

Advancing the Science of Community Engaged Research

Innovative and Effective Methods of Stakeholder Engagement in Translational Research

Washington, DC; Association of American Medical Colleges

Novel Approaches to Training Researchers and Stakeholders in Community Engaged Research

Cheryl Anne Boyce, Ph.D.

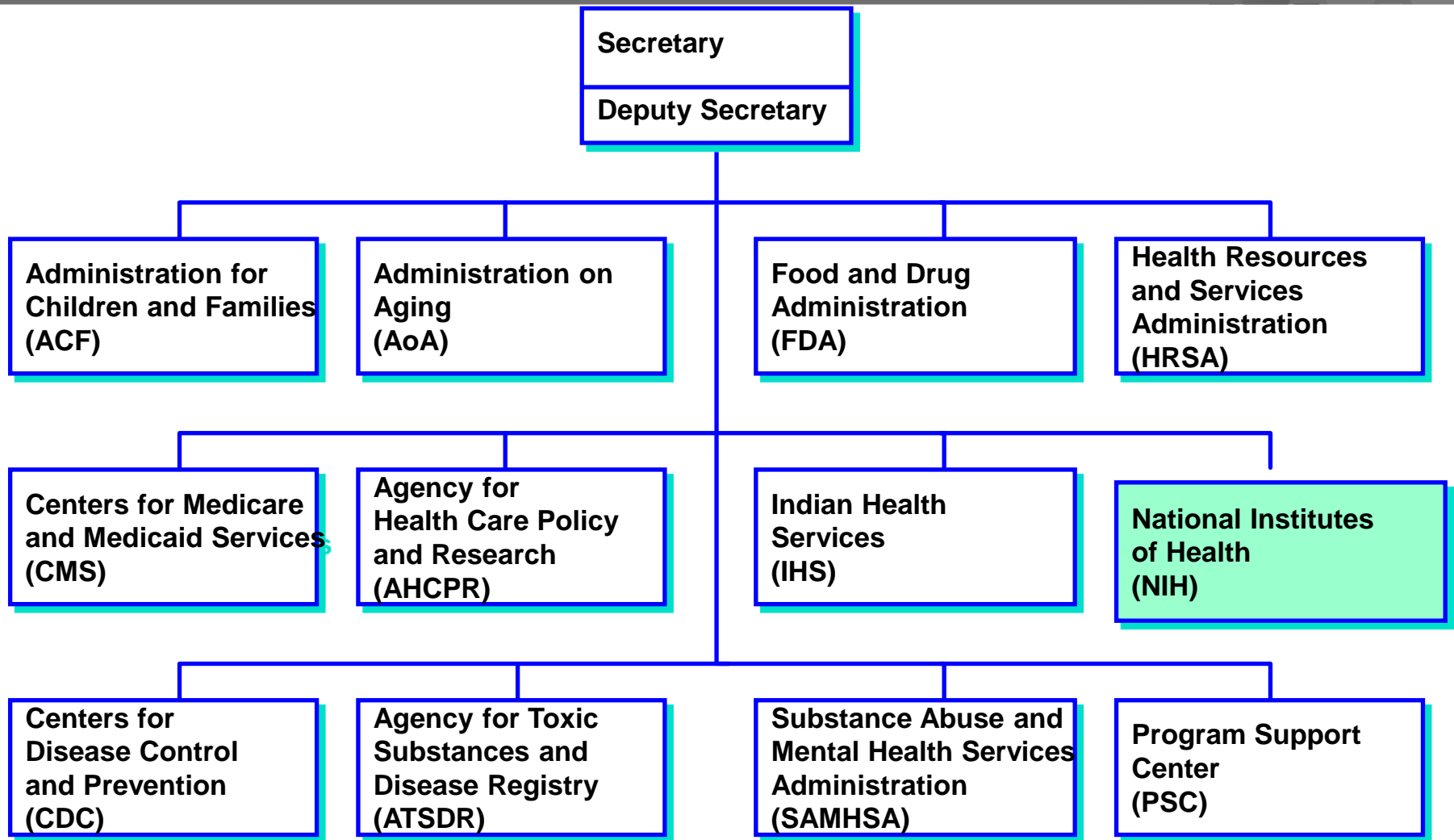
Chief, Implementation Science Branch,
Center for Translation Research and Implementation Science

**The views expressed are those of the author and do not necessarily reflect the views of the National Institutes of Health (NIH), Department of Health and Human Services (DHHS).*

