Engaging Stakeholders in Community-Based Participatory Research

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Clinical and Translational Science Awards (CTSA) Program

- National Institutes of Health (NIH) program
- Launched in 2006
- A national consortium of 64 institutions
- **Mission:** to develop innovative solutions that will improve the efficiency, quality and impact of the process for turning observation in the laboratory, clinic and community into interventions that improve the health of individuals and the public
Spectrum of Clinical and Translational Research

Bench to Bedside...

...to Widespread Clinical Practice...

...to Public Health...

...to Health Policy

Translation (T1)

Translation (T2)

Translation (T3)

Translation (T4)
Tufts CTSI’s Mission & Purpose

Established in 2008 to translate research into better health

- Stimulate and expedite innovative clinical and translational research, with the goal of improving the public’s health
- *Entire spectrum* of clinical and translational research is critical to meeting the promise and the public’s needs of biomedical science
39 Tufts CTSI Partners

12 Tufts Schools & Centers
Cummings School of Veterinary Medicine
Fletcher School of Law & Diplomacy
Friedman School of Nutrition Science & Policy
Graduate School of Arts & Sciences
Institute for Clinical Research & Health Policy Studies at Tufts Medical Center
Jean Mayer USDA Human Nutrition Research Center on Aging
Sackler School of Graduate Biomedical Sciences
School of Dental Medicine
School of Engineering
School of Medicine
Tisch College of Citizenship & Public Service
Tufts Center for the Study of Drug Development

7 Tufts-Affiliated Hospitals
Baystate Medical Center
Lahey Clinic
Maine Medical Center
New England Baptist Hospital
Newton-Wellesley Hospital
St. Elizabeth’s Medical Center
Tufts Medical Center

6 Industry/Non-Profit Partners
Blue Cross Blue Shield of Massachusetts
Eli Lilly and Company
Institute for Systems Biology and P4 Medicine Institute
Minuteman Health Network
Pfizer, Inc.
Tufts Health Plan

10 Community-Based Partners
Action for Boston Community Development (ABCD)
Asian Community Development Corporation
Asian Task Force Against Domestic Violence
Asian Women for Health
Boston Chinatown Neighborhood Center
Center for Information and Study on Clinical Research Participation
Greater Boston Chinese Golden Age Center
Health Resources in Action
Museum of Science, Boston
New England Quality Care Alliance

4 Academic Partners
Brandeis University
Harvard Clinical Research Institute
Northeastern University RAND Corporation
How Can CTSI Help?

• **Connections** with other researchers, industry, the community, and policy-makers across the Tufts CTSI network and national CTSA consortium via our Navigators & Research Collaboration team.

• **Consultations** on comparative effectiveness, one health, research process improvement and stakeholder and community engagement projects and grants, as well as regulatory issues and other areas of translation.

• **Study design and data analysis** (pre- and post-award) through the **Biostatistics, Epidemiology, and Research Design (BERD) Center**, including drop-in sessions.
How Can CTSI Help?

• 24/7 clinical trial support through our Clinical and Translational Research Center (CTRC).

• Informatics tools for electronic data capture (REDCap), resource sharing, and collaboration.

• Training & professional development including MS and PhD degrees, certificate programs, seminars & workshops, and paid career development awards and fellowships.

• Funding through one-year interdisciplinary pilot studies grants that support the initial stages of research.
How to Request Tufts CTSI Services

• Visit www.tuftsctsi.org and submit a request
Live seminars are recorded for our I LEARN site. Seminar videos can be viewed at any time, and are free!
Get Connected: CTSI Happenings

- Weekly e-newsletter with news, professional development and funding opportunities, resources, and success stories.
- Issued every Monday at 8AM
- Sign up on our website or at http://eepurl.com/C4d9X
Upcoming Tufts CTSI Events

• Stakeholder and Community Engagement Symposium (March 7, 2017)

• Mentor Training (March 29, 2017)

• Pfizer Investigator Training Program (April 18 & 19, 2017)

• Tufts CTSI – Northeastern Joint Symposium (April 27, 2017)

Visit www.tuftsctsi.org to register today!
Questions?
Three Traditions of Community Engagement

