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The Importance of Community Engagement for Translational Research

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The Importance of Community Engagement for Translational Research

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MAY 8, 2014

NCATS Mission



To catalyze the generation of innovative methods and technologies that will enhance the development, testing and implementation of diagnostics and therapeutics across a wide range of human diseases and conditions.

NCATS Mission: an informal but important modification



*To catalyze the generation of innovative methods and technologies that will enhance the development, testing and implementation of **interventions that tangibly improve human health** across a wide range of human diseases and conditions.*

Translational Sciences

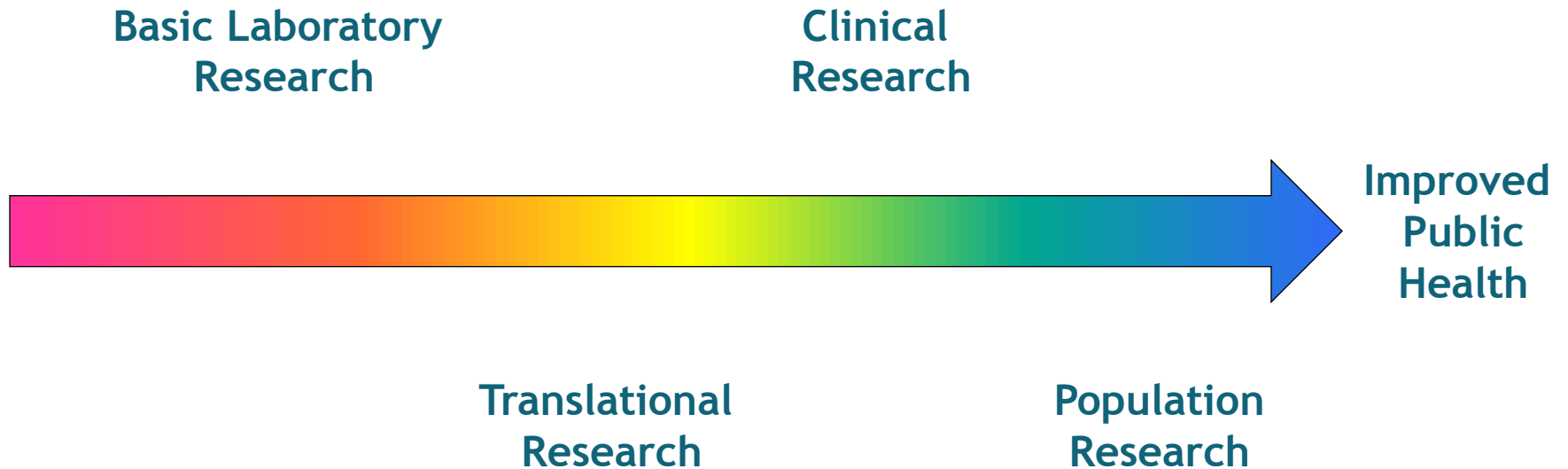
- Translational sciences comprise the process of **turning observations** in the laboratory and clinic into **effective interventions** that **improve the health of individuals and the public** - from diagnostics and therapeutics to medical procedures and behavioral changes.