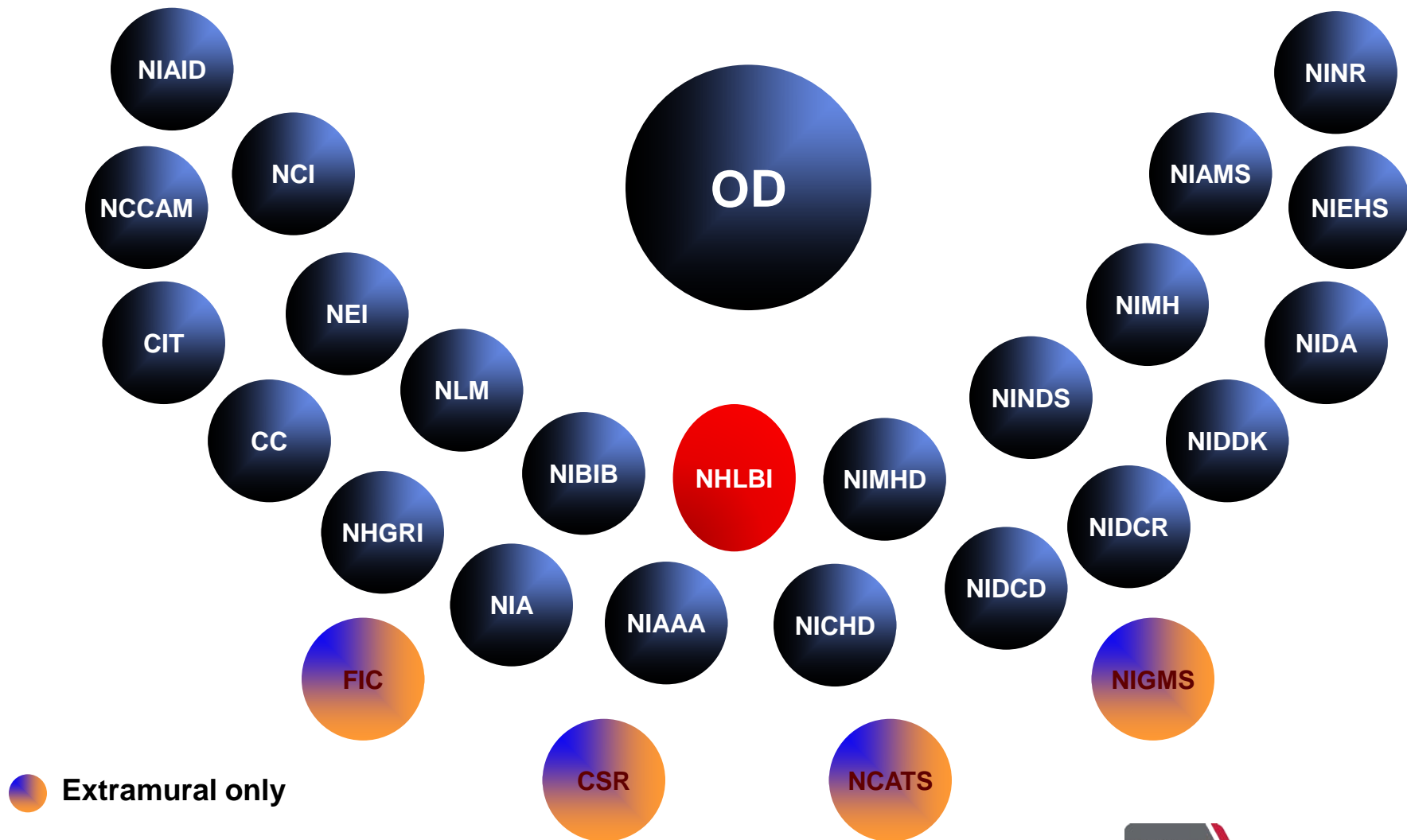
August 26, 2016



US Department of Health and Human Services (DHHS)



Structure of the NIH: 27 Institutes and Centers

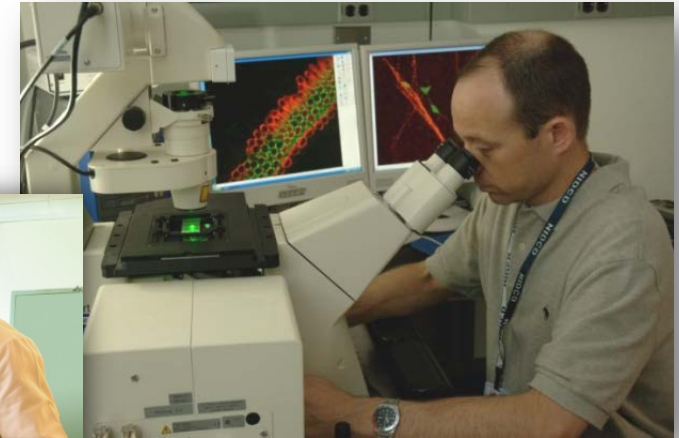


Center for Translation Research and Implementation Science (CTRIS)

National Heart, Lung and Blood Institute

Mission:

Provide **global leadership** for **research, training, and education** programs to promote the **prevention and treatment** of heart, lung, and blood diseases and enhance the health of all individuals so that they can live longer and more fulfilling lives.



Center for Translation Research and Implementation Science (CTRIS)

NHLBI Strategic Goals

1

Understand
Human
Biology

2

Reduce
Human
Disease

3

Advance
Translational
Research

4

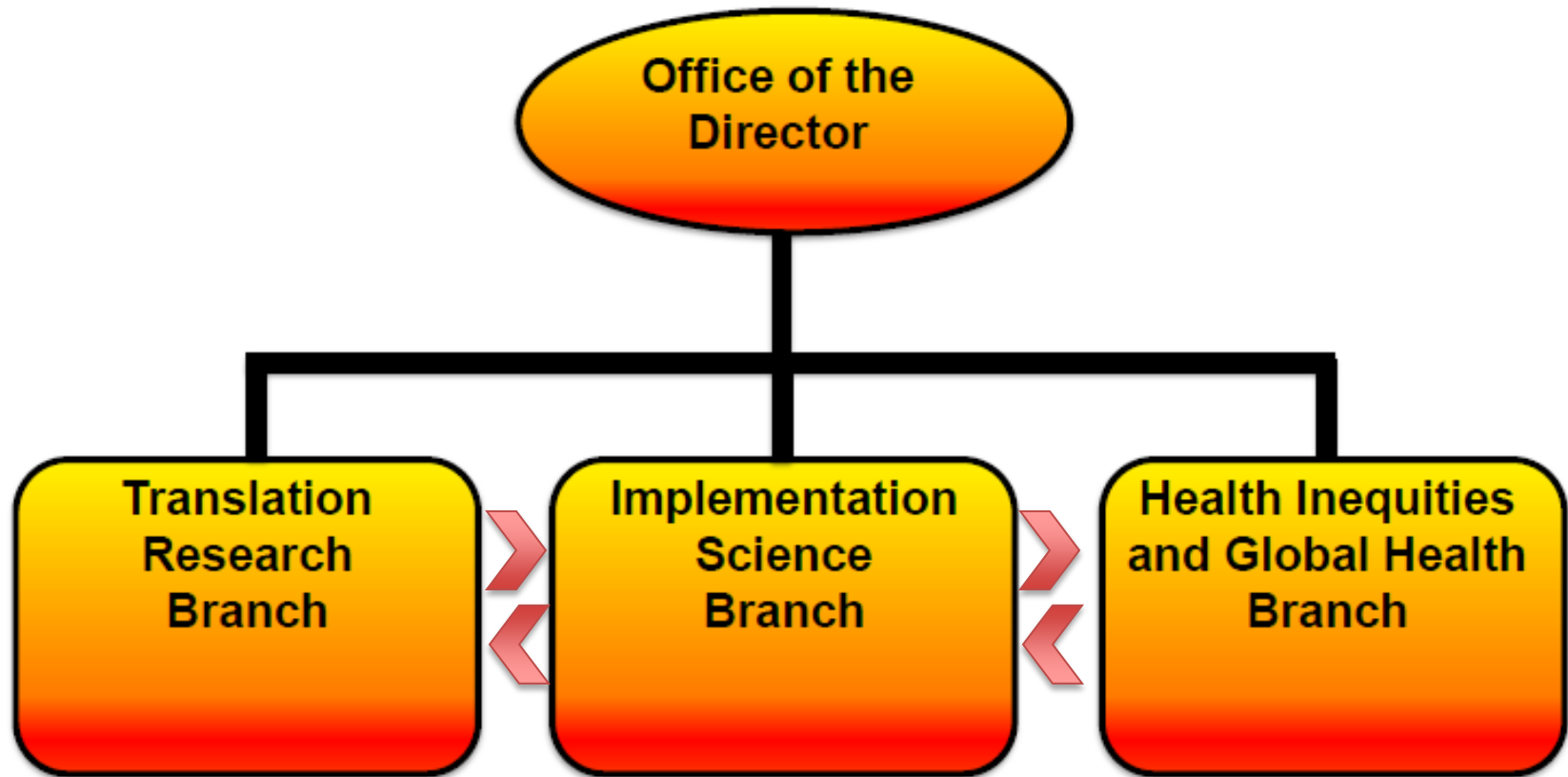
Develop
Workforce &
Resources

The four Strategic Goals for the Strategic Visioning process span the NHLBI mission and include research on normal health and disease in heart, lung, blood, and sleep (HLBS) systems, the *translation of research for prevention, diagnosis, and treatment of diseases, and the support of training and resources for biomedical researchers across the NHLBI landscape.*

