Connecting Research and Policy in Early Psychosis Treatment

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Early Psychosis Prevention and Early Intervention: Science Informing Policy Symposium
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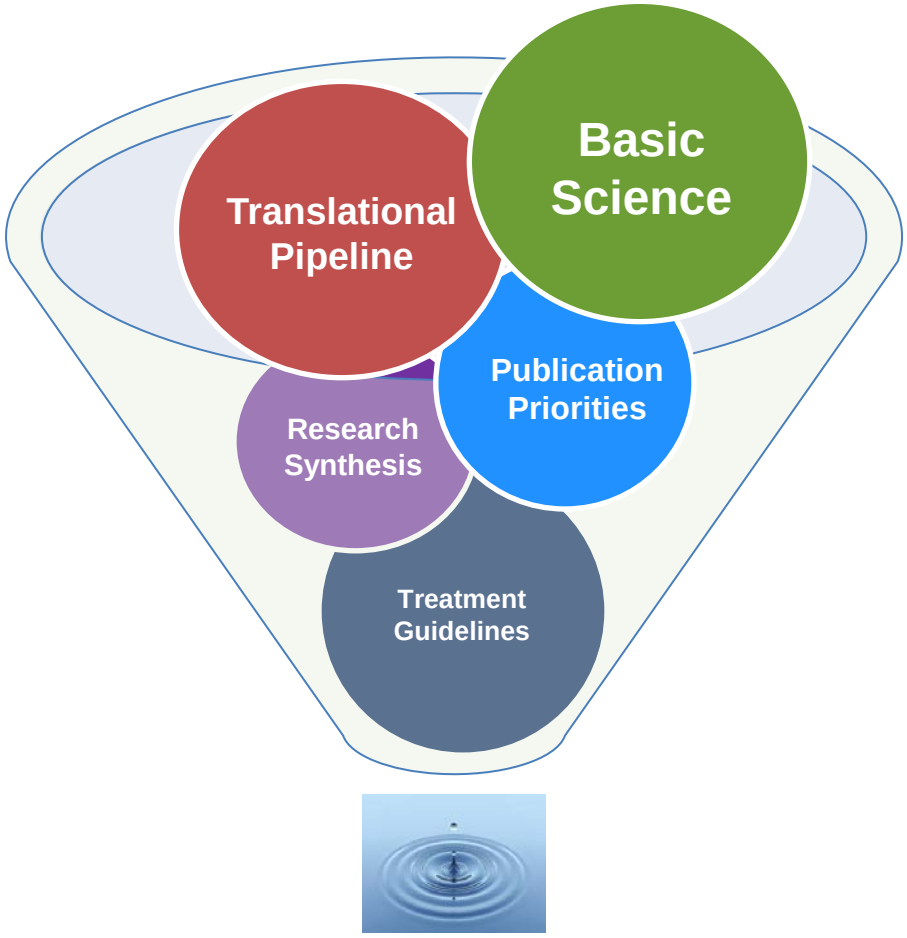
National Institute of Mental Health

Disclosures

- I have no personal financial relationships with commercial interests relevant to this presentation
- The views expressed are my own, and do not necessarily represent those of the NIH, NIMH, or the Federal Government

Science
Policy

Scientific Discovery ≠ Uptake

