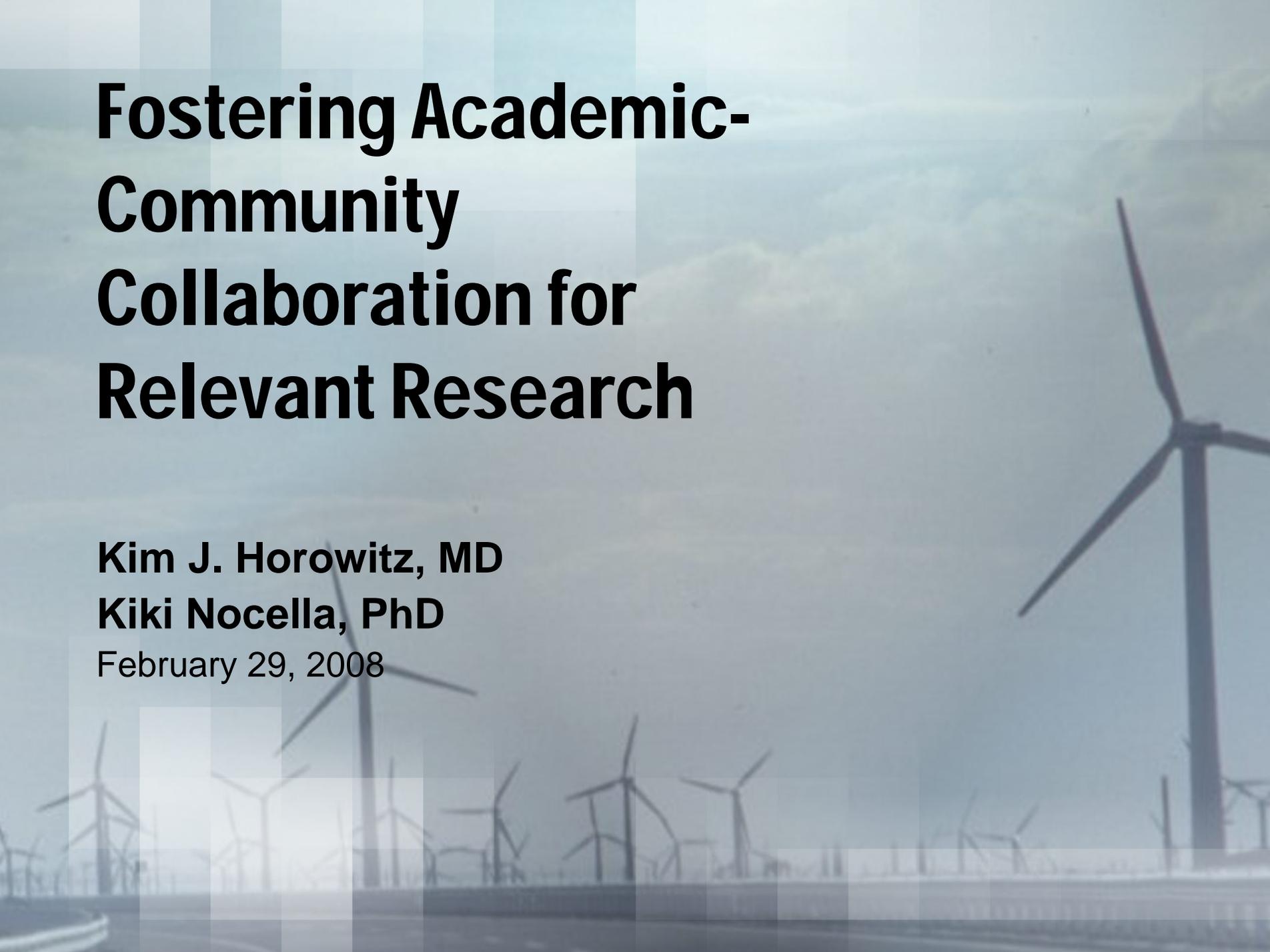


Fostering Academic- Community Collaboration for Relevant Research

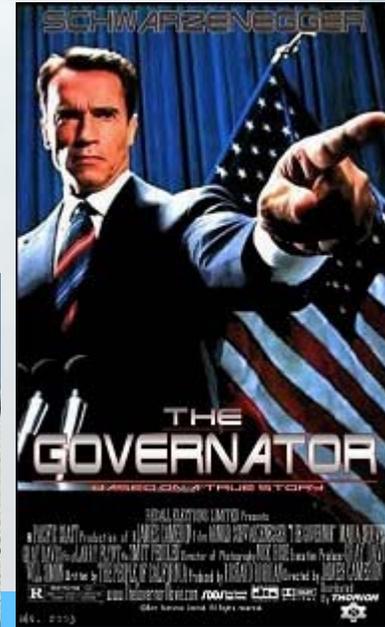
Kim J. Horowitz, MD

Kiki Nocella, PhD

February 29, 2008



Rural California



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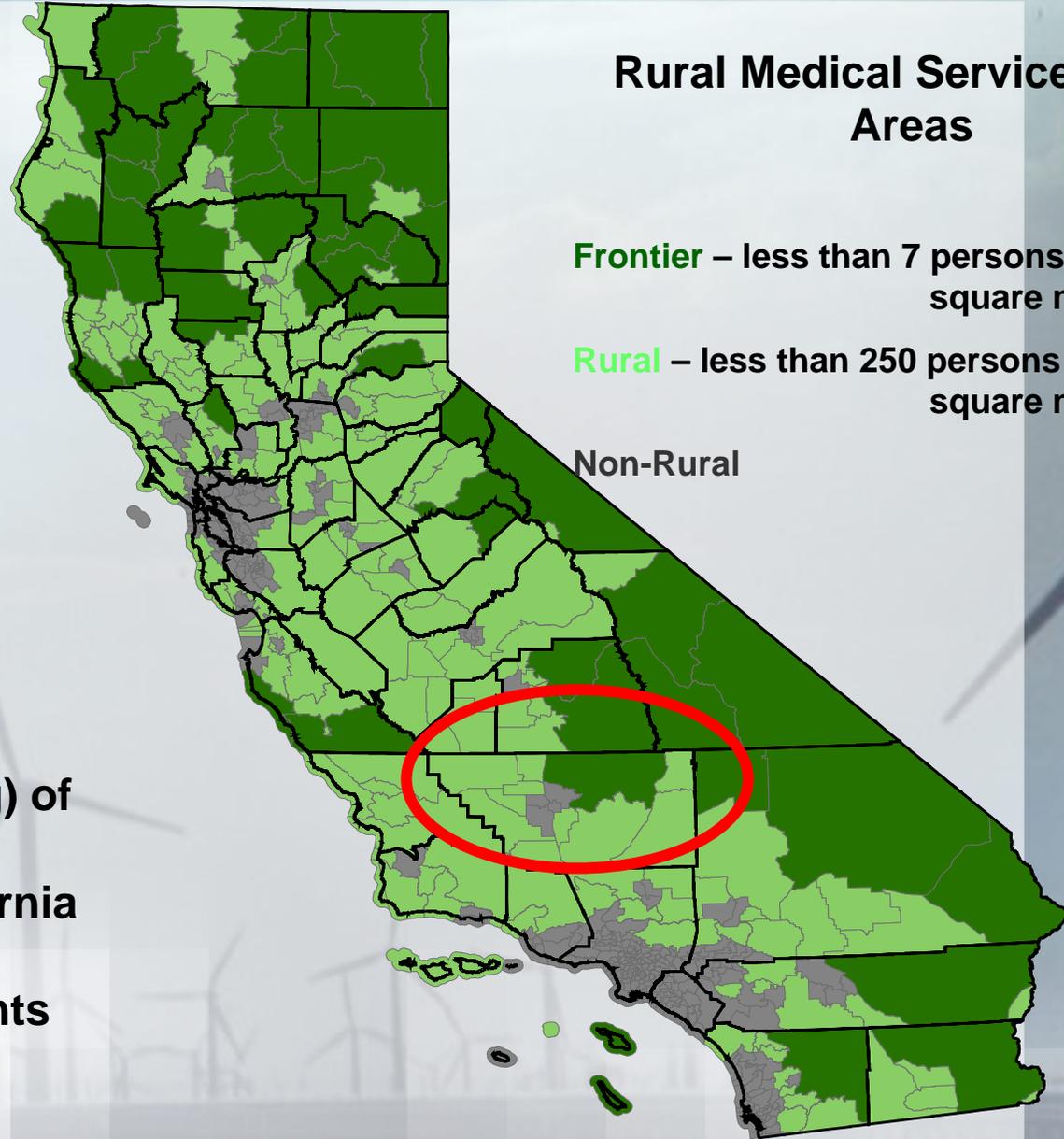
Who we are