CTRIS Announcement, January 23, 2014

*The Center for Translation Research and Implementation Science (CTRIS) will serve as a strategic focal point for **T4 translation research, implementation science, and a research agenda** that addresses both **domestic and global health inequities**, and **research training** for a workforce to achieve these goals.*

Center for Translation Research and Implementation Science (CTRIS)



Focusing on Late Stage Translation Research (T4)

Biomedical Model

Bench Research

- Fundamental Discovery Science
 - Animal Studies

Bedside

- 1st Human Studies
- Controlled Observations
- Phase I Clinical Trials

Patients

- Phase II and III Clinical Trials

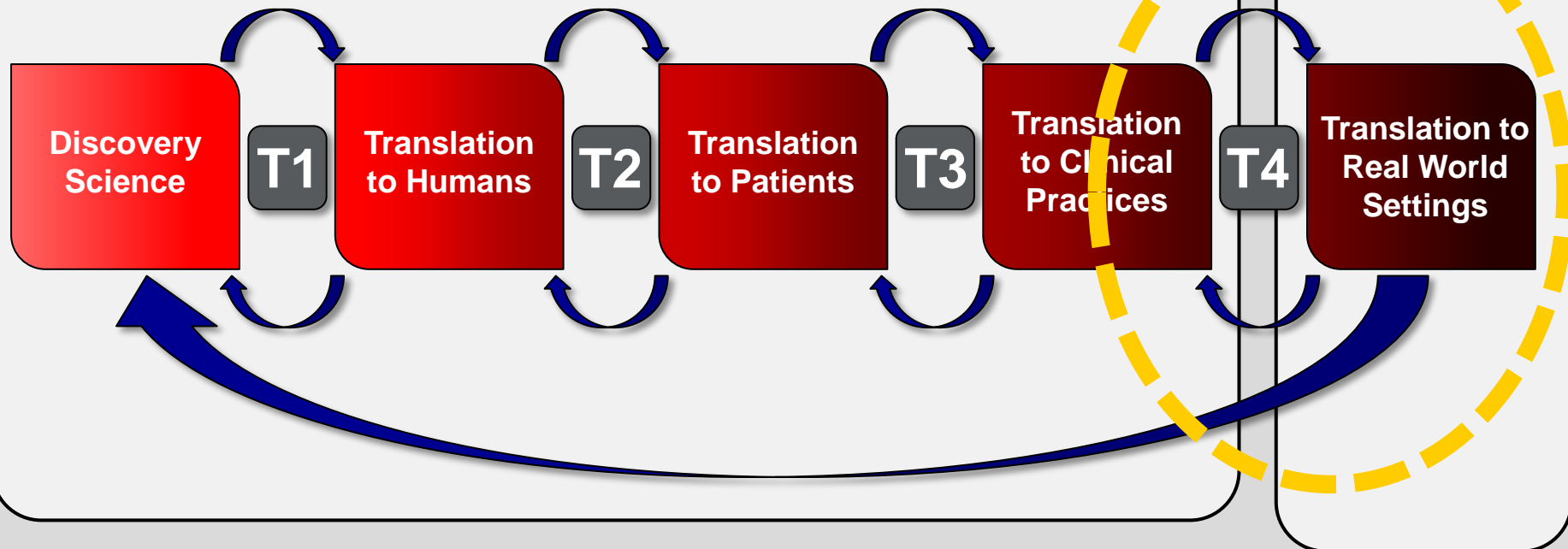
Practices

- Phase IV Clinical Trials
- Comparative Effectiveness Research

Biomedical and Socioecological Model

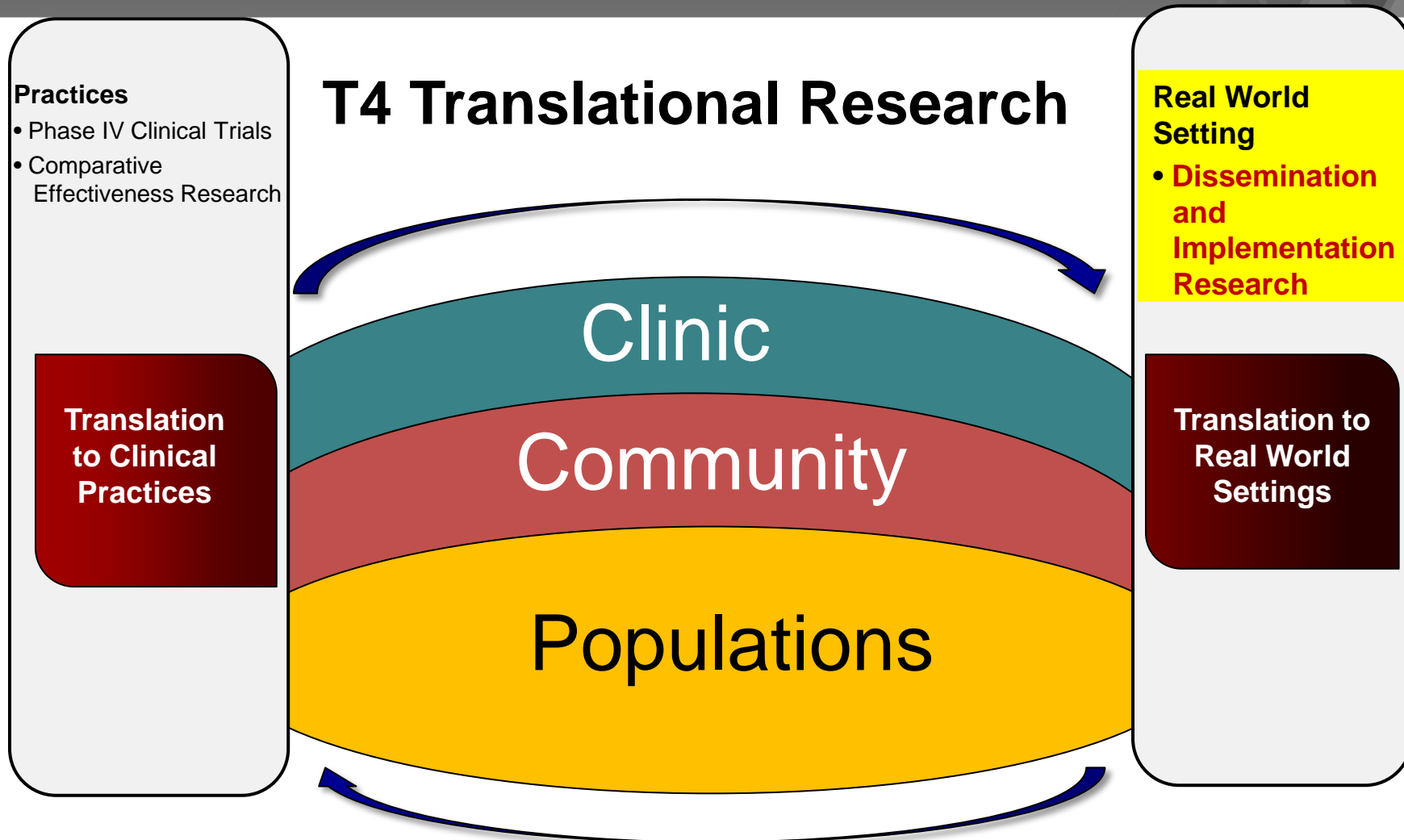
Real World Setting

- Dissemination and Implementation Research



Mensah. *Global Heart* September 2013;8(3): 283-284. Based on and informed by the models of Khoury et al. *Genet Med* 2007;9:665-74, and the Harvard Catalyst; The Harvard Clinical and Translational Science Center, available at: <http://catalyst.harvard.edu/pathfinder/>. Accessed August 28, 2013.

Late Stage T4 Translation Research



* Authors conclusion – T4 research occurs in other settings but these are key for population impact

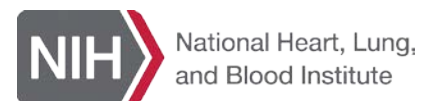
Center for Translation Research and Implementation Science (CTRIS)

T4 Translation Research - Approach

- Multilayered
 - Community
 - Health care system
 - Providers
 - Patients
 - Families
- Multifaceted
 - Interventions at several layers
 - Aligned with common outcome
 - Specific targets at each level
- Engages stakeholders/key partners at each level
- Population-level impact

T4

Funding Opportunities



NHLBI Research Career Development Programs in T4 Implementation Research (K12)- RFA

Program Goal

- Build a new trans-disciplinary implementation research workforce to investigate strategies that, when scaled up improve health outcomes for NHLBI-related diseases and conditions.
