Community Engagement for Cancer Prevention and Control

MCW Cancer Center Leadership Committee
January 18, 2012

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Community Engagement in Research (CEnR)

Cancer Prevention Community-Academic Partnerships funded by the Healthier Wisconsin Partnership Program (HWPP)

American Cancer Society Funded CEnR Projects

National Cancer Institute Designated Cancer Centers Practicing CEnR

Future Directions
Community Engagement in Research (CEnR)

Definition, Evolution and Core Principles
Definition and Scope of Community Engaged Work

I fail to see how 350 of us are going to fit in here
Community Engagement in Research (CEnR)

- CEnR is a **process of inclusive participation** that supports mutual respect of values, strategies, and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community or focus.

Community Engagement in Research (CEnR)

- CER is a core element of any research effort involving communities. It requires **academic members to become part of the community and community members to become part of the research team**, thereby creating a unique working and learning environment before, during, and after the research.
Evolution of CEnR

CCPH: Community-Campus Partnerships for Health
NAPCRG: North American Primary Care Research Group
AHRQ: Agency for Healthcare Research & Quality
NIH STEP: Staff Training in Extramural Programs
NIH: National Institute of Health
CDC: Center for Disease Control & Prevention
PRC: Prevention Research Center
COPR: NIH’s Director’s Council of Public Representatives
CTSA: Clinical Translational Research Award
Foundations: examples Kellogg and RWJF
Why CEnR?

- Community Demand → Can not be just guinea pig
- Failure of “Traditional” research approaches:
  - 98% of Americans receive their health care outside of academic medical centers
- Funder Demand → Need to see impact
- Demand for elimination health disparities → Potent alternative to “outside expert” driven research
Why CEnR?

- The challenge of “Translational Research”
- Active participation of the target population
- Interest in the contextual factor (e.g. social, economical, cultural, environmental, etc.)
NIH Director’s Council of Public Representatives (COPR)

- Federal Advisory Committee
- Consists of 21 members of the public who provide input and feedback from the public’s perspective on emerging health issues and research priorities as identified by the COPR and/or the NIH Director
- A diverse group with a wide range of backgrounds and perspectives
Core Principles of Community Engagement in Research (CEnR)

- Defined Community & Program Scope
- Strong Community-Academic Partnership
- Equitable Power and Responsibility
- Capacity Building
- Effective Dissemination Plan

CEnR
Community Engagement Framework for Advancing Translational Research

**Academic Resources**
- Dissemination of scientific discoveries
- Best practices
- Evaluation techniques
- Training of future scientists

**Academics Engage as Citizen Scientists**
- Understanding of community sensitivities toward research
- Understanding of how community partnerships may inform research
- Understanding of how best to communicate research findings to community audiences
- Effective community partnerships

**Vehicles for Meaningful Engagement**
1. Communities as Scientific Citizens
   - Community-academic partnerships for advancing the translation of research
   - Science Cafe
   - Citizen Forums
   - Healthier WI Partnership Program
2. Academics as Citizen Scientists
   - Community-based participatory research
3. Infrastructure
   - Citizen Advisory Committee (CAC)
   - Communication/Informatics
   - Education, training and mentoring
   - Policy and practice

**Community Resources**
- Diversity
- Needs Assessment
- Active participation
- Empowerment
- Advocacy

**Communities Engage as Scientific Citizens**
- Increased scientific literacy
- Understanding of how communities may inform research
- Increased knowledge of benefits of research, including clinical trials
- Increased participation in clinical trials and other research
- Increased participation in IRB

**Engaged Partner Approach**
- Bidirectional

**Current Approach**
- Unidirectional

**Integration with other key functions**
- Communication
- Trust and Genuine
- Negotiation and Conflict resolution

**Transformation**
- Disconnect between bench/bedside and community
- Collaboration
- Bench to bedside to community and back
Cancer Prevention Educational Programs

Healthier Wisconsin Partnership Program (HWPP)
Funded Projects
To Increase Access to culturally specific education and support to Increase STD, HIV, and Cancer Prevention Screenings among Latino families

- Development Award- $200K
- Grant Cycle- 1/2012-12/2013
- Community Partners:
  - Planned Parenthood of Wisconsin, Inc.
  - CORE/El Centro Proyecto Salud
  - Holy Angels Old Catholic Church
  - Council for the Spanish Speaking
- Academic Partners:
  - Julia Lechuga, PhD- Department of Psychiatry