Catalyzing Collaboration within NCATS Across the Translational Spectrum

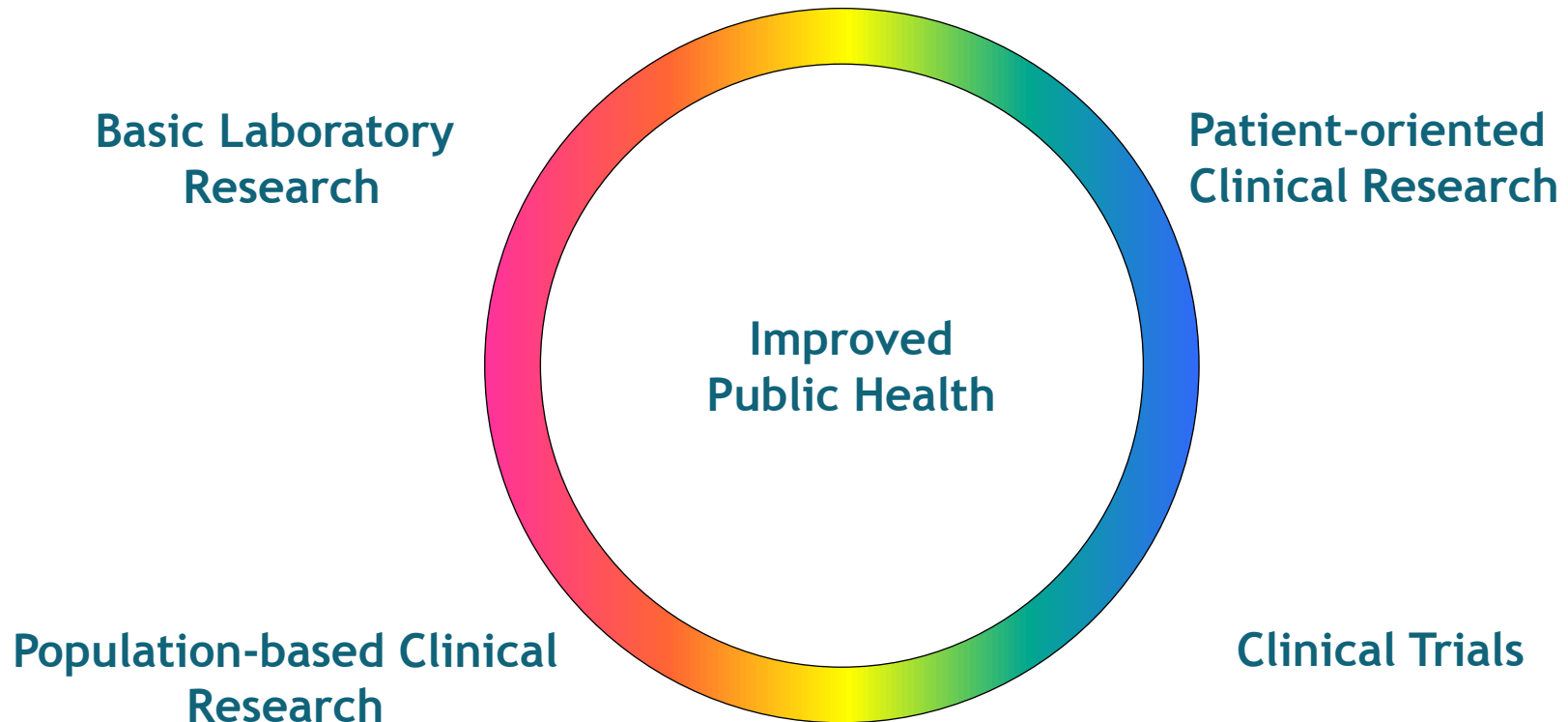


- What is meant by “community”?
- We really mean “communit^{ies}”
 - Patients, families, disease advocacy groups, non-profits, health care providers, clinical researchers, PBRNs, geographic groupings, cultural groups, faith-based organizations, local health departments, “the public”
- Consistent involvement is critical for meaningful prioritization, focus, and outcomes
- Particular focus on “innovative methods and technologies” to address critical research questions and advance translation T1-T4