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-HL-17-016.html>

- RFA-HL-17-016
- Letter of Intent Due Date(s):
 - **September 13, 2016**
(not required)
- Application Receipt Date:
 - **October 13, 2016**
- Earliest Start Date:
 - **September 2017**

Programmatic Contact:

Helena O. Mishoe, PhD, MPH

mishoeh@nhlbi.nih.gov

(301) 451-5078

K12



National Heart, Lung,
and Blood Institute

NHLBI Research Career Development Programs in T4 Implementation Research (K12)- RFA

- Year 1: Planning; Years 2-5: Implementation
- Mentoring by a multidisciplinary research team
- Scholars must hold a research or health-professional doctoral degree
- Scientific and training environments beyond disciplines.
- Collaborations across diverse and non-academic institutions
- Partnerships/collaborative training linkages with practice settings

K12

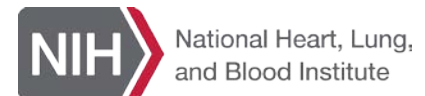
Strategies to Increase Delivery of Guideline-Based Care to Populations with Health Disparities (R01)- PAR

Program Goal

- Innovative and feasible studies to test strategies to accelerate the adoption of guideline-based recommendations into clinical practice among populations with health disparities.
- <http://grants.nih.gov/grants/guide/pa-files/PAR-15-279.html#sthash.uMjziN1h.dpu>

- PAR-15-279
- Application Receipt Dates:
 - **October 21, 2016**
 - **June 21, 2017**
 - **October 20, 2017**
 - **June 21, 2018**
- Expiration Date:
 - June 22, 2018

R01



NIH Support for Conferences and Scientific Meetings (Parent R13)- PA

Program Goal

- Support high quality scientific conferences that are relevant to the NIH's mission and to the public health. A conference is defined as a symposium, seminar, workshop, or any other organized and formal meeting, whether conducted face-to-face or via the internet, where individuals assemble (or meet virtually).
- PA-16-294
- Standard Application Receipt Dates (three times per year)
- <http://grants.nih.gov/grants/guide/pa-files/PA-16-294.html>