Rural Medical Service Study Areas

Frontier – less than 7 persons per square mile

Rural – less than 250 persons per square mile

Non-Rural



**80% of land mass
14% (and growing) of
population
live in rural California**

4.9 million residents

Source: 2000 census data

Pacific Ocean

Proximity

	distance	travel time*
Local Airport		
City of Tehachapi Public Airport	in town	< 5 min.
Commercial Airport		
Meadows Field/Bakersfield	45 mi.	50 min.
Burbank	112 mi.	1.5 hrs.
Ontario	128 mi.	2.5 hrs.
International Airport		
Los Angeles International	130 mi.	2.5 hrs.
Rail		
Burlington Northern & Union Pacific: Piggy Back Service/Fresno	150 mi.	varies
Piggy Back Service/Los Angeles	120 mi.	varies
Motor Freight		
Interstate 5 North/South interchange	65 mi.	1 hr.
Highway 58 East/West	local	< 5 min.
Highway 14 North/South	20 mi.	30 min.
Highway 99 North/South	45 mi.	45 min.
Highway 40 East/West	86 mi.	1.5 hrs.

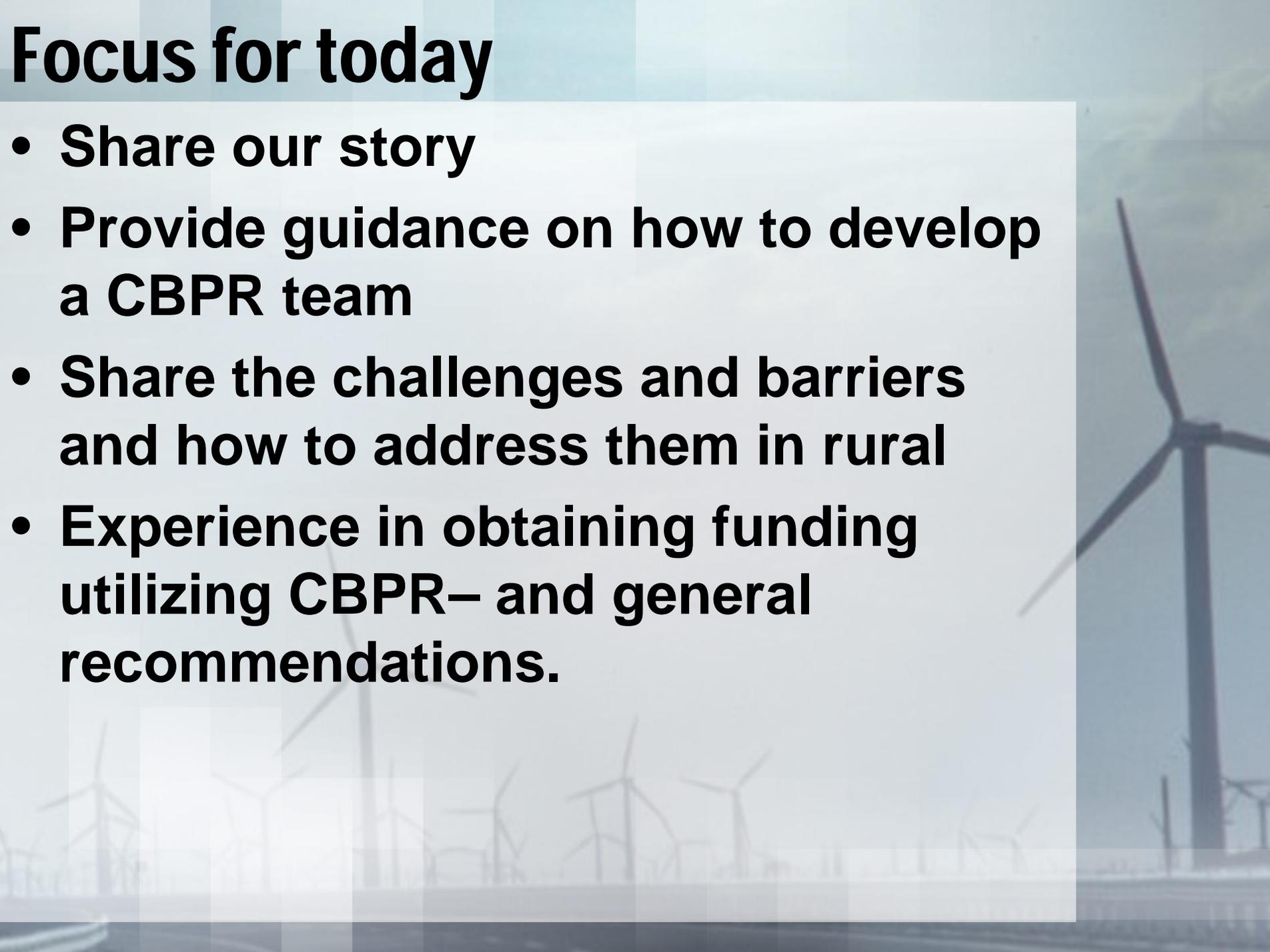
*Average



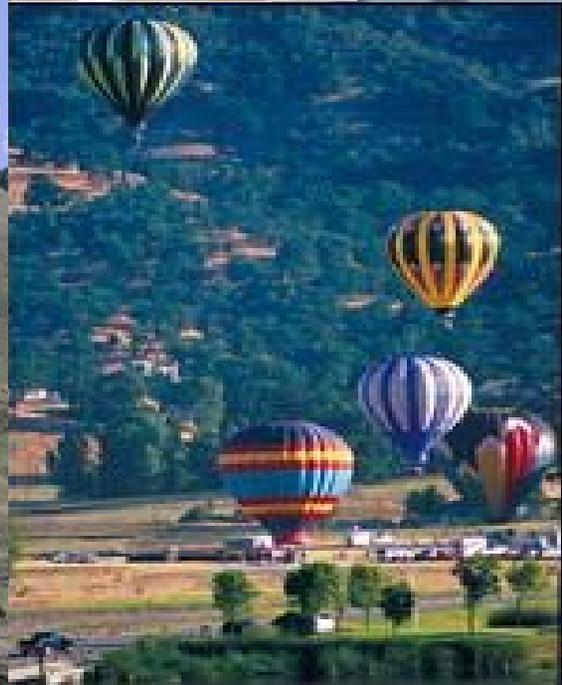
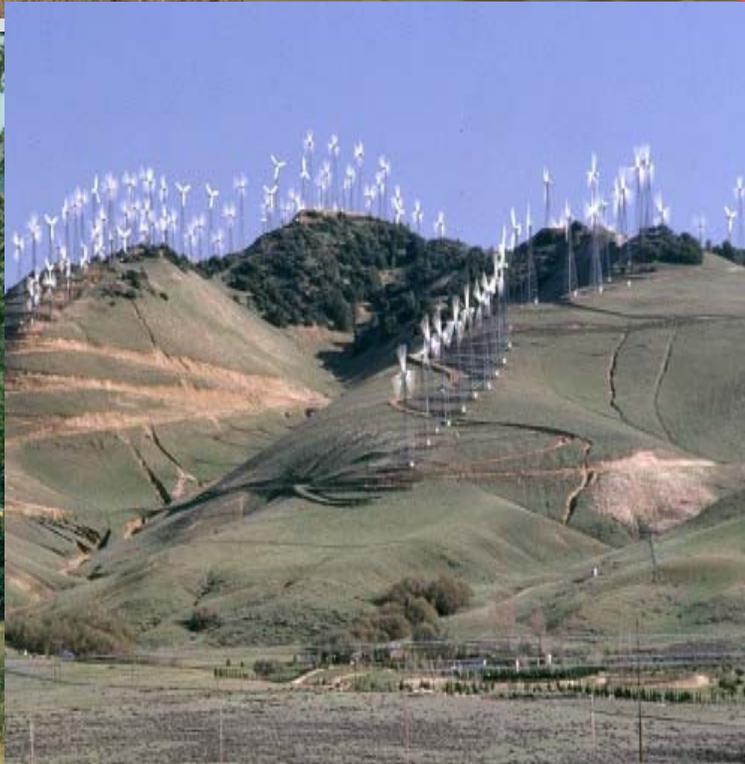
MEXICO

Focus for today

- **Share our story**
- **Provide guidance on how to develop a CBPR team**
- **Share the challenges and barriers and how to address them in rural**
- **Experience in obtaining funding utilizing CBPR– and general recommendations.**



Our Story



In the beginning.....

- **Academia meets Tehachapi**
- **President Bush – “Paperless by 2010”**