Standard Model



The Way It Should Work

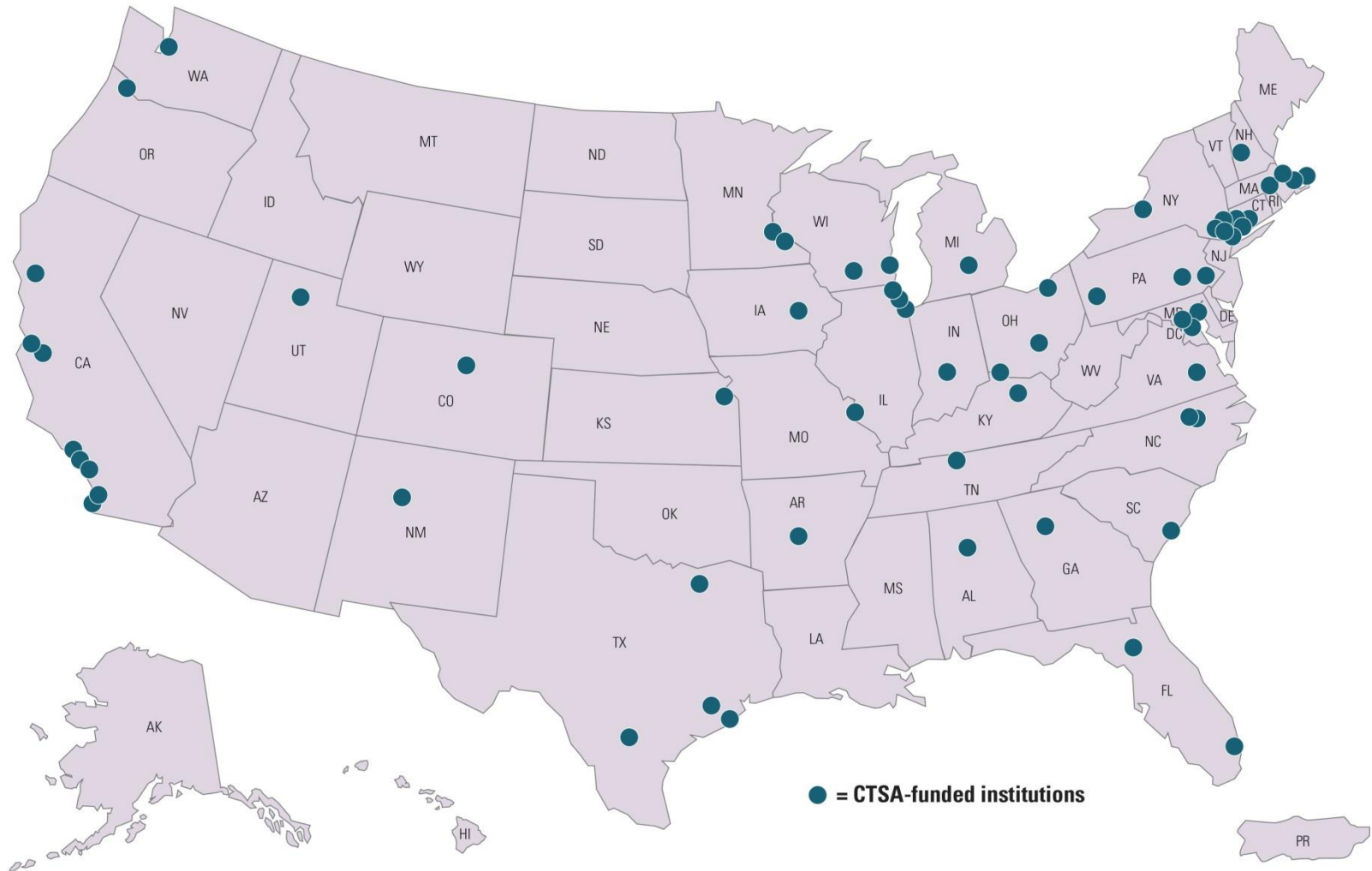


Clinical and Translational Science Awards

Led by NCATS Division of Clinical Innovation

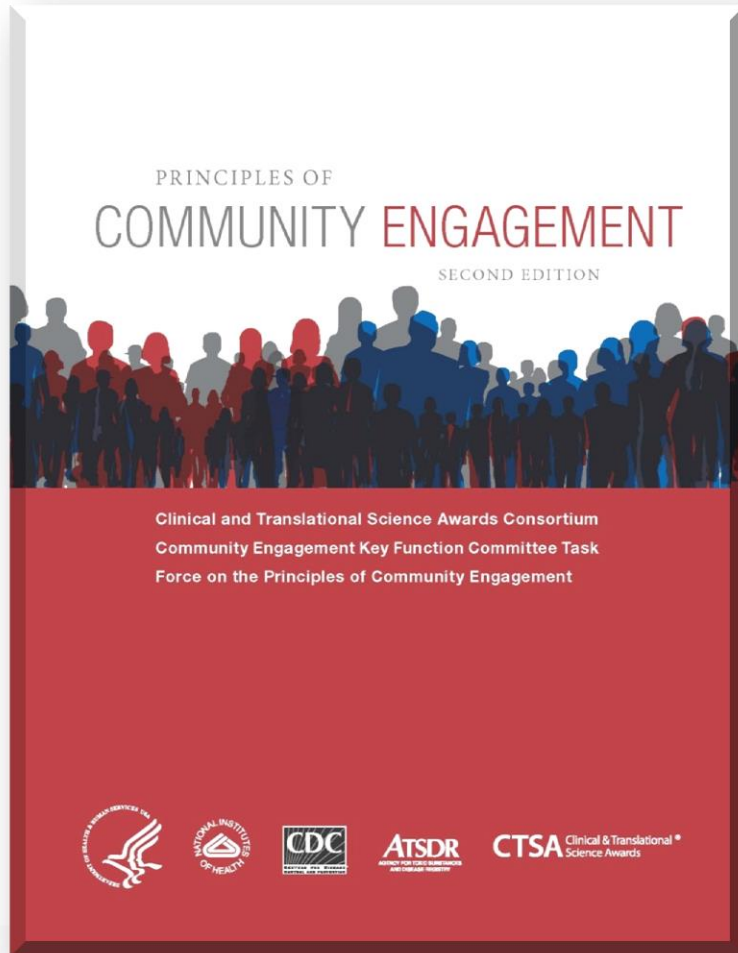
- A national consortium of 62 medical research institutions
- Collaborate to improve the way clinical and translational research is conducted nationwide
- Goals:
 - Accelerate the process of translating laboratory discoveries into treatments and interventions
 - Provide innovative training for clinical and translation researchers
 - Engage communities in clinical and translational research