R13

NHLBI Program Project Applications (P01)- PAR

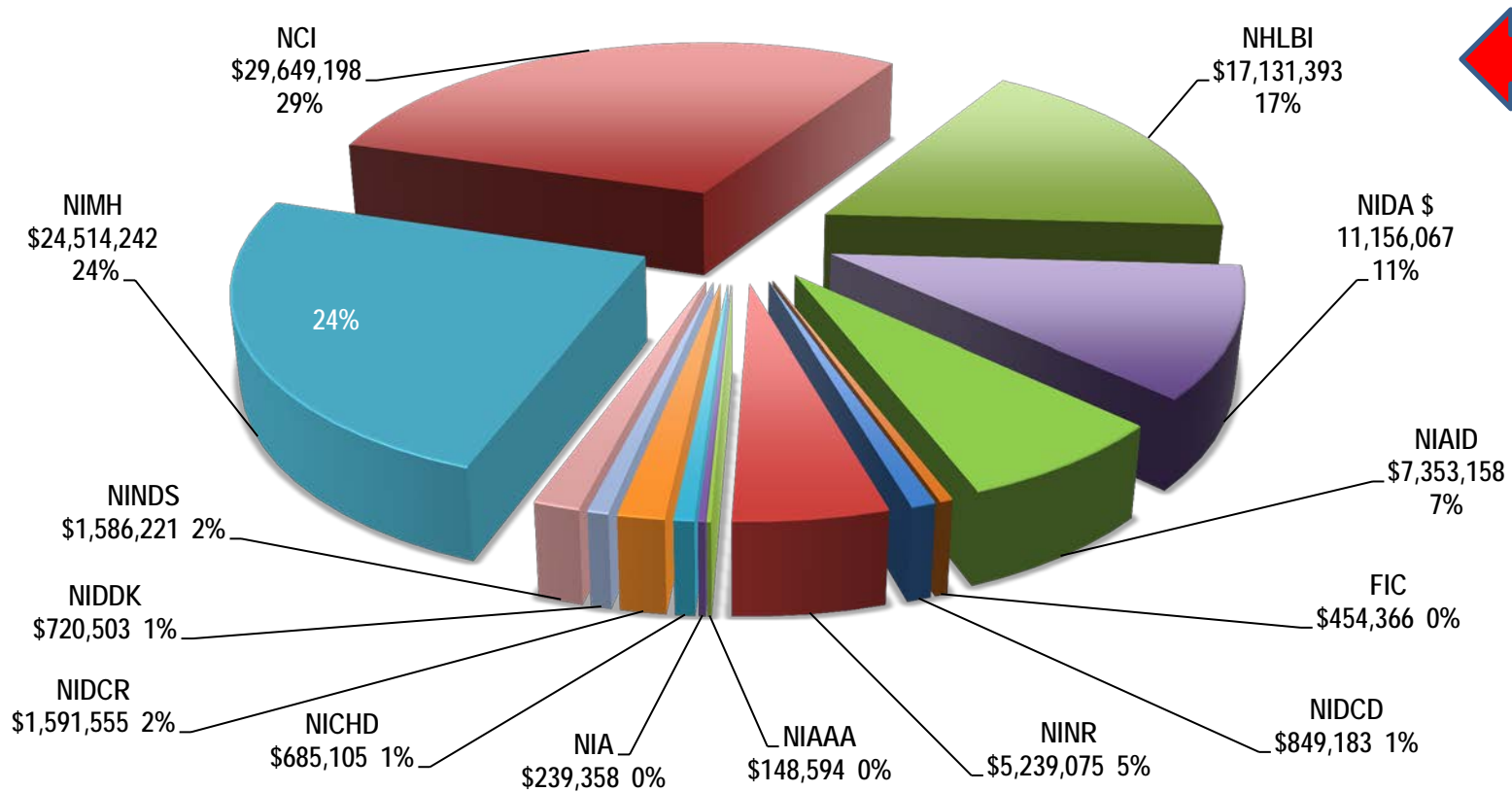
Program Goal

- Support minimum of three interrelated research projects that investigate a complex biomedical theme or research question. Program Project Grants support collaborative research effort can accelerate the acquisition of knowledge more effectively than a simple aggregate of research projects that have no interaction or thematic integration.
- PAR-16-402
- Standard Application Receipt Dates (three times per year)
- <http://grants.nih.gov/grants/guide/pa-files/PAR-16-402.html>

P01

R01 Funded D & I Studies 2005-2015

Funded RO1 D&I Studies 2005-2015



(Method from Tinkle et al, 2013 using data from NIH Reporter Accessed February, 2016)

DIRH Study Section (Review Committee)

- The Dissemination and Implementation Research in Health (DIRH) Study Section reviews applications intending to bridge gaps between public health, clinical research, and everyday practice.
- The focus of the studies reviewed is on the transmission and implementation of knowledge from scientific discovery to transform healthcare delivery, improve health outcomes, and manage acute and chronic illness.



Dissemination and Implementation Research in Health Study Section [DIRH] Share | X |

The Dissemination and Implementation Research in Health (DIRH) Study Section reviews applications intending to bridge gaps between public health, clinical research, and everyday practice by building a scientific knowledge base about mechanisms whereby health information, interventions, and scientifically based clinical practices are adopted in public health and healthcare service use in a variety of settings. The focus of the studies reviewed is on the transmission and implementation of knowledge from scientific discovery to transform healthcare delivery, improve health outcomes, and manage acute and chronic illness.

Rosters

[DIRH Membership Roster](#) [DIRH Meeting Rosters](#)

"How will this study advance the field of implementation science?"

Dissemination and Implementation Research in Health (R01)

Program Goal

- Support grant applications that will identify, develop, test, evaluate and/or refine strategies to disseminate and implement evidence-based practices (e.g. behavioral interventions, prevention, early detection, diagnosis, treatment, disease management interventions, quality improvement programs) into public health, clinical practice, and the community.
- <http://grants.nih.gov/grants/guide/pa-files/PAR-16-238.html>

- PAR-16-238 , R01
Research Project Grant

R01

- Companion grants
 - PAR-16-236, R21
Exploratory/Developmental Grant

R21

- PAR-16-237, R03
Small Grant Program

R03

- Standard Application Receipt Dates (three times per year)

Non-HHS Agency D & I Partners

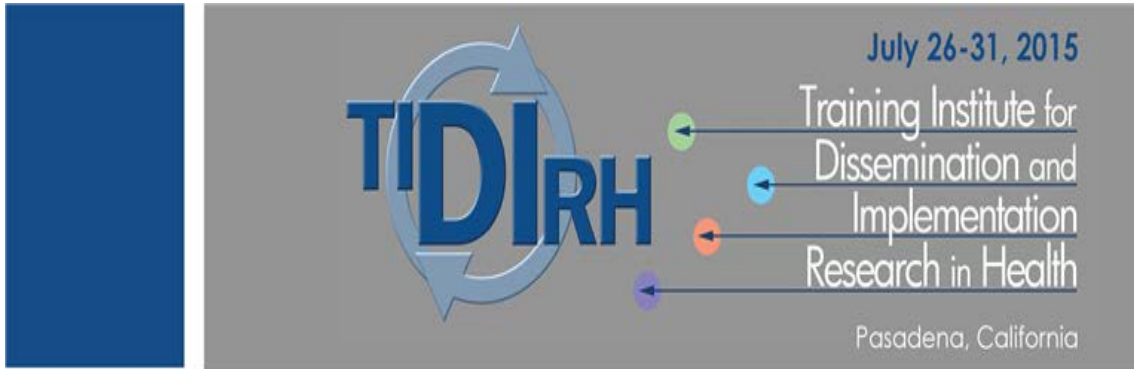
- Patient-Centered Outcomes Research Institute
- Department of Education
 - Pediatric populations
 - School health clinics
- Department of Justice
- Department of State
- Department of Veterans Administration



Research and Training Opportunities and Resources



D&I RESEARCH TRAINING: TIDIRH

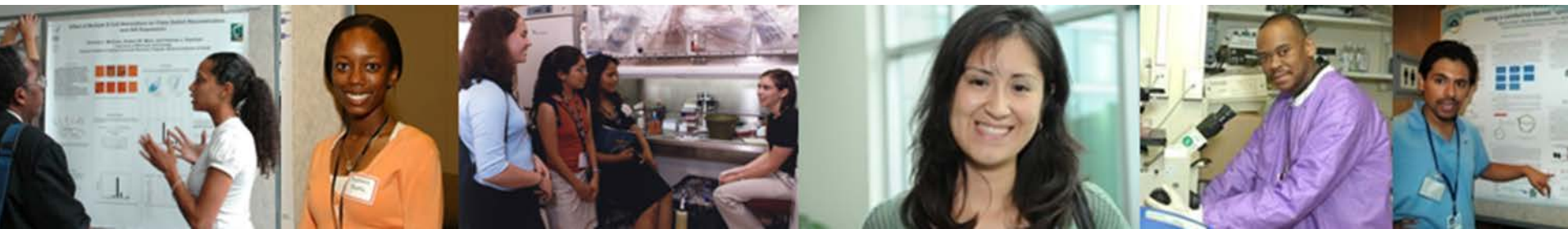


Applications are
due on
August 26, 2016.

