists
- **Goal 3:** Enhancing Consortium-Wide Collaborations
- **Goal 4:** Enhancing the Health of Our Communities and the Nation

more rural communities shaped by a tradition of agriculture, encouraged the CTSA to emulate the USDA Cooperative Extension Model. While the original mission of this program was disseminating information to individual small farms, the program now serves farming and non-farming communities alike. It draws on the collective strength of an entire community and dedicates resources to providing information. One participant suggested that the Agency for Health Care Research and Quality (AHRQ) provide extension agents in all areas of the country to provide physicians and

their communities with the best information and education.

Participants throughout the workshops discussed the importance of diffusion theory and stressed some of the key principles illustrated in the work of Everett Roger's "Diffusion of Innovation"¹⁵ and Malcolm Gladwell's "The Tipping Point."¹⁶ For innovation to "stick" it needs to be "trial-able" for physicians and the community.

Also, it is important to identify and nurture the right partners. Just as a good pharmaceutical sales person can influence the uptake of a new drug, the right community partner can help encourage her neighbors to prevent the onset of diabetes. Finding the right advocate can speed diffusion.

Partnering with practicing clinicians working outside of the AHC and within the community is an important challenge. The vast majority of medical care in this country is delivered by community-based practitioners, not those located in AHCs. If we are to truly change the delivery of health care, we must effectively engage these clinicians to help them provide evidence-based care that is tailored to the needs of each individual in the community. Practice-based research networks are a useful tool to involve clinicians in research, but most clinicians will never participate in such a network. Other approaches are also needed. The factors that determine the practices of clinicians are poorly understood, and research helping us better understand how changes in clinical practice are disseminated, adopted, implemented, and maintained represents an exciting opportunity. CTSA's should be viewed by practicing

clinicians as a resource that provides them with the tools that they need to take the best care of every patient every day.

Researchers must also work to fight context. As seen in the rapid rise in national obesity, norms of what is healthy can shift. To truly effect change we need to examine the context in which communities are living their lives.

Diffusion is not just important in the community at-large, it is also crucial within the CTSA community. There is strength in partnerships with communities outside of academia but also strength within. It is not easy to breakout of the mindset of constant competition for grant money and prestige, but to truly affect population outcomes overall we must share ideas.

Conclusion:

At each regional workshop, the strongest message from researchers who have been successful in community research was the importance of understanding that community engagement is a long-term commitment. At one workshop, participants likened "engagement" to romantic relationships in which two people commit to a lifetime of partnership; while at another they likened partnership to "glue."

Another analogy offered: what happens when there is a knock at your front door? Is the person a "wanted stranger" – someone offering to help – or is someone selling you something you don't want and didn't ask for?

For many researchers, who have lived highly competitive, intellectually fast-paced lives, community engagement

requires a mindset that has never previously been rewarded in their careers: being patient, being humble, leading from behind instead of ahead of a project. But to affect national change and achieve overall improved health outcomes, CTSA sites must shift how they work.

To truly achieve outcomes that matter – improved quality and access to care, prevention of disease, and safer, healthier, happier communities (as well as new treatments that save lives) – researchers and their institutions must shift from the mindset of thinking of “the community” as a means to an end – carrying out clinical trials – to the end goal itself.

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APPENDIX A: Community Engagement Workshop Planning Committee Members

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- Bernadette Boden-Albala (Columbia University)
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- Jenny Cook (Duke University)
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- Fred Taylor (NIH/NCRR)
- Molly White (University of Michigan - Ann Arbor)
- Linda Ziegahn (University of California- Davis)
- David Warner (Mayo Clinic)

APPENDIX B: Clinical Translational Science Awards (CTSA)