- **Agency for Healthcare Research and Quality funded initiatives**
 - **September, 2004 – 1 year planning**
 - **September, 2005 – 3 year Implementation grant**
 - **Purpose is to “promote the use of health information technology (health IT) to”**
“Increase our knowledge and understanding of the clinical, safety, quality, financial, and organizational value and benefits of health IT”.
 - **CBPR was required**

Status of IT in the Region - 2005

- **Approximately 17 primary care physicians and 7 midlevels in 17 sites in 4 towns**
- **Various stages of IT adoptions**
 - **Some with no computerized practice management systems**
 - **Some without internet access**
 - **No customized databases**
- **One with an EHR**
 - **No data exchange occurring**
 - **System not being used for reporting**
- **Hospital with multiple systems at different levels of functionality and not interfaced**

Scope of our Project

- **Infrastructure**
- **Telemedicine**
- **EHRs and CHIE**
- **PHRs**
- **Diabetes Education**
- **Health professions training**



Imagine for a moment

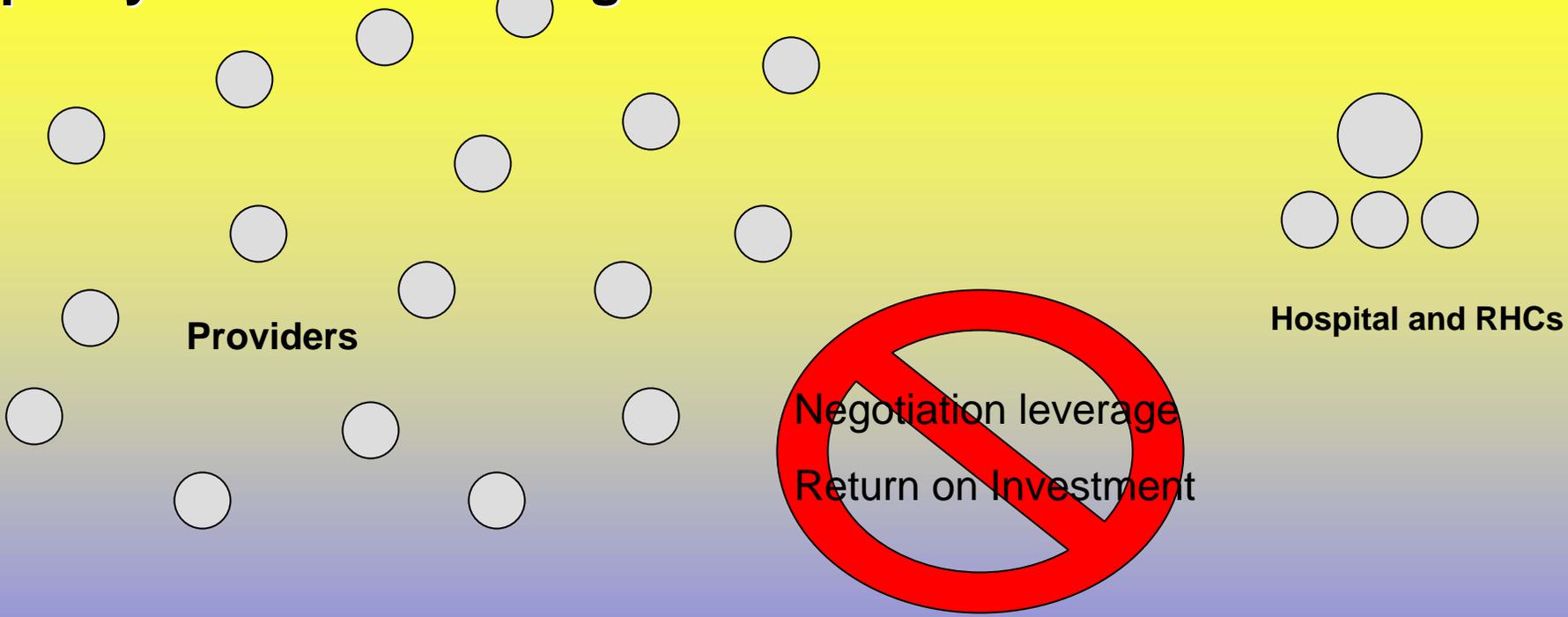
- That you are a rural community planting the seeds and tending the delicate garden that is your health care delivery system
- How would you design your medical landscape?



This is what happens when there is a lack of unified effort, goal, direction, or effective communication over time