Clinical and Translational Science Awards (CTSA) Program Sites



CTSAs

CE Accomplishments



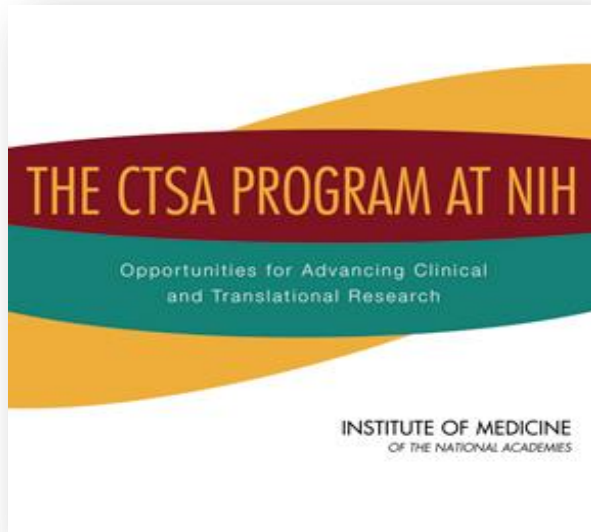
- Principles of Community Engagement, 2nd edition
 - Primer developed by CDC and updated by the CE KFC taskforce
- Community Engagement Consultative Service (CECS)
 - Helps individual CTSAs successfully engage with internal and external groups
- Has been a driving force in the CTSAs program

Community Engagement and the CTSA Program

- CE has been a key component of the CTSA program that has evolved over time
- Each CTSA tailors their CE activities based on their expertise in this area (community outreach to CBPR)
- As the CTSA program has expanded and matured, there has been an increasing commitment to CE activities
- CE has largely focused on the latter phases of the translational research spectrum

IOM Report on the CTSA Program

Recommendations



- IOM CTSA Report released June 2013
- Report includes 7 recommendations
 1. Strengthen leadership of the CTSA program by NCATS
 2. Reconfigure and streamline CTSA consortium
 3. Build on the strengths of the individual CTSAs across the spectrum of research
 4. Formalize and standardize clear, consistent, and novel metrics
 5. Advance innovative education and training models with a focus on team science, leadership, and entrepreneurship
 6. **Ensure community engagement in all phases of research**
 7. Strengthen translational research relevant to child health

IOM Report

Community Engagement

- NCATS and the CTSA program should ensure that patients, family members, health care providers, clinical researchers, and other community stakeholders are involved across the continuum
- NCATS and the CTSA program should...
 1. Define community engagement broadly
 2. Ensure active and substantive community stakeholder participation in priority setting and decision making across all phases
 3. Define and clearly communicate goals and expectations and ensure the broad dissemination of best practices
 4. Explore opportunities and incentives to engage a more diverse community



Community Engagement Across the Translational Spectrum

- Integrate CE into all phases of translational research from basic science (T0) to community and population health research (T4)
 - Identify community health needs and priorities
 - Provide input on relevant research questions
 - Contribute to appropriate research design and methods
 - Develop culturally-sensitive and ethical protocols
 - Enhance the recruitment and retention of research participants
 - Implement and disseminate research findings more effectively



NCATS and Community Engagement

Next Steps

- Implementation of IOM report
 - Working group of NCATS Advisory Council will present their report at May 16 NCATS Council meeting
- NCATS Advisory Council Subcommittee on Patient Engagement
 - Charged with making recommendations on how to engage the public/communities/patients in achieving the mission of NCATS
 - Committee comprised of Council members from patient advocacy organizations and NCATS program staff
 - Report and recommendations to be presented at May Council meeting

Considerations for Community–Engaged Translational Research

- How to meaningfully identify and involve communities from earliest stages of research
- How to change the culture of research to incorporate this
- How to achieve bidirectional interaction between community and researchers
- How to measure the outcome (not just process) metrics to gauge success (or lack thereof) of our CE interventions and innovations



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