Institutions

Since 2006	Since 2007	Since 2008
<ul style="list-style-type: none"> • Duke Translational Medicine Institute Duke University • Irving Institute for Clinical and Translational Research Columbia University • Mayo Center for Translational Science Activities Mayo Clinic • Oregon Clinical and Translational Research Institute Oregon Health & Science University • Rockefeller University Center for Clinical and Translational Science The Rockefeller University • The UCSF Clinical and Translational Science Institute University of California, San Francisco • UC Davis Clinical and Translational Science Center University of California, Davis • University of Pennsylvania Institute for Translational Medicine and Therapeutics University of Pennsylvania • University of Pittsburgh Clinical and Translational Science Institute University of Pittsburgh • University of Rochester Clinical and Translational Sciences Institute University of Rochester School of Medicine and Dentistry • University of Texas Houston Center for Clinical and Translational Sciences University of Texas Health Science Center at Houston • Yale Center for Clinical Investigation Yale University 	<ul style="list-style-type: none"> • Atlanta Clinical and Translational Science Institute (Atlanta-CTSI) Emory University (partnering with Morehouse School of Medicine and Georgia Institute of Technology) • CTSA at Case Western University Case Western Reserve University • CTSA at Weill Cornell Medical College Weill Cornell Medical College (partnering with Hunter College) • Johns Hopkins Institute for Clinical and Translational Research Johns Hopkins University • Michigan Institute of Clinical and Health Research University of Michigan at Ann Arbor • North and Central Texas Clinical and Translational Science Initiative University of Texas Southwestern Medical Center at Dallas • The University of Chicago Institute for Translational Medicine University of Chicago • University Of Wisconsin - Madison Institute for Clinical and Translational Research University of Wisconsin – Madison • University of Iowa's Institute for Clinical and Translational Science University of Iowa • University of Washington Institute of Translational Health Sciences University of Washington • Vanderbilt Institute for Clinical and Translational Research Vanderbilt University (partnering with Meharry Medical College) • Washington University Institute of Clinical and Translational Sciences Washington University in St. Louis 	<ul style="list-style-type: none"> • Albert Einstein-Montefiore Institute for Clinical and Translational Research Albert Einstein College of Medicine (partnering with Montefiore Medical Center) • Clinical and Translational Science (BU-BRIDGE) Institute Boston University • Colorado Clinical and Translational Sciences Institute University of Colorado Denver • Harvard Catalyst: The Harvard Clinical and Translational Science Center Harvard University • Indiana Clinical and Translational Science Institute Indiana University School of Medicine • Institute for Integration of Medicine and Science (IIMS) The University of Texas Health Science Center at San Antonio • North Carolina Translational and Clinical Sciences (TraCS) Institute The University of North Carolina at Chapel Hill • Northwestern University Clinical and Translational Sciences Institute Northwestern University • The Ohio State University Center for Clinical and Translational Science The Ohio State University • The Scripps Translational Science Institute The Scripps Research Institute • The Stanford Center for Clinical and Translational Education and Research Stanford University • Tufts Clinical and Translational Science Institute Tufts University • UAB Center for Clinical and Translational Science The University of Alabama at Birmingham • University of Utah Center for Clinical and Translational Science The University of Utah

APPENDIX C: Workshop Details

Hosting Institution/ Date:	CTSA sites in attendance:
NIH-NCRR Bethesda, MD May 15 th , 2007	Representatives from CTSA Institutions and other organizations.
NIH-NCRR Los Angeles, CA September 14 th , 2007	Representatives from CTSA Institutions and other organizations.
NIH-NCRR/APTR/CDC Bethesda, MD May 9 th , 2008	Representatives from CTSA Institutions and other organizations.
Washington University in St. Louis/ St. Louis, MO September 5 th , 2008	Duke University Emory University University of Alabama – Birmingham University of North Carolina – Chapel Hill University of Texas – San Antonio University of Texas – Houston University of Texas – Southwestern Vanderbilt University-Meharry Medical College Washington University in St. Louis
University of Chicago/ Chicago, Ill. September 12 th , 2008	University of Iowa University of Wisconsin University of Indiana Mayo Clinic Northwestern University Participants The University of Chicago The University of Michigan
Weill Cornell Medical College/ New York, NY September 25 th , 2008	Albert Einstein, College of Medicine Boston University Columbia University Cornell University Harvard School of Public Health University of Rochester The Rockefeller University CCTS Tufts Medical College Yale University
University of Pennsylvania/ Philadelphia, PA October 13 th , 2008	Case Western Reserve University Ohio State University Johns Hopkins University of Pennsylvania University of Pittsburgh
University of California – Davis Sacramento, CA Oct 17 th , 2008	Oregon Health and Science University Scripps Research Institute Stanford University University of California - Davis University of California, San Francisco University of Colorado University of Utah University of Washington

APPENDIX D: Workshop Agendas

APPENDIX E: Index of Best Practices

For the purposes of this document “Best Practices” is defined as a set of approaches to community engaged research gleaned from the 2007-2008 Community Engagement National and Regional workshops.