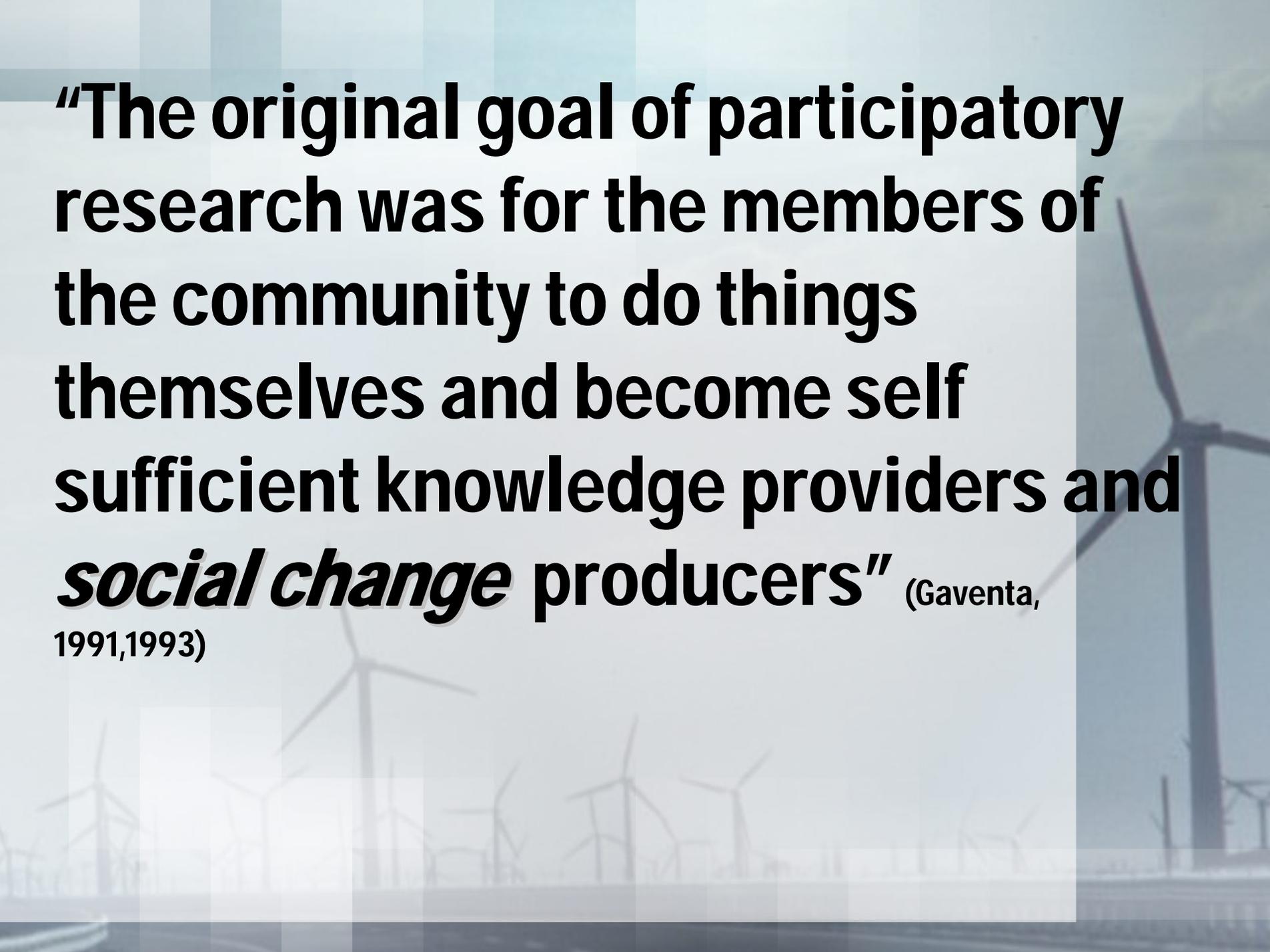


Before....no infrastructure to facilitate information technology, quality or disease management



Presence of consistent and coordinated community oriented approach ???

- ~~Acquisition and Dissemination of information technology~~
- ~~Community Based Quality Improvement Programs~~
- ~~Continuing Education~~
- ~~Research~~
- ~~Practice Management Support~~
- ~~Evidence Based Medicine~~
- ~~Workforce Development~~



“The original goal of participatory research was for the members of the community to do things themselves and become self sufficient knowledge providers and *social change* producers” (Gaventa, 1991,1993)

Finding Our Special Purpose

- Did we have a common purpose?
- or Conflicting purposes?
- Where was the intersect?
 - Research question with AHRQ.....**what does it take to implement HIT in rural?**
 - **Community identified economic and IT inefficiencies**
- HIT implementation could provide:
Accurate and timely communications to bridge the healthcare gaps created by time and distance in our over fragmented healthcare system.



CBPR is about Social Change!

- **“Research” is only one component of CBPR, not the sole goal**
- **CBPR grants promote goals beyond research, including:**
 - **Knowledge and skills development**
 - **Mutually beneficial partnerships**
 - **Camaraderie**
 - **Engagement that results in “wins” for researcher and the community**
 - **Findings with benefits**
(data and publications, positive outcomes)

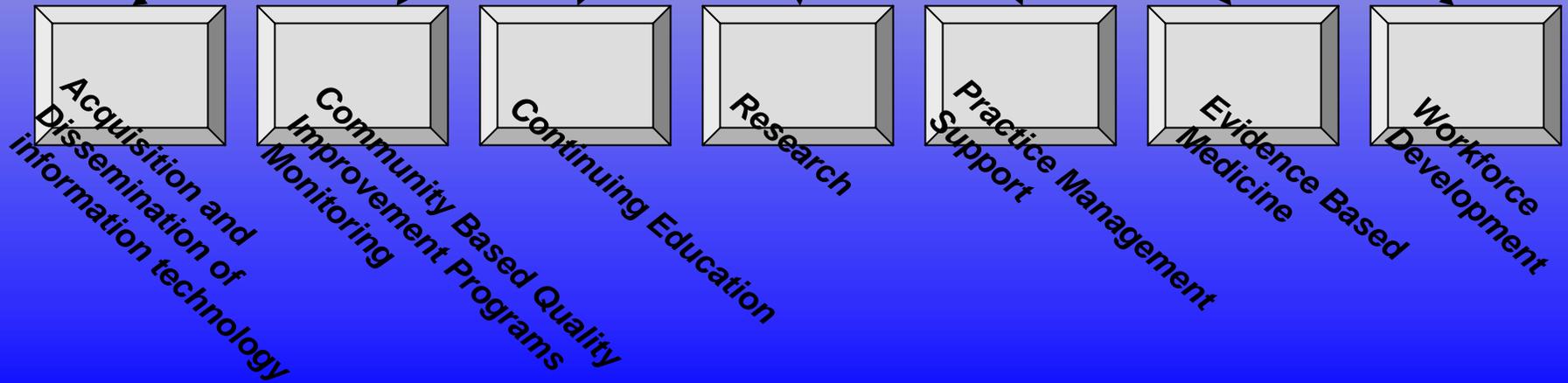
Partnership requires developing flexible infrastructures that promote TRUST

Provider leadership team

Governance



Consistent, Coordinated, Integrated, Community Approach to Health



This is what is possible with effective CBPR

- **Communication**
- **Collaboration**
- **Trust**



What is CBPR?