- Initiated in 2011: The TIDIRH used a 5-day residential immersion to maximize opportunities for trainees and faculty to interact. Over 200 have been trained.
- Harvard University and the Dana-Farber Cancer Institute with support from NCI, NHLBI, NIDDK, NIMH, OBSSR, ODP, and VA.

[https://researchtoareality.cancer.gov/discussions/marking-five-great-years-di-training.](https://researchtoareality.cancer.gov/discussions/marking-five-great-years-di-training)

http://obssr.od.nih.gov/about_obssr/about.aspx



9th Annual D&I Conference

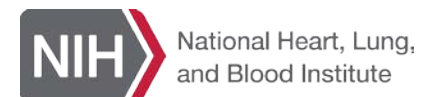
NIH Sponsored in Partnership with OBSSR, VA and now Academy Health
“State of the Science” Venue

- 2007: “Showcase,” ~350 participants
- 2009: “Building Capacity,” > 500 registrants
- 2010: “Methods and Measures,” 900 registrants
- 2011: “Policy and Practice,” 1200 registrants
- 2012: “D and I at the Crossroads,” 1200 registrants
- 2014: “Transforming Health Systems to Optimize Individual and Population Health,” 1200 registrants
- 2015: “Optimizing Personal and Population Health,” 1200 registrants



9th Annual Conference on the Science of
Dissemination and Implementation in Health

■ Co-hosted by the National Institutes of Health and AcademyHealth
December 14-15, 2016 | Washington, DC



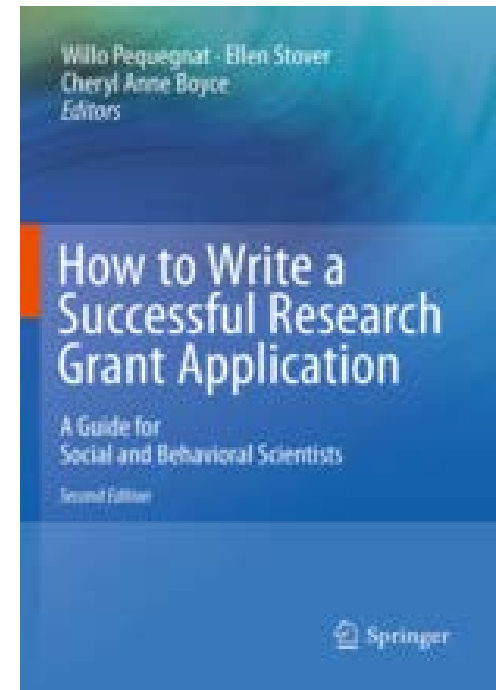
Developing Successful Research Grants

“How to Write a Successful Research Grant Application: A Guide for Social and Behavioral Scientists” (Pequegnat, Stover & Boyce, 2011).

- *Developed from HIV/AIDS grant research workshops.*
- *The only collaborative book written by federal personnel and research investigators who have participated in the process of reviewing research grants.*

Chapters of interest:

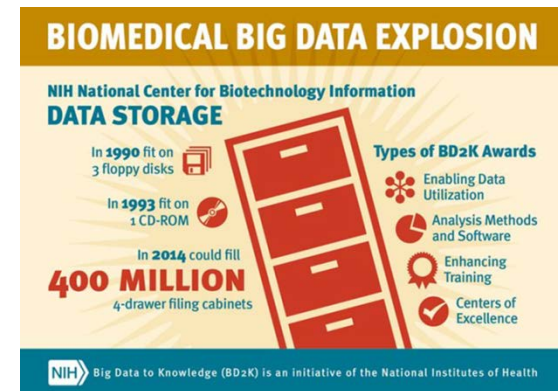
- “Community-Based Collaborations: Designing, Conducting and Sustaining Prevention Programs” (McKay, Bell & Blake, 2011)
- Selecting the Appropriate Research Mechanism: Finding the Right Match (Boyce & Ferrell Aklin, 2011).



<http://www.springer.com/medicine/book/978-1-4419-1453-8>

Future Prospects and Innovations

- Precision Medicine Initiative
- Team Science
- Big Data
- Data Harmonization
- Affordable Health Care
- Electronic Health Records
- Neuroepidemiology
- Population neuroscience



NIH Precision Medicine Initiative



WHAT IS IT?

Precision medicine is a groundbreaking approach to disease prevention and treatment based on people's individual differences in environment, genes and lifestyle.

The Precision Medicine Initiative® Cohort Program will lay the foundation for using this approach in **clinical practice**.

WHAT ARE THE GOALS?

Engage a group of **1 million or more U.S. research participants** who will share biological samples, genetic data and diet/lifestyle information, all linked to their electronic health records. This data will allow researchers to develop more precise treatments for **many diseases and conditions**.

Pioneer a new model of research that emphasizes **engaged research participants, responsible data sharing and privacy protection**.



Research based on the cohort data will:

- Lay **scientific foundation** for precision medicine
- Help identify new ways to **treat and prevent disease**
- Test whether **mobile devices**, such as phones and tablets, can encourage healthy behaviors
- Help develop the **right drug** for the **right person** at the **right dose**

<https://www.nih.gov/precision-medicine-initiative-cohort-program>

Data Harmonization and Toolkits



Team Science Toolkit

The screenshot shows the homepage of the Team Science Toolkit. At the top, the National Cancer Institute logo and name are on the left, and the text "at the National Institutes of Health | www.cancer.gov" is on the right. Below this is the main header "Team Science Toolkit" with a subtitle: "An interactive website to help you support, conduct and study team-based research." A navigation bar contains links for Home, About Team Science, About the Toolkit, Discover (highlighted), Contribute, Connect, News & Events, and About Us.

