ADVANCING THE ART & SCIENCE OF COMMUNITY ENGAGEMENT

Syed M. Ahmed, MD, MPH, DrPH, FAAFP
Senior Associate Dean for Community Engagement
Professor, Family and Community Medicine
Professor, Institute for Health and Society
Director, Healthier Wisconsin Partnership Program
Director, CTSI, Community Engagement Key Function
EYES ON THE FUTURE
1. Definitions in Community Engagement (CE)
   - Community, Community Engagement (CE) and Community Engagement in Research (CEnR)

2. Background of Community Engagement in Research (CEnR)
   - Principles of Community Engagement
   - Rationale, Evolution and Challenges

3. Community Engagement at MCW
   - Office of the Senior Associate Dean for Community Engagement
   - Healthier Wisconsin Partnership Program
   - Community Engagement within the Clinical and Translational Science Institute
DEFINITIONS IN COMMUNITY ENGAGEMENT (CE)

**Community**

- A community is an interdependent group of people who share a set of characteristics and are joined over time by a **sense that what happens to one member affects many or all of the others**. ¹

**Community Engagement**

- Community Engagement is defined as the **collaboration** between institutions of higher education and their larger communities (local, regional/state, national, global) for mutually beneficial exchange of knowledge and resources in a **context of partnership and reciprocity**. ²

**Community Engagement in Research**

- Community Engaged Research (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 of focus. ³

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2. Carnegie Foundation’s elective classification for Community Engagement; copyright 2007 the Carnegie Foundation for the Advancement of Teaching
BACKGROUND OF CEnR

PRINCIPLES OF COMMUNITY ENGAGEMENT

Ahmed, SM, Medical College of Wisconsin, 2010
Community

- Community Demand → Can not be just “subject”
- Demand for elimination health disparities → Potent alternative to “outside expert” driven research
- Active participation of the target population
- Incorporation of local knowledge which overcome “community distrust” of academic research
- Provides resources (e.g. funds, training, job opportunities for communities^6
- Interest in the contextual factor (e.g. social, economical, cultural, environmental, etc.)

Academic

- Failure of “Traditional” research approaches:
  - 98% of Americans receive their health care outside of academic medical centers
- The challenge of “Translational Research”
- Enhance the relevance and use of the research data by all partners
- Funder Demand → Need to see impact
- Educating public health professionals for the 21\textsuperscript{st} century^7
- Opportunities for Advancing Clinical and Translational Research^8

Ahmed, SM, Medical College of Wisconsin, 2010
6. (Israel et al, 1998)
7. IOM report 2003, Who Will Keep Public Healthy?
8. IOM report 2013, The CTSA Program at NIH
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
NCATS: National Center for Advancing Translational Science
PCORI: Patient-Centered Outcomes Research Institute

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

• Cold War  • Race to Space  • Student Unrest  • Diversity/Equity Embraced
• Clinical Trials  • Civil Rights  • Budget Cuts  • Baby Boomer
• Boyer  • CE Movement
• Research  • Impact Measurement  • Learning Outcomes

# Challenges of CEnR

## National
- Slow evolution of CEnR
- Resistance to new concepts
- Questions of legitimacy as a research paradigm
- Questions of lack of data on effectiveness of CEnR
- Lack of leadership
- Lack of funding

## Institutional
- “Novel” idea
- Lack of leadership
- Lack of faculty with CEnR expertise
- Lack of infrastructure support
- Faculty development issues
- IRB issues
- Missing “boat” vs. Jumping on “bandwagon”

## Community
- Lack of trust of academia
- Not Same missions / goals / priorities
- Lack of understanding of CEnR
- Lack of understanding of roles / responsibilities
- Lack of skills in developing partnerships with academics
- Funding issues
- Who disseminates?
- Considerable investment of time and energy to build and sustain relationship
- Location of “power” in the partnership
- Definition of “community”
- Communities are not mono-liths

## Individual
- Lack of education/training
- Lack of role model
- Skepticism
- Promotion & tenure issues
- Lack of support: departmental & institutional
- Considerable investment of time and energy to build and sustain relationship