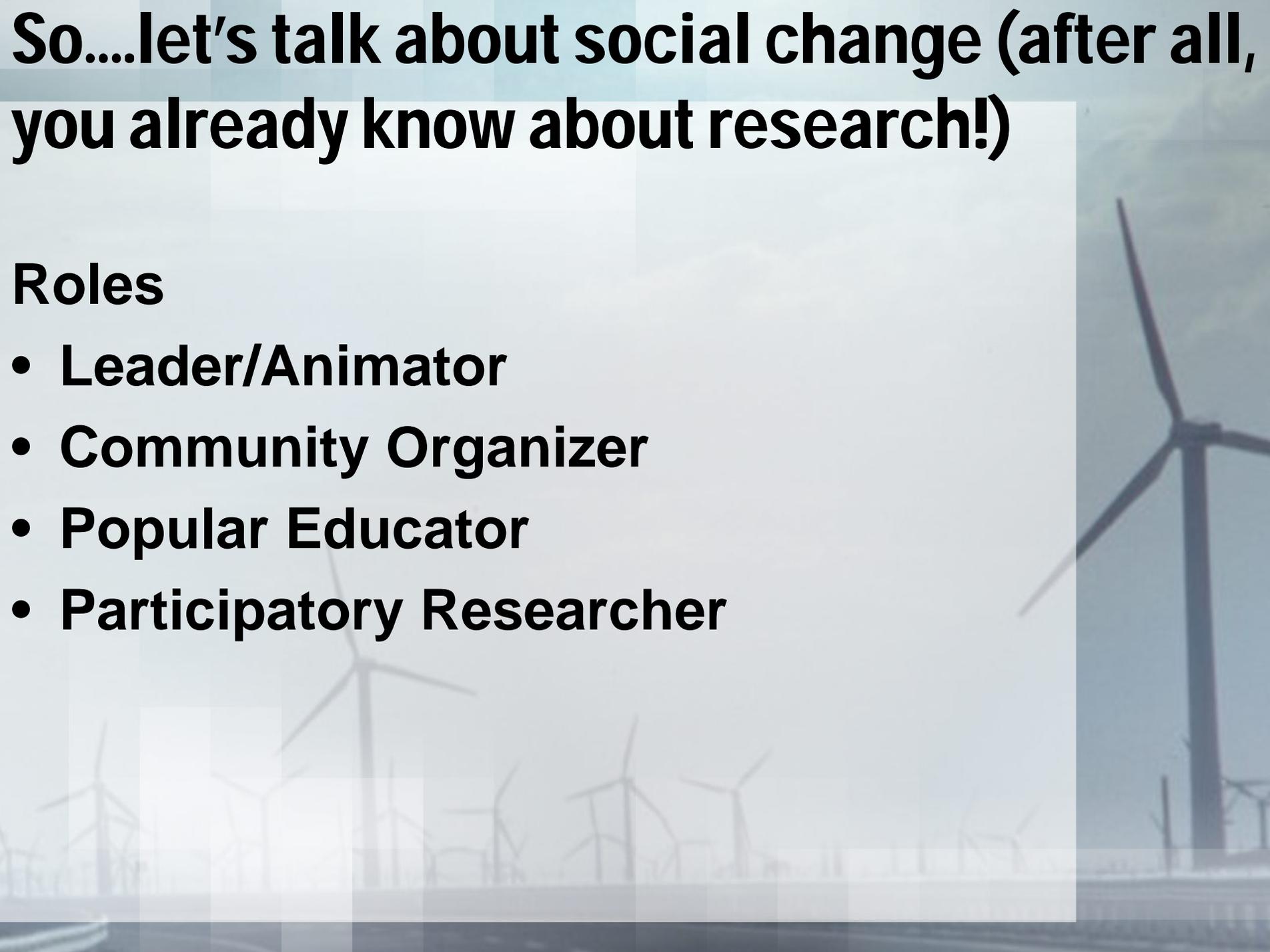
- **Acknowledges community as a unit of identity**
- **Builds on strengths and resources within the community**
- **Facilitates a collaborative, equitable partnership in all phases of research**



So...let's talk about social change (after all, you already know about research!)

Roles

- Leader/Animator**
- Community Organizer**
- Popular Educator**
- Participatory Researcher**



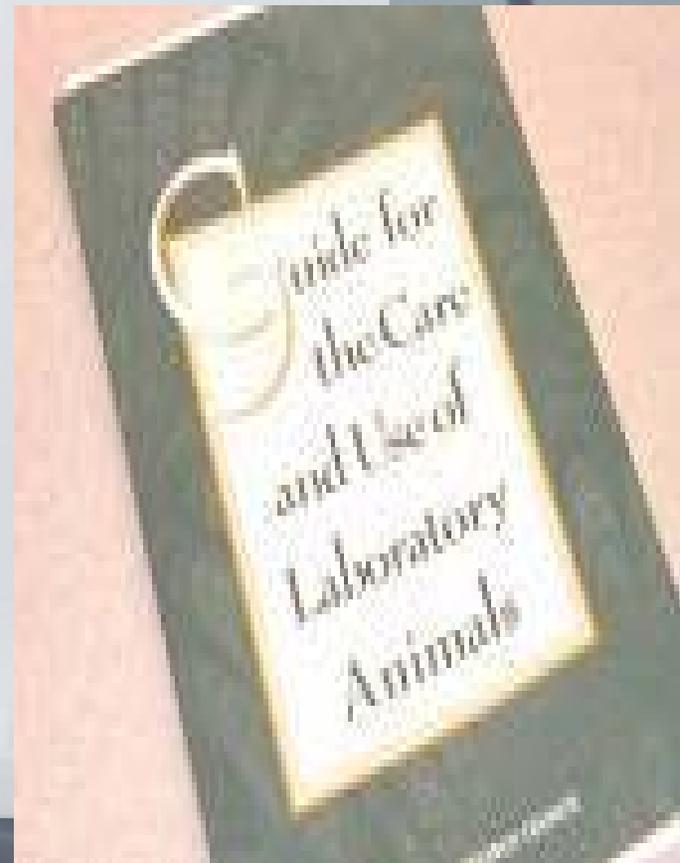
Approaches for Academics to CBPR

- **Initiator**
- **Consultant**
- **Collaborator**

- **The approach and roles depend on:**
 - **The objectives of the project**
 - **Your skills**
 - **How much participation the community desires**
 - **The extent to which the community is organized**
 - **The level of resources that exist within the community**

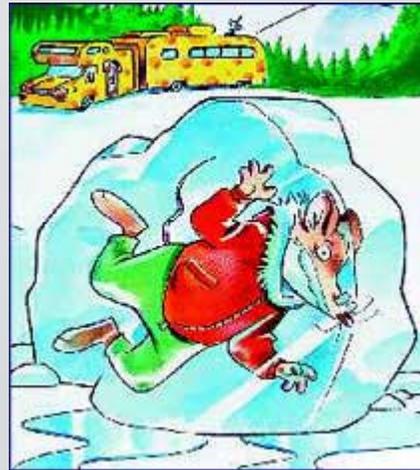
Tell us about the community you're considering.

- Highly organized?
- Low level of organization?
- Resources?



So which do you choose?

- Depends on the community
- Depends on your interest and skills



Researchers who know how to organize

- **Serve as a catalyst**
- **Can facilitate a community's ability to formulate their sense of a problem into a identifiable problem to be addressed**
- **Stimulate people rather than impose on them**
- **Emphasize process over task**
- **Facilitates people doing things themselves**
- **Empowers**
- **Enables**
- **Starts where they are**
- **Focuses on human development in addition to solutions to problems**
- **Able to build community control as the project progresses**
- **Capacity builder**



Can you be trusted?

- Why should I trust you not to poke, prod, probe, starve, or engorge me?
- Why should I trust that your goal of “findings” will not get in the way of real change and sustainability.
- Why should I trust that you will not create a mess in my sand box?
- What is in it for you and me?
- **Is your hidden agenda showing?**

Treat the community as you would
trust of a child



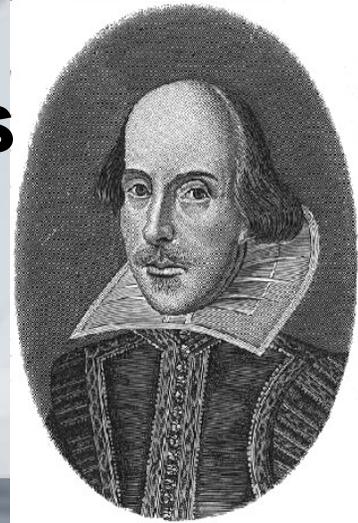
Skills beyond Research Prowess

Do you **REALLY** have what it takes to do CBPR?

- **“To thine own self be true, and it must follow, as the night the day, thou canst not then be false to any man”.**

(William Shakespeare)

- **Ask yourself some critical questions**



- **What is your area of comfort? Just research?**
- **Are you good at facilitating discussion?**
- **Can you communicate abstract theory into practical discussion?**
- **Can you build confidence in others?**
- **What is your emotional intelligence?**
- **Can you interpret and communicate amongst diverse populations and perspectives?**
- **Are you prepared....do you desire...to become an “honorary citizen”**
- **Are you willing, if needed, to alter the character of the research?**
- **Are you flexible....in thought? With time? With deliverables?**

• If you are short on these skills....then...