The main content area features a large banner for the "SciTS 2016 Conference! May 16-19, 2016". The text describes the conference location (Mayo Clinic in Phoenix, AZ), registration status, and lists confirmed plenary speakers: Michael Crow, Barry Bozeman, Christian Schunn, Julie Thompson-Klein, Ruth Wageman, and Edward Hackett. A "Learn More" link is provided. To the right of the text is a graphic with the SciTS 2016 logo and the tagline "Building the knowledge base for effective team science". Below the graphic, it says "SciTS 2016 Conference | May 16-19, 2016 | Phoenix, Arizona".

Below the banner, there are three main sections:

- Discover what resources are available.** This section includes a search bar with a "Search" button and a link to "Advanced Search". Below it, there is a dropdown menu for "Browse by type of resource or goal" and a "Browse" button.
- Contribute new resources to the Toolkit.** The text encourages users to "Share your knowledge by uploading tools and information about the practice or study of team science."
- Connect to colleagues across disciplines.** The text invites users to "Join expert discussions on the blog, add your name to the directory, or stay up-to-date on News and Events."

On the right side of the page, there is a "Login | Register" link. Below it, a "What Users Are Saying" section features a small profile picture and a link. The "Recently Added Resources" section lists three items: "RD and Team Building Senior Program Administr...", "SESYNC Postdoctoral Fellowships and Collabora...", and "Microbiology Leaves the Solo Author Behind". Below this list, it states "The Toolkit currently includes 2672 resources." The "Resources" section lists "Tools", "Measures", "Bibliography", and "Editors' Picks". The "Connections" section lists "Recent Blog Posts", "Listserv", "Communication Materials", and "Team Science Experts".

<https://www.teamsciencetoolkit.cancer.gov/Public/Home.aspx>

Common Data Element (CDE)

- **Common Data Element (CDE)** - A data element that is common to multiple data sets across different studies.
 - Commonality may be intentional or unintentional
 - CDEs improve data quality and promote data sharing. .
- **Types**
 - **Universal** - may be used in studies, regardless of the specific disease or condition of interest, e.g., demographic information of study subjects, medical history, certain patient-reported outcomes.
 - **Domain-specific** - designed and intended for use in studies of a particular topic, disease or condition, body system, or other classification, e.g., sickle cell disease, etc.
 - **Required** - required or expected, as a matter of institutional policy (e.g., research funder or performer), to be collected for all subjects in studies of a particular type.
 - **Core** - required or expected to be collected in particular classes of studies.



<https://www.nlm.nih.gov/cde/glossary.html>

Phenotypes and eXposures (PhenX) Toolkit



PhenX Toolkit



Log In
Register

- Home
- Browse
- Search
- Registration
- Resources
- News
- Help
- About

Welcome to the PhenX Toolkit

The PhenX (consensus measures for **Phenotypes** and **eXposures**) Toolkit is a catalog of recommended, standard measures of phenotypes and environmental exposures for use in biomedical research. PhenX measures can be used to expand a study design beyond the primary research focus. Use of PhenX measures facilitates cross-study analysis, potentially increasing the scientific impact of individual studies. The PhenX Toolkit is a Web-based resource and is available for use at no cost. [More >>](#)



Citation and
Guidance



Research Domains



Top Measures



Search



Mental Health
Research



Sickle Cell Disease
Research



Substance Abuse
and Addiction



Tobacco Regulatory
Research

<https://www.phenxtoolkit.org>



National Heart, Lung,
and Blood Institute

Grid-Enabled Measures Database (GEM)

The screenshot shows the GEM website interface. At the top, the National Cancer Institute logo and name are on the left, and the U.S. National Institutes of Health website is on the right. A navigation bar contains links for Home, Constructs, Measures, Datasets, Workspaces, About, My GEM, and Glossary. A search bar is located in the top right corner. The main content area is divided into three columns. The left column is a 'Content Areas' sidebar with a scrollable list of categories such as Anthropometrics, Cancer, Cardiovascular, Diabetes, Education, Training, and Career Development, Environment, HIV/AIDS, Mental Health, Methods, Nutrition, Obesity, Occupational Health, Pain, Physical Activity, Pregnancy, Risk and Decision Making, Sexual Behaviors, Sleep, Smoking/Tobacco, Spirituality, Stress, and Substance Abuse. The middle column features a 'Welcome to GEM' message, a list of user capabilities (adding constructs, updating metadata, rating measures, sharing data, and searching), and a 'Community News' section with two articles: 'Check out the Team Science Toolkit blog about GEM' and 'Inaugural GEM-inar! GEM Care Planning: Advancing Survivorship Care Planning'. The right column contains 'Recent Workspaces' and 'My Subscriptions' sections.

National Cancer Institute

U.S. National Institutes of Health | www.cancer.gov

You are not logged in. [Login](#) [Register](#) [Why register?](#)

GEM Grid-Enabled Measures Database

Home | Constructs | Measures | Datasets | Workspaces | About | My GEM | Glossary

Home

Content Areas

- Anthropometrics
- Cancer
- Cardiovascular
- Diabetes
- Education, Training, and Career Development
- Environment
- HIV/AIDS
- Mental Health
- Methods
- Nutrition
- Obesity
- Occupational Health
- Pain
- Physical Activity
- Pregnancy
- Risk and Decision Making
- Sexual Behaviors
- Sleep
- Smoking/Tobacco
- Spirituality
- Stress
- Substance Abuse

Welcome to GEM, a web-based collaborative tool containing behavioral, social science, and other relevant scientific measures.

The goal of GEM is to support and encourage a community of users to drive consensus on best measures and share the resulting data from use of those measures.

GEM enables users to:

- Add constructs or measures to the database
- Contribute to and update existing information (metadata) about constructs and measures
- Rate and comment on measures to drive consensus on best measures
- Access and share harmonized data
- Search for and download measures

[Learn more about GEM](#)

▼ Community News ▲ Recent Additions

Check out the Team Science Toolkit blog about GEM

See a recent blog by Richard Moser and Kisha Coa about how GEM can be used to facilitate team science on the Team Science Toolkit website (<https://www.teamsciencetoolkit.cancer.gov>). Make sure to explore this helpful site that has information and... [More](#)

[Click here to read the blog](#)

Inaugural GEM-inar! GEM Care Planning: Advancing Survivorship Care Planning

In case you missed it, click the link below to watch the first GEM-inar that highlights real-world application and use of GEM. NCI's Carly Perry, PhD, MA, MSW and University of Pittsburgh's Ellen Beckjord, PhD, MPH presented on the GEM-Care... [More](#)

[Click here to watch the Gem-inar](#)

[More Community News](#)

Recent Workspaces
Customizable virtual areas to collaborate on a specific project


- CaPTC-AC3-MADCaP Consortia Clinical Measures SIG
This work space represents the CaPTC-AC3-MADCaP Consortia... [More](#)
- CaPTC-AC3-MADCaP Consortia Behavioral Measures SIG
CaPTC-AC3-MADCaP Consortia Behavioral Measures workspace... [More](#)
- CaPTC-AC3-MADCaP Consortia Epi & Genetics Measures SIG
This work space represents the CaPTC-AC3-MADCaP Consortia... [More](#)

My Subscriptions
Login to receive updates on constructs, measures, data, and workspaces.