Use of a Lay Health Advisor Model
To Bring Sexual and Reproductive Justice to Latinos in Milwaukee
To Increase Awareness and Literacy regarding HPV among urban adolescents who engage in high risk behaviors with a long-range goal of Increased Vaccination Intent

- **Development Award**: $200K
- **Grant Cycle**: 1/2012-12/2013
- **Community Partners**:
  - Milwaukee Health Department
  - Boys and Girls Club of Milwaukee
- **Academic Partners**:
  - Denise Uyar, MD - Department of Obstetrics and Gynecology
  - Staci Young, PhD – Department of Family and Community Medicine
To Build the Public Health Capacity of Wisconsin’s rural and urban American Indian communities and clinics to accurately target and culturally tailor Specific Cancer Program and Services

**Fighting Cancer**

*in Wisconsin’s American Indian Communities.*

- Development Award- $200K
- Grant Cycle- 1/2012-12/2013
- Community Partners:
  - Red Cliff Reservation
  - Red Cliff Community Health Center
  - Indian Health Clinic in Milwaukee
- Academic Partners:
  - J. Frank Wilson, MD – Department of Radiation Oncology
  - Elaine Drew, PhD – Department of Family and Community Medicine
American Cancer Society Community Engaged Projects (CEnR) at MCW

Principle Investigator: Elaine Drew PhD
ACS Funded MCW
Community Engaged Projects
Elaine Drew PhD- Principle Investigator

1. Investigating Barriers to Breast Cancer Screening for Latinas in Milwaukee
   
   Community Partner: United Community Center
   Project Dates: 11/5/2010 - 1/12/2013
   Amount: $50,000

2. Reducing Barriers to Early Detection of Breast Cancer in First-Degree Relatives of African American Women Diagnosed with Premenopausal Breast Cancer
   
   Community Partner: Froedtert Hospital, Wisconsin Well Woman Program, Sisters Network
   Project Dates: 11/5/2010 - 1/12/2013
   Amount: $50,000

3. Reducing Clinical Breast Health Screening and Treatment Timelines for African American Women
   
   Community Partner: Froedtert Hospital, Wisconsin Well Woman Program, Sisters Network
   Project Dates: 11/5/2010 - 1/12/2013
   Amount: $50,000
National Cancer Institute -
Designated Cancer Centers
Practicing Community Engagement in Research (CEnR)
Being a partner with the OCECD has been an empowering experience. Under the leadership of Dr. Kim, I am excited that the OCECD has built an infrastructure to address the cancer disparities facing Asian Americans. The OCECD team has shown a strong commitment to recognizing the integral role of the community in the fight against cancer and exemplifies the need for conducting collaborative community-based participatory research.”

Edwin Chandrasekar, Executive Director, Asian Health Coalition

http://cancer.uchicago.edu/community/engagement/testimonials.shtml as assessed on 1/13/2012
M-POWER works to build and sustain partnerships with the local community to develop and improve methods for reducing cancer disparities.

Objectives:

• Strengthening community collaborations, relationships and partnerships with local groups targeting underserved communities
• Providing health education to empower communities to make positive health choices

http://www.moffitt.org/site.aspx?spid=8C382A517EEF4F53809013482A448CF3&ForwardFrom=C750ACCBE21540F4AA795EE7ACFAE346 as assessed on 1/13/2012
Future Directions

• Community Dissemination, Education and Information Activities
  • Community-Engaged Public Health Research to address health disparities
  • Translation of clinical research which investigates or includes minority populations in a substantial way
  • “Cancer Centers not only generate new knowledge but also interact within their communities to assure that new knowledge benefits systems, providers and people.”
    • Providing cancer information and outreach programming to local community, including those that address special problems of the community
    • Developing screening, therapeutic and/or preventive interventions along with the community through every stage of development through collaborations with not for profit or for profit community based organizations

The Cancer Centers Branch of the National Cancer Institute, Policies and Guidelines Relating to the Cancer Center Support Grant, September 2008 (p.55-56)
“When facing a difficult task, act as if it is impossible to fall. When going after Moby Dick, bring along the tartar sauce.”

Anon