RECRUIT!!



Recruit and organize participants into an effective, trusted team that will augment your efforts and enhance your outcome

Academic Paralysis

- “Academic” – in the dictionary, found under “c” for “conservative”...or “r” for “risk adverse” (Anonymous, 2008)

- Easy to become paralyzed or self preserve in the notion that...



“There are no failures. Only findings and publications” (Anonymous 2, 2006)

- This may work for the Academic Test Tube Researcher.
- **NOT! , However in CBPR.....**

CPBR is Research with Consequences

Failure at the community level may result in:

– Long term adverse effects for your community partners such as:

- **Loss of community standing**
- **Reputation**
- **Income**
- **Future**

For the Researcher:

– Published Findings (success or failure) are the end result

For the Community:

– Project failures can be potentially devastating



Failure is NOT an Option

- Failure should not be an acceptable finding when embarking on CBPR.
- Projects should be approached with progressive, stepwise goals and deliverables in order to mitigate the possibility of large scale disastrous outcomes.
- Planned damage control.
- Planned great successes - in steps.



.....ANY success Is GREAT SUCCESS

- **Even small accomplishments create cascading, long term, positive effects.**

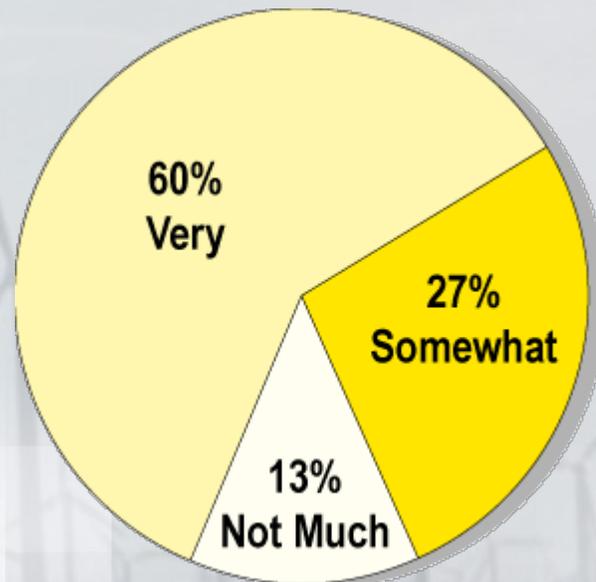


This is a lot to think about

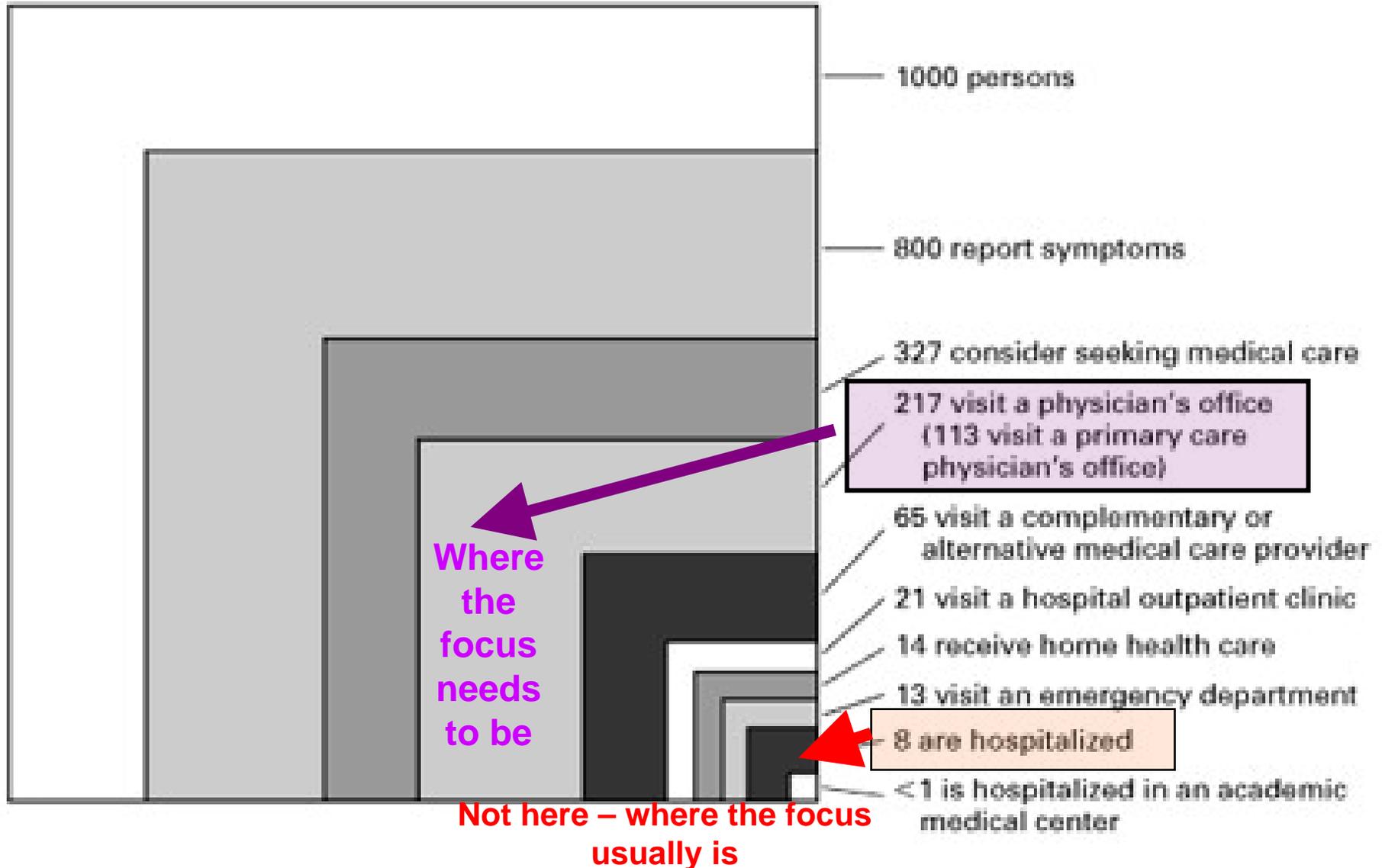


“The word “academic” is a synonym for irrelevant” Saul Alinsky (1946/69 p.ix)

- Do you want to be relevant?**
- Do you know how to be relevant?**



The Ecology of Medical Care (2000)