<https://www.gem-beta.org/Public/Home.aspx>

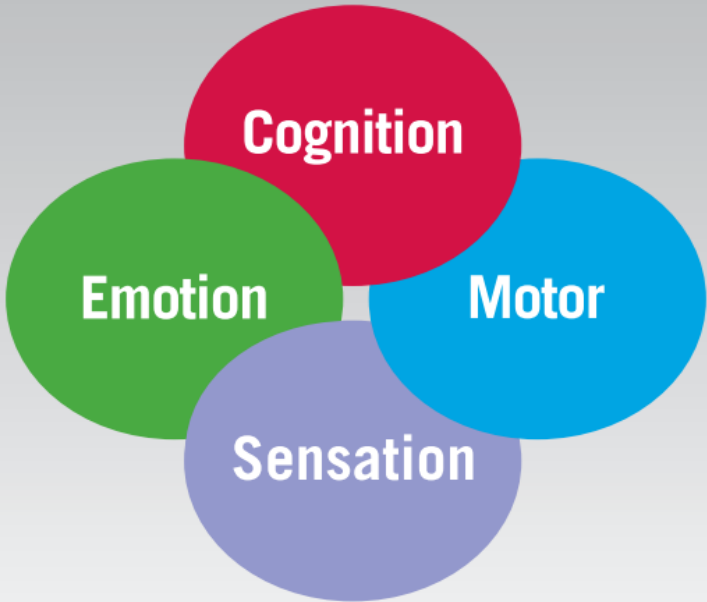
NIH Toolbox

- Monitors neurological and behavioral function over time, and measures the domain constructs across developmental stages.
- Facilitates the study of functional changes across the lifespan, including evaluating intervention and treatment effectiveness.
- App available on iTunes
<https://itunes.apple.com/us/app/nih-toolbox/id1002228307?mt=8>



The NIH Toolbox is a multi-dimensional set of brief, royalty-free measures to assess cognitive, sensory, motor and emotional function that can be administered in two hours or less across diverse study designs and settings.

For Assessment of Neurological and Behavioral Function™



Four domain level batteries available in English and Spanish

Developed by more than 250 contributing scientists at 80 institutions

Individual measures nationally normed for ages 3-85

PROMIS (Patient-Reported Outcomes Measurement Information System)*



PROMIS® (Patient-Reported Outcomes Measurement Information System) is a set of person-centered measures that evaluates and monitors physical, social, and emotional health in adults and children. It can be used with the general population and with individuals living with chronic conditions.

INTRO TO PROMIS

OBTAIN &
ADMINISTER
MEASURES

MEASURE
DEVELOPMENT &
RESEARCH

Why Use PROMIS?

- Developed and validated with state-of-the-science methods to be psychometrically sound and to transform how life domains are measured
- Designed to enhance communication between clinicians and patients in diverse research and clinical settings
- Created to be relevant across all conditions for the assessment of symptoms and functions
- Translations available in Spanish and many other languages

PROMIS, Patient-Reported Outcomes Measurement Information System, and the PROMIS logo are marks owned by the U. S. Department of Health and Human Services.

<http://www.healthmeasures.net/explore-measurement-systems/promis>

*Northwestern University, NIH grant U2C CA186878

ASCQ-Me (Adult Sickle Cell Quality of Life Measurement Information System)*



ASCQ-MeSM (Adult Sickle Cell Quality of Life Measurement Information System) is a patient-reported outcome measurement system that evaluates and monitors the physical, social, and emotional well-being of adults with sickle cell disease (SCD).

INTRO TO ASCQ-ME

OBTAIN &
ADMINISTER
MEASURES

MEASURE
DEVELOPMENT &
RESEARCH

Why Use ASCQ-Me?

- Developed and validated with state-of-the-science methods to be psychometrically sound
- Designed to be comprehensive when used with PROMIS[®]
- Created to be complementary with physiological measures of disease severity
- Supports treatment planning as well as clinical and health services research

ASCQ-Me, the Adult Sickle Cell Quality of Life Measurement Information System, and the ASCQ-Me logo are marks owned by the U. S. Department of Health and Human Services.

<http://www.healthmeasures.net/explore-measurement-systems/ascq-me>

*Northwestern University, NIH grant U2C CA186878



NHLBI: People...Science...Health

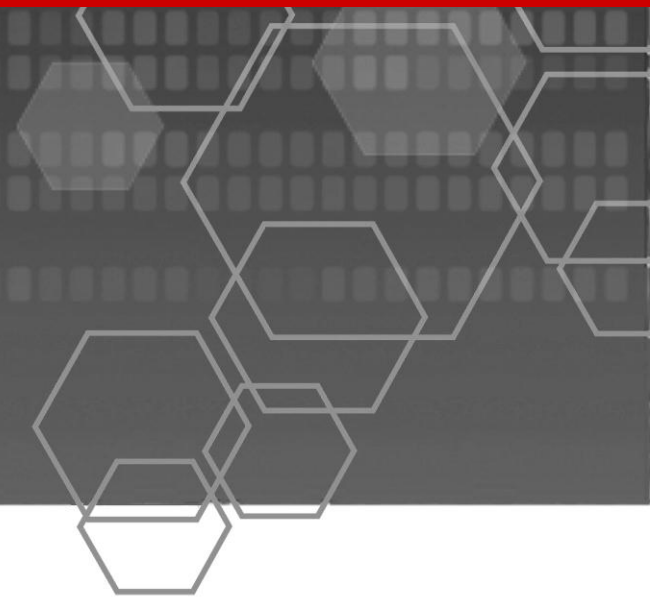
Please keep in touch with us:

- Website: <http://www.nhlbi.nih.gov>
- Facebook: <http://www.facebook.com/nhlbi>
- Twitter: [@nhlbi_nih](https://twitter.com/nhlbi_nih)

For more information:

- NIH Website: <http://www.nih.gov>
- NIH Office of Extramural Research Website: <http://grants.nih.gov/grants/oer.htm>

Thank You, Gracias, Merci,
Shukran, Xièxie, Obrigado,
Ngiyabonga, Teşekkürler



Center for Translation Research and Implementation Science (CTRIS)





National Heart, Lung,
and Blood Institute