Ahmed, SM, Medical College of Wisconsin, 2010
BREAKDOWN OF ACADEMICS WITH POTENTIAL TO DO CEnR

Healthier Wisconsin Partnership Program

Community-Academic Partnerships for Health

• More than 140 programs that weave public and community health partnerships into education, research and patient care

Funding and Leveraging Resources

• Through nine separate funding cycles, HWPP has awarded over $45M
• More than $21M has been leveraged by HWPP awarded projects

Nationally Recognized

• Received several awards, including the 2005 AAMC Award for Outstanding Community Service
Example of Community-Academic Partnership

- Community-Based Chronic Disease Management (CCDM)

- **Project Goal Statement:** CCDM will effect prevention of complications by screening for/managing hypertension, diabetes, and obesity at churches and food pantries that serve Milwaukee's poor and by promoting low-cost medicine, nutrition, and education in a tiered community model.

- **Community Partner:**
  Primary Community Partner: Bill Solberg, MSW, LCSW, Columbia-St. Mary's

- **Academic Partner:**
  Primary Academic Partner: Jim Sanders, MD, MPH, Department of Family and Community Medicine
HEALTHIER WISCONSIN PARTNERSHIP PROGRAM
Example of Community-Academic Partnership

• Changing the Culture of Risky Drinking

• **Project Goal Statement:** To create a sustainably safe environment for alcohol consumption through:
  – changes in local alcohol licensing policies; practices on college campuses, in taverns, and at festivals; and by educating current and future leaders in community collaboration.
  – Reducing underage access and use of alcohol in La Crosse County by translating evidence-based strategies into action according to a community-developed strategic plan.
  – And forming an Alcohol Risk Reduction Task Force in La Crosse to address the burden of at-risk alcohol use and abuse and injury.

• **Primary Community Partner:**
  Catherine Kolkmeier, La Crosse Medical Health Science Consortium

• **Academic Partners:**
  Primary Academic Partner: Stephen Hargarten, MD, MPH, Injury Research Center
HEALTHIER WISCONSIN PARTNERSHIP PROGRAM
Example of Community-Academic Partnership

• Use of a Lay Health Advisor Model to bring Sexual and Reproductive Justice to Latinos in Milwaukee

• **Project Goal Statement:** To evaluate the implementation of a Lay Health Advisor Model, including culturally competent social marketing and home health education gatherings, to improve sexual and reproductive health outcomes for Latino youth and adults in Milwaukee.

• **Community Partner(s):**
  Primary Community Partner: Tanya Atkinson, Planned Parenthood of Wisconsin

• **Academic Partners:**
  Primary Academic Partner:
  – Carol Galletly, JD, PhD, Department of Psychiatry and Behavioral Medicine (starting August 2013)
  – Julia Lechuga, PhD, Department of Psychiatry and Behavioral Medicine (through July 2013)
OVERLAP BETWEEN BASIC, CLINICAL, AND COMMUNITY ENGAGEMENT IN RESEARCH

“Science in isolation is by its nature selfish without community it is sterile.”
–Elazer Edelman, TedMed 2013- How do we bridge the gap in medical innovation?
COMMUNITY ENGAGEMENT WITHIN CLINICAL AND TRANSLATIONAL SCIENCE INSTITUTE

Clinical and Translational Research

- Part of a national initiative to speed collaborative research for therapies that improve human health
- Eliminate barriers between academic disciplines, between laboratory and clinical research, between scientists, doctors, patients, and communities
- Foster a rich research and educational environment to develop the next generation of researchers
- Engage the community as partners in research

Specific Aims

- AIM 1. Engaging communities as **Scientific Citizens** by increasing scientific literacy regarding the benefits of research.
- AIM 2. Engaging research investigators as **Citizen Scientists** by improving community-engaged scholarship and community-based participatory research.
COMMUNITY ENGAGEMENT OF CTSI

Education

Science Cafes (26)
• >1K total registrants (duplication not accounted for), Ahmed SM et al\(^3\)

CE Internal/External Education Workshops
• CTSI institutional collaborators (3), HWPP collaborators (3)
• Registrant mix in 2013 was approximately 40/40/20 (community/academic researcher/health service, national/international, other)