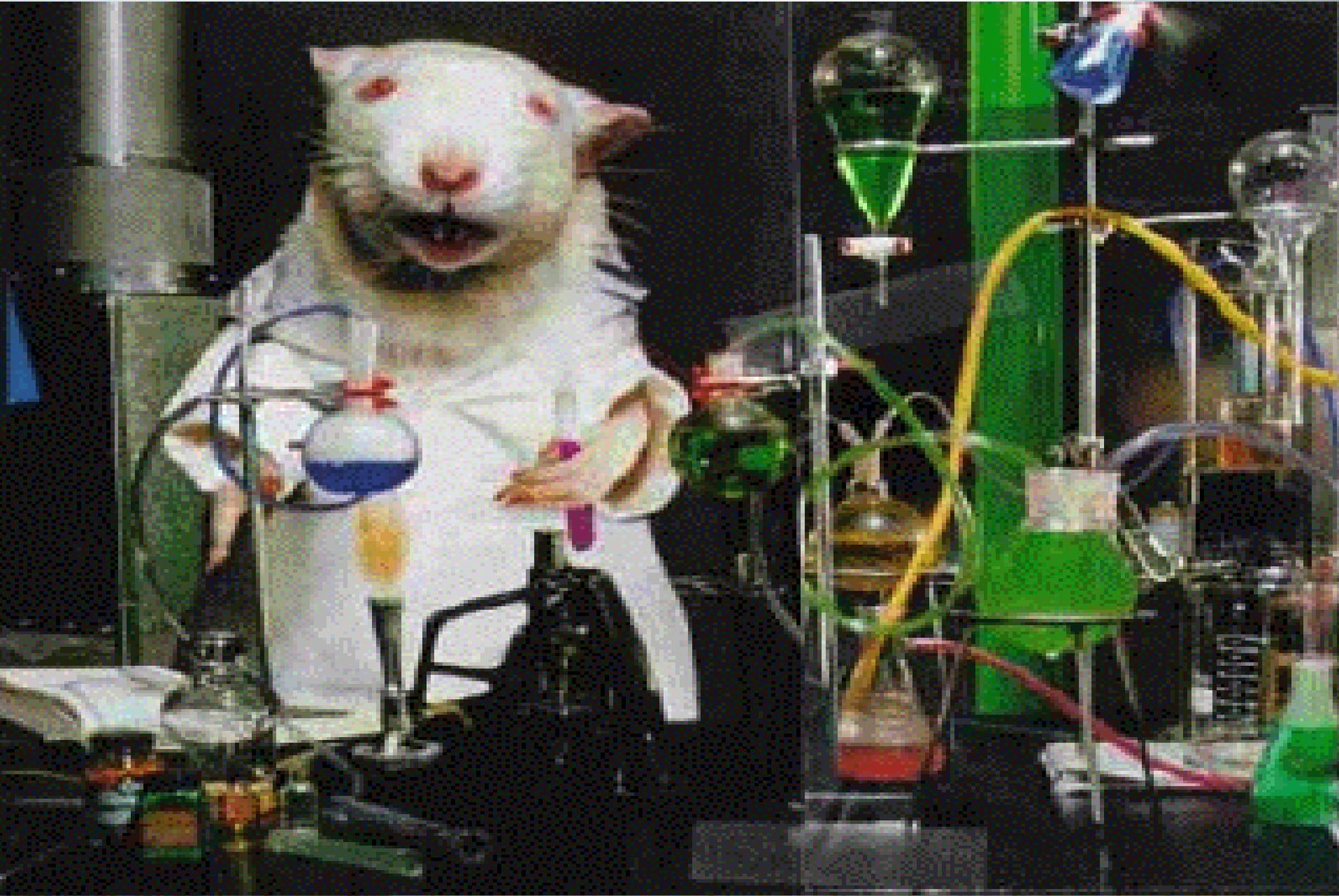


Are you ready to get relevant?

- **Do you have legitimacy? Or a yenta?**
- **Get to know the community – its history, assets, fears, and power structure**
- **Have cultural humility**
- **Be visible, be present....but be humble**
- **Don't rush....you may make the submission deadline, but won't make the relationship (or project)**
- **Be aware of the baggage of your institution**
- **Be aware of insecurities, issues of power imbalance (real or perceived)**
- **Are you prepared to make a long-term commitment....regardless of \$\$\$**

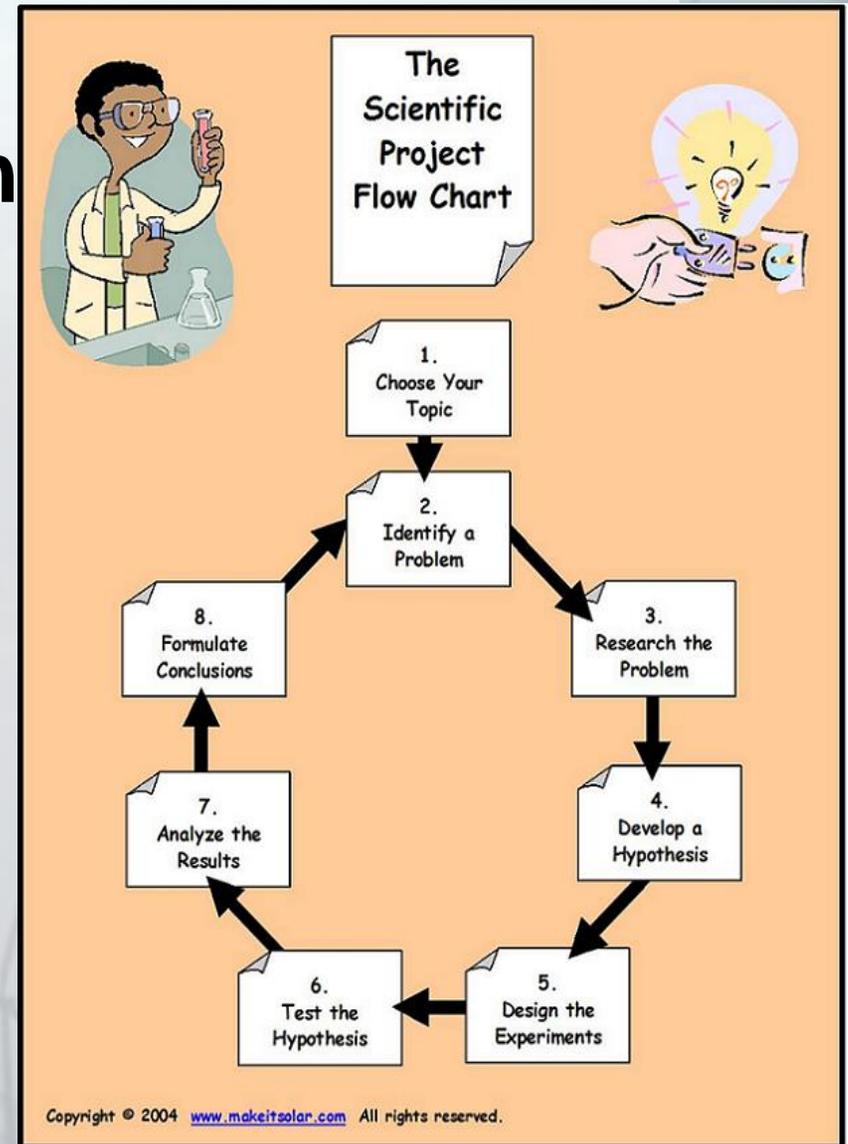


Oh...that's right...we're Human Lab 101!



Traditional Research Design

Formulate the question
Research the question
Form a Hypothesis
Design your Methods
Test the Hypothesis
Analyze and Report



But then there are the challenges

- **Confounding Variables**
- **CBPR potentially has many Challenges**
- **Incongruent or WILD Variables....**
 - **We lovingly dubbed them our “Windmills”**



What challenged us – our windmills

- Fear
- Local politics
- Control issues
- Deep scars
- Hunkered down community



What facilitated collaboration?

- A common need
- The value of key informant interviews
 - Listening and maintaining confidentiality
- A need for healing
- Consultants who gave us hope
- Doctors with open minds
- Doctors who could be leaders
- Facilitation – stirring the pot
- Collaboration
- Consensus on methods
- Trust
- Knowing their world
- Valuing each other as equals

**Are you paying
attention?**

**Really important
slide!!!**

What results in physician buy-in

(in terms of EHRs)

- **Relevance**
 - How does this research help my pts or my practice or my community
 - Is the data collection/time effort/culture change worth it?
- **Big Brother**
- **Will participation lead to my data be stolen by.....**
- **Are you increasing my overhead?**
- **Talk their language**
- **HIPAA, system failure and other hidden costs and dangers**



And then there is culture

- “Something I had not considered is that we need trust building to get the local people to give us access to their data”
- “We’re mixing the academic practices with the more concrete practice” (and hence the need to separate the two)
- “There is research that I can do that requires no community input’ (said with some anger)
- “Doesn’t that (having a community member as a co-pi) imply that they have the skill?”
- “You’re sheer presence implies partnership....and we’re not ready for that”

What Academia can do

- **Important to be Switzerland**
 - Though sometimes even Switzerland goes to war
- **Who is going to back up Switzerland?**
 - Provide a safety net for your research team
- **Re-wire academic institutions**
 - Contracts and grants process
 - IRB oversight
 - Creating incentives for both faculty and administrative units to assist communities
 - Don't just come in and leave....have a sustainability plan
- **Educate researchers on philosophy, approach, and ethics of community based research**
- **The challenges of time and tenure**



What researchers can do

- **Show early value**
- **Share resources**
- **Eliminate (or try to) the barriers to participation**
- **When the going gets tough....**
- **Partnerships not Paternalism**
- **Do no harm – your presence and your project impacts their lives, not yours**
- **Plan for sustainable independence**
 - **Either “leave no trace” or “teach them to fish”**



What review committees can do

- Look for grantees who have the skills to:
 - To break into a community.....**need an advance scout**
 - Affable (no dry personalities)
 - Learn the local politics
 - Understand the players
 - Identify participants, their roles and their “hooks”
 - Learn and speak the local “cultural” language
 - Bring “beads” (tools for change)



“Take thy Planning Grant and Go walk amongst the people” (granitcus 0001.5bc)



**CBPR properly
planned and
executed
translates to
GREAT SUCCESS**



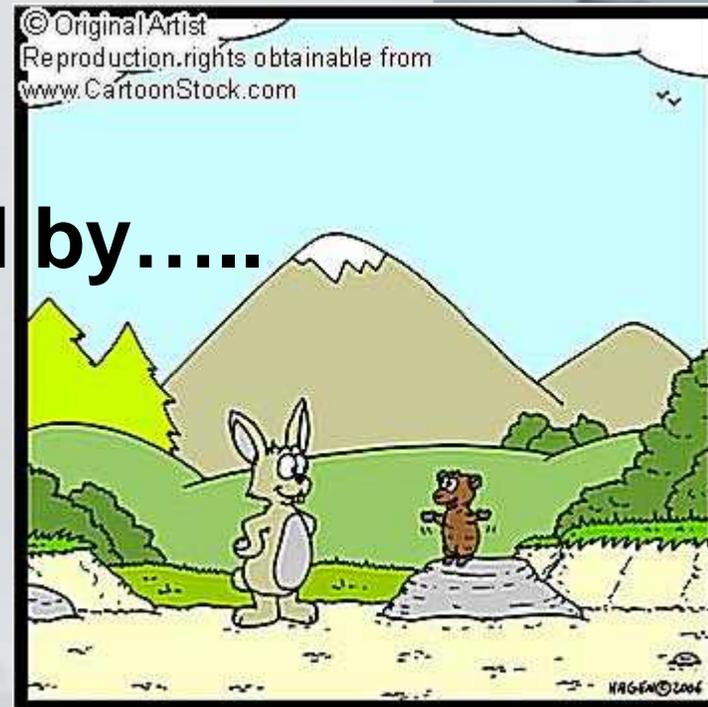
Issues to incorporate in your grant

- **Start with the physicians – not the institutions.**
 - May not be as efficient, but will be more effective
- **Don't recruit from top down - recruit from top and bottom**
- **Anyone who initially funds a project such as this – that impacts others – need to appreciate the long term effects and plan for follow-up projects for these communities to sustain the initiatives while gathering further useful research information**
- **Ought to pay market rates – but instead research exists on the will of those willing to work below market rates**



Communities: What to require from the researcher

- Access to university support – such as IRB, grants management, etc.
- Regular (monthly) reports to governance entity
- Data owned by community
- Intellectual property owned by.....



Yeah, it's great being a Guinea Pig:
At work, I get to try out new stuff all the time...

Communities: What to require from the researcher

- **Publication requirement- specifically naming community**
- **Co authorship and presentations**
- **No “Helicopter” Research**



And researchers.....the community shouldn't even have to ask for this – you should have already offered!

Community based research can be messy

Grantors and Academia take heart, and
support your PI



Sometimes the Bunny
Fights back!!

*Academia tends to
view this as
problematic*

Community ... the WILD VARIABLE

CBPR involves
Taking risks
Culture change

Some Community
members may
Object

Smear campaigns
Community elections
Grand jury
investigation on
Prime awardee



Develop a partnership agreement?

- The “Pre-Nup”
- We didn’t...
- But I’ll never support them doing that again!



I'll be nicer,
when you're smarter.

Emotional Intelligence

- You're going to deal with conflict
- Divorce is not an option
- Never going to bed mad
- Extending the olive branch – even when its not your fault
- Recognizing the pressures and needs of all of the different stakeholders – which are probably different than yours.



At the end of the day...

- **Would you work with me again?**
- **Would I work with you again?**



Who's Your Bunny?



Funder?

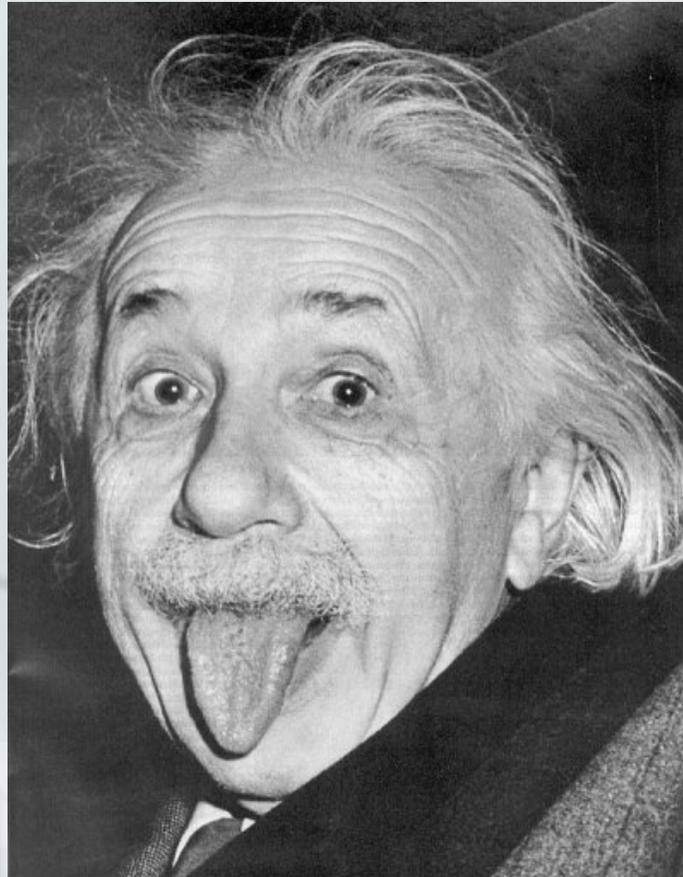
Academia?

Community?

With whom
have you built
rapport?



“If we knew what we were doing, it wouldn't be called research” Einstein



Partners

This project funded by the
Agency for Healthcare Research and Quality



e-MDs



Browsersoft, Inc.

CBPR is not for the faint of heart

Kim Horowitz, MD

sierrafamcare1@aol.com

Kiki Nocella, PhD

kiki.nocella@ucr.edu



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