Activists
Communities
Initiate

Partners
Researchers & Communities
Initiate Together

Scientists
Researchers
Initiate

Tufts CTSI
Tufts Clinical and Translational Science Institute
Three Traditions of Community Engagement

**Stakeholder Engagement**
Who are the stakeholders in translational science and how can they be involved?
PCORI: clinical outcomes, CER

**Citizen Science**
How can researchers respond effectively to patient demands for translational science?
FDA, NIH, CMS: HIV/AIDS, vaccination, cancer

**CBPR**
How best can researchers and communities work together in translational science?
CDC, NCATS: ADAPT, community health
Seminar Series to Address the Three Traditions

- Stakeholder Engagement in Patient-Centered Comparative Effectiveness Research, Tom Concannon, PhD (September 28, 2016)
- Preparing for Patient-Centered and Stakeholder-Engaged Research, Tom Concannon, PhD (October 25, 2016)
- Civic Life & Health Research, Peter Levine, PhD (January 25, 2017)
- Engaging Stakeholders in Community-Based Participatory Research Partnerships, Carolyn Rubin, EdD, MA (February 7, 2017)

All of these seminars will be added to I LEARN as a four module Stakeholder and Community Engagement Course!
Engaging Stakeholders in Community-Based Participatory (CBPR) Research

Carolyn Rubin EdD, MA

Director, Addressing disparities in Asian populations through translational research
Assistant Professor, Department of Public Health and Community Medicine
Learning objectives

• Describe the definition, origin, and benefits of CBPR
• Identify strategies for building authentic long-term partnership
• Reflect on your or your institutional relationships with local communities and potential next steps towards CBPR
Presentation Outline

• Definitions
• Overview of CBPR
• Case studies of successful CBPR projects
• Capacity-building for CBPR
• Model of long-term engagement: ADAPT
What is Translational Research?

• **Translation** is the process of turning observations in the laboratory, clinic and community into interventions that improve the health of individuals and the public — from diagnostics and therapeutics to medical procedures and behavioral changes.

• **Translational research** is bridging the gap “between biomedical researchers and the patients who need their discoveries”
What’s the Disconnect?

- Helicopter research (Ferriera and Gendron 2011)

- Research fatigue (Hacker et al. 2012)

- Definitions of “health” (Martinez et al. 2011)
What is Community-Based Participatory Research (CPBR)?
(Israel 1998)

"Community-based research in public health is a collaborative approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process."
CBPR and Translational Science
(Martinez et al 2008)

• Involves those traditionally left out of the research process.
• Convene stakeholders representing diverse perspectives to determine research priorities
• Provides input on how to translate to policy or practice
• Provides common language
• Demystifies the science
• Creates bi-directional information pathways
History of CBPR
(Wallerstein 2008)
Case study: Somerville Community Immigrant Worker Health Project

Community partnership between Tufts, Cambridge Health Alliance and five community agencies in Somerville that looked at immigrant occupational health and safety issues. This project built community capacity to collect and disseminate the data using teen surveyors.

One major accomplishment was the establishment of the Vida Verde Co-Op which empowers its members and uses “green” cleaning products.

Principle Investigators: David Gute and Alex Pirie
Case Study: The Community Assessment of Freeway Exposure and Health Study (CAFEH)

- Environmental justice project that looked at the health effects of low-income minority groups living near highways
- Collected data in Somerville, Chinatown and Dorchester
Major Characteristics of CBPR
(Israel 1998)

• **Community** as a unit of identity
• Recognizes and builds upon the strengths and resources that **already exist**
• Facilitates an **equitable** partnership in all phases of research, that involve and are not limited to a power-sharing process that promotes empowerment
• **Co-learning** and capacity building among all partners
Major Characteristics of CBPR (cont.)

• Research topics focus on the local relevance of public health issues and on socio-ecological perspective that contribute to the multiple determinants of health
• Partnership draws on the capacity and competency of each partner to engage in the process of CBPR development
• **Dissemination** of information involves all partners
• Long-term research process that is focalizes on sustainability within the community
Questions for You

• Who are the communities most impacted by your research?

• Have you sought to engage them? Why/why not?