Best Practice Area	Practice Actions and Strategies
Changing the Frame p. 6	<ul style="list-style-type: none"> • Expanding types of research methods • Community engagement is an art and a science. • Move from an “Us” to a “We” orientation. • Community first.
The Importance of Defining Community Broadly p. 7	<ul style="list-style-type: none"> • Understand the multiple memberships of community. • Work with Clinicians Outside of the AHC • Partner with public health departments. • Work with children to impact the whole community. • Remember that political support begins with community engagement. • Understand the power of community normalization.
Attracting Partners to the Research Agenda p. 8	<ul style="list-style-type: none"> • Be aware of the community’s perception. • Ask the community what it wants • Help to provide expansion and closer coordination of services. • Host community events. • Identify long-term community leaders. • Creatively use media. • Identify and address barriers. • Acknowledge historical mistakes. • Raise the prestige of participating in research • Find ways to reward community engagement within the AMC.
Learning How to Interact Successfully with Community Partners p. 10	<ul style="list-style-type: none"> • Make time to build un-funded connections. • Bi-directional partnerships are crucial. • Understand the various meanings of “power.” • Sharing power involves respecting what all groups bring to the endeavor. • Include partners in planning. • Pay community partners fairly. • Food, parking and parties. • Ideally, work yourself out of a job, but leave a trace.
Developing A Common Language for Community Engagement p. 12	<ul style="list-style-type: none"> • Understand and navigate the differences between multilateral and bilateral communication. • Listen! • Don’t get lost in translation.

<p>Identifying Fundable Roles for Community Partners in Research Grants p.13</p>	<ul style="list-style-type: none"> • Consider sub-contracts to and from partners. • Provide and encourage “how-to” training in your institution. • Consider a variety of structures. • Pilot projects.
<p>Developing New Relationships with Data p. 14</p>	<ul style="list-style-type: none"> • Customize research to work for the community. • Use measurement to change practice. • Remember that the primary goal of data collection is to help the community. • Build in plans for null or negative results.
<p>Working with PBRNs p. 15</p>	<ul style="list-style-type: none"> • When working with PBRNs, understand what doctors need and want. • Primary care physicians are looking for root causes. • Remember to work with an entire practice and not just individual physicians. • Partner with Health Center Controlled Networks
<p>Integrating Community Involvement Into Decision-Making and Review Process p. 16</p>	<ul style="list-style-type: none"> • Address barriers to including community members on IRBs. • Provide training for community members. • Get Help! • Consider giving decision-making control to community for funding.
<p>Dissemination: Evolving Beyond Publishing p. 16</p>	<ul style="list-style-type: none"> • Dissemination plans should be part of the grant application process. • Start at the IRB Level. • Disseminate information/outcomes back to the community throughout a study. • Don’t forget referring physician. • Provide information to the community outside of studies. • Study dissemination strategies.
<p>Build a Pipeline of Community Engaged Researchers p. 18</p>	<ul style="list-style-type: none"> • Partner with educational organizations in the community. • Work with AHECs. • Provide incentives for researchers to do community engaged work. • Make community engagement a competency at all levels of training. • Provide research training for community members.

APPENDIX F: Suggested Literature

Reports by the NIH Directors Council of Public Representatives (COPR)

- Community Engagement Framework for Peer Review Guidance: Peer Review Criteria for Assessing Community Engagement in Research Proposals
http://copr.nih.gov/reports/Peer_Review_Framework_508c.pdf
- Community Engagement Framework for Development of Education/Training for Researchers: Values, Strategies, and Outcomes for Investigators Who Want to Engage Communities in Their Research
http://copr.nih.gov/reports/Comm_Eng_Educ_Framework_508b.pdf
- COPR Role of the Public in Research Work Group, Presented to NIH Director, October 31, 2008
http://copr.nih.gov/reports/Definitions_of_CE_and_PP_Revised_508.pdf

Community Based Participatory Research

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