

Tufts Clinical and Translational Science Institute

Engaging Stakeholders in Community-Based Participatory
Research

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February 7, 2017

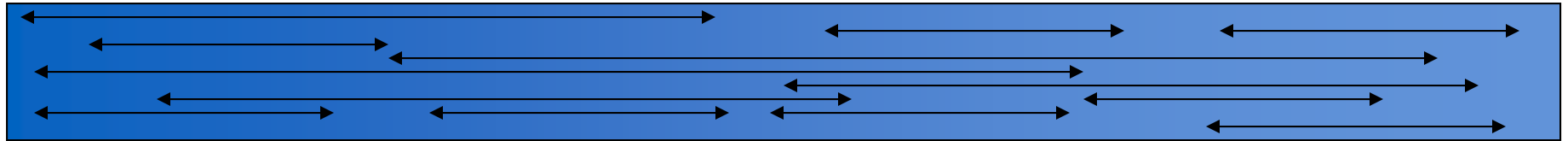
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Clinical and Translational Science Awards (CTSA) Program

- 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)*

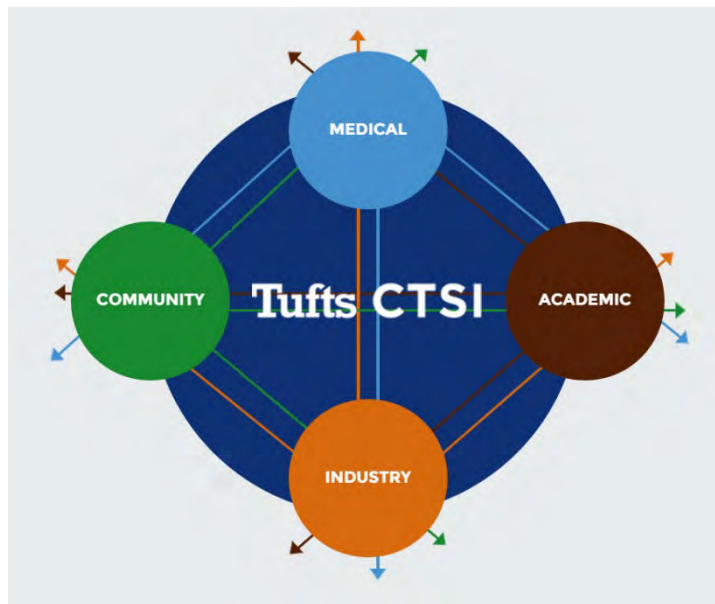
*Translation
(T4)*

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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

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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

4 Academic Partners

Brandeis University
Harvard Clinical Research Institute
Northeastern University RAND
Corporation

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

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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

The screenshot shows the homepage of the Tufts Clinical and Translational Science Institute (CTSI). The header includes the Tufts CTSI logo and navigation links for REDCap, LEARN VIDEOS, PROFILES, and WORKSPACE LOGIN. Below the header is a main navigation bar with links for Research Services, Education, Funding Opportunities, Our Impact, Faculty & Staff, and About Us. The main content area features a large blue banner with the text "Accelerating translation of research into clinical use, medical practice, and health impact" and a list of services: Research Design & Analysis, Research Collaboration, Clinical Studies & Trials, Informatics, Professional Development, and Pilot Studies Funding. Below this banner are three columns: "WANT HELP WITH YOUR RESEARCH?" (circled in red), "EVENTS", and "NEWSFEED". The "WANT HELP WITH YOUR RESEARCH?" section includes a call to action "Fill out a request and we will be in touch within two business days." and two photos of staff members: Daniel E. Welner, MD, MS and Genevieve M. Allison, MD, MSc, FACP. A "SUBMIT A REQUEST" button is located below their photos. The "EVENTS" section lists "DROP-IN SESSIONS" for Sep 23, Sep 30, and Oct 06. The "NEWSFEED" section features a "SUCCESS STORY" about a research study.

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<http://ilearn.tuftsctsi.org/>

Live seminars are recorded for our I LEARN site.
Seminar videos can be viewed at any time, and are free!