• What do you see are the benefits of engaging communities in your research?
Capacity-Building for CBPR

Community engaged pedagogy
(Rubin et al 2012)

- Relational approach to partnership building
- Establishment of a learning community
- Organic curriculum model
- Collaborative teaching mechanism with diverse faculty
- Applied learning
Lessons Learned
(Rubin et al 2012 and 2014)

- Co-learning
- “Actors in the process”
- Increase research literacy
- Negotiation
- Disrupt the “culture of power” (Delpit)
Model of Long-Term Engagement: ADAPT

Case study of ADAPT (Addressing disparities in Asian populations through translational research)
Boston Chinatown

- Median household income $14,829
- 30% below federal poverty level
- 60% less than a high school degree
- 1/3 of residents non-proficient in English
- 79% do not own their own homes
ADAPT Stakeholders

Greater Boston Chinese Golden Age Center

Tufts University | Jonathan M. Tisch College of Civic Life

Asian Community Development Corporation

ASIAN TASK FORCE
Against Domestic Violence

P.O. Box 120108
Boston, MA 02112

24-hour Multilingual Helpline: 617.338.2355
Tel: 617.338.2350 • Fax: 617.338.2354
www.atask.org

abod

Tufts Public Health
WORKING ACROSS DISCIPLINES AND GLOBAL BOUNDARIES

Tufts Clinical and Translational Science Institute

School of Medicine
Our Vision & Mission

• **Vision**
  Healthy Asian communities where everyone has the necessary individual, social, economic, and environmental resources to successfully lead healthy lives.

• **Mission**
  We are a community-academic partnership whose mission is to assess, improve and promote health and well-being among underserved Asian-American communities in the Greater Boston area through research, education and advocacy.

• **Values**
  – Spirit of collaboration and co-learning among partners
  – Equity in health & resources
  – Commitment to inclusion
  – Asset and strength based approaches
  – Principles of integrity, transparency, and mutual respect
  – Community-focused practices for collective action & advocacy
Coalition-building
(Kegler and Swan 2011)

- Power with, versus power over (Wallerstein et al 2015)
- Build social capital (Green and Kreuter 2005)
- Enhance social network (Valente 2015)
- Build community capacity (Wendel 2009)
- Change social norms (Smessler 1998)
- Enhance community participation (WHO 2002)
Strengths and challenges

**Assets**
- Strong relationships
- Shared values
- Diversity of organizations involved
- Holistic definition of health
- Regular forum for dissemination
- Support for infrastructure
- Sustained and deep engagement

**Challenges (Freeman et al)**
- Building trust takes time
- Mismatch between academic and community goals
- Building equitable partnerships
- Definition of Chinatown
- Expansion to other Asian enclaves in the Boston region
- Identifying collective goals

Tufts CTSI
ADAPT as “incubator”

**Establish and build trust**
- Asian American breast cancer awareness
- Defining the empowerment process
- Health of Asians and chronic diseases pilot study

**Listen to the community: Building deeper partnerships**
- Increasing Utilization of Preventive Care in Asian American Women in Massachusetts
- Healthy Chinatown:
- Health of Boston Chinatown:
- Pathways to Autism Diagnosis and Services within a Chinese-American Community Population:
- Care Coordination for Asian Elders:

**Expand definition of health: Community identified priorities**
- Health and Housing: Assessing baseline health and housing characteristics of new residents in the Chinatown affordable housing units
- Gentrification and health
Looking Ahead: Addressing Community-Identified Research Priorities

- Gentrification: preserving culture and community
- Health and stable housing
- Problem gambling
- Public safety
- Collective impact
Resources

• Campus-Community Partnership for Health
  – https://ccph.memberclicks.net/

• Progress in Community Health Partnership
  – https://www.press.jhu.edu/journals/progress_in_community_health_partnerships/

• Building Your Capacity Curriculum Guide

• ADAPT

• Community Assessment of Freeway Exposure for Health
  – http://sites.tufts.edu/cafeh/cafeh-study-2/
References

• Somerville Community Immigrant Health Project https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2774174/
Images

- http://www.davidfichter.com/images/m/murals078.jpg
- http://media4.s-nbcnews.com/j/newscms/2015_46/1300391/boston_chinatown-maxim_coffee_house_4997a6aa84a102c41d5e4116a0e95f60.nbcnews-ux-2880-1000.jpg
Thank you!