CE graduate course
• 1\(^{st}\) of its kind nationally, Master of Clinical and Translational Science, multi-credit hour, asynchronous, online course offered Fall 2012, 13’, 14’

SMART Teams (78)
• SMART Team Mentor (ave. 24/yr.) institutional affiliations mix included MCW, MU, UWM, BC, MSOE, and community organizations

Partnerships

262 collaborators
• Institutional (179)
• Community (86)

National CTSA Collaborations Projects and International Councils (20+)

Outreach and Measures
CE workshops, Science Cafes, CTSI CE evaluation, funding proposals, translational/community-academic partnership research projects, assistance with partnership development, formal and informal mentoring, dissemination

Leverage

28 proposals
• National- NIH (3), VA (1), PCORI (1)
• Local/Regional- HWPP (11), AHW R&E (1), CTSI (6)
• Private (5)

Granted 56% of total funds requested approximately 4 M

Dissemination

Publications (34)
**Sampling:** Ahmed SM & Palermo AG\(^2\), Michener L et al\(^5\), Kusch J et al\(^7\), Aguilar-Gaxiola et al\(^8\), Solomon S et al\(^10\), Hayes AJ et al\(^11\), Ahmed SM et al\(^12\), Marriott LK et al\(^14\), Eldredge C et al\(^15\), Ahmed SM et al\(^3\), Ahmed SM et al\(^16\)

Presentations (116)
• oral (50), poster (66)
• International (4), National (47), Local (65)
COMMUNITY ENGAGEMENT OF CTSI
COLLABORATIVE APPROACH ON MULTIPLE LEVELS

- Faculty and Staff
- Citizen’s Advisory Council
- Leadership Team

- Workgroups: Outcomes and Metrics, Education and Training, Community Partner Integration, Annual Conference Planning, Resource Development, Evaluation
- International: ISCRAM and EnRICH
- External Advisory Board Member and Consultation to other CTSAs

- Infrastructure

- Local Partnerships

- National Priorities and Leadership

- Multi-CTSA Initiatives

- CTSI Institutional Partners: MU, UW-M, MSOE, CHW, Froedhert, BCW, MCW
- Community Based Organizations: multiple

- Dissemination on National CE Priorities and CEnR within CTSAs
  - Social Networking Analysis
  - Ethical Protections
  - Clinical Data Research Network
  - Evaluation and Metrics: Institutional Community Engagement Assessment
Since 2004, the Healthier Wisconsin Partnership Program has awarded funds in excess of $40M to over 140 community-academic partnerships committed to improving the health of Wisconsin residents.
COMMUNITY ENGAGEMENT OF CTSI RESEARCH ON PAST AND CURRENT COMMUNITY-ACADEMIC PARTNERSHIPS

Social Networking Analysis
Preliminary Visualizations of Funding Cycles: Projects and Partners

SNA of HWPP Funding Years 2005-2008
MCW C-A Partnerships

SNA of HWPP Funding Years 2009-2013
MCW C-A Partnerships

CEKF Shares Research Results with HWPP (and Nationally other CTSAs and CEnR Practitioners)
and this enhances their knowledge of (1) External and Internal Conditions, (2) Support Needs, (3) and Other Factors Impacting C-A Funded Partnerships to Inform Future Research Priorities.
COMMUNITY ENGAGEMENT OF CTSI
APPROACH TO INCORPORATING CE THROUGHOUT THE RESEARCH CONTINUUM

ACES (Advancing Community Engagement Sciences) through Evaluation, Research & Dissemination

CTSI Community Engagement Signature Programs

Health Science Shop (HSS)
Mechanisms in which communities (broadly defined) present issues, concerns, & needs they feel warrant a collective, multi-disciplinary research solution CTSI research infrastructure can support and aid in action.

Community Engagement Compass (CEC)
Mechanism for creating a pathway for CE interested investigators to connect with community through various CE resources.

Services & Resources
Networking and Partnership
Community Research Ambassadors
Advanced Science Cafes

CE Workshops
Formal & informal Curriculum
Community Advisory Council

Partnership Facilitation Services
CE Resources Repository
Mentoring & CE Consultation
Educational Resources

T0-T4 Translational Continuum