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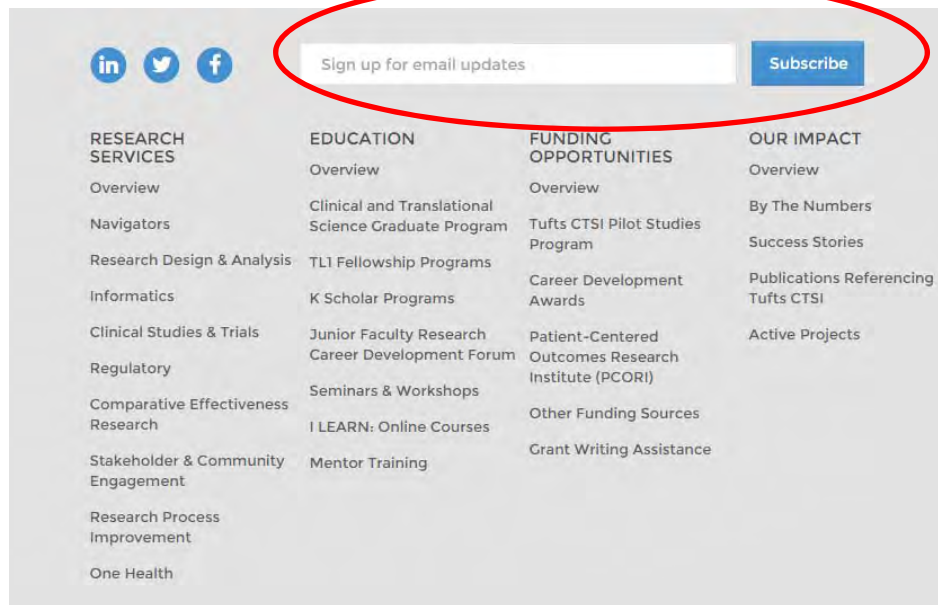
Welcome to I LEARN, the Tufts CTSI interactive education website. Tufts CTSI I LEARN is a new resource that offers a comprehensive library of educational courses in clinical and translational research for both professional development and CME credit. Building on our unique curriculum, we are offering some of our courses and workshops in an online learning format, combining professionally videotaped recordings of live lectures with other learning materials to transcend the traditional in-classroom experience.

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Get Connected: CTSI Happenings

Tufts | CTSI Tufts Clinical and Translational Science Institute 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!

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Questions?

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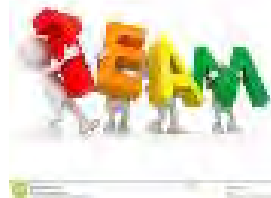
Three Traditions of Community Engagement



Activists
Communities
Initiate

Partners
Researchers &
Communities
Initiate
Together

Scientists
Researchers
Initiate



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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 9 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

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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”
 - Declan Butler *Nature* **453**, 840-842 (2008)

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)



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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

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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

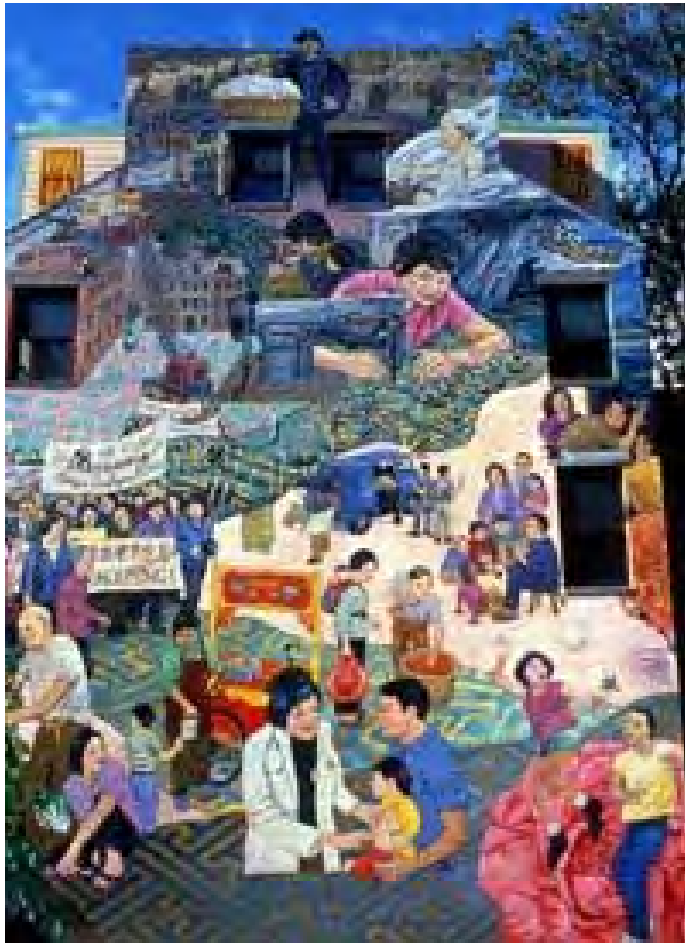
Lessons Learned

(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
中華耆英會



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



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Tufts Public Health

WORKING ACROSS DISCIPLINES AND GLOBAL BOUNDARIES



School
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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

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
 - <http://www.tuftsctsi.org/wp-content/uploads/2015/08/Building-Your-Capacity-Curriculum-2012.pdf>
- ADAPT
 - <http://www.tuftsctsi.org/research-services/stakeholder-community-engagement/adapt/>
- Community Assessment of Freeway Exposure for Health
 - <http://sites.tufts.edu/cafeh/cafeh-study-2/>

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Images

- <http://www.davidfichter.com/images/m/murals078.jpg>
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- <http://boston-chinatown.info/wp-content/uploads/sites/3/2015/04/chinatown-1-960x600.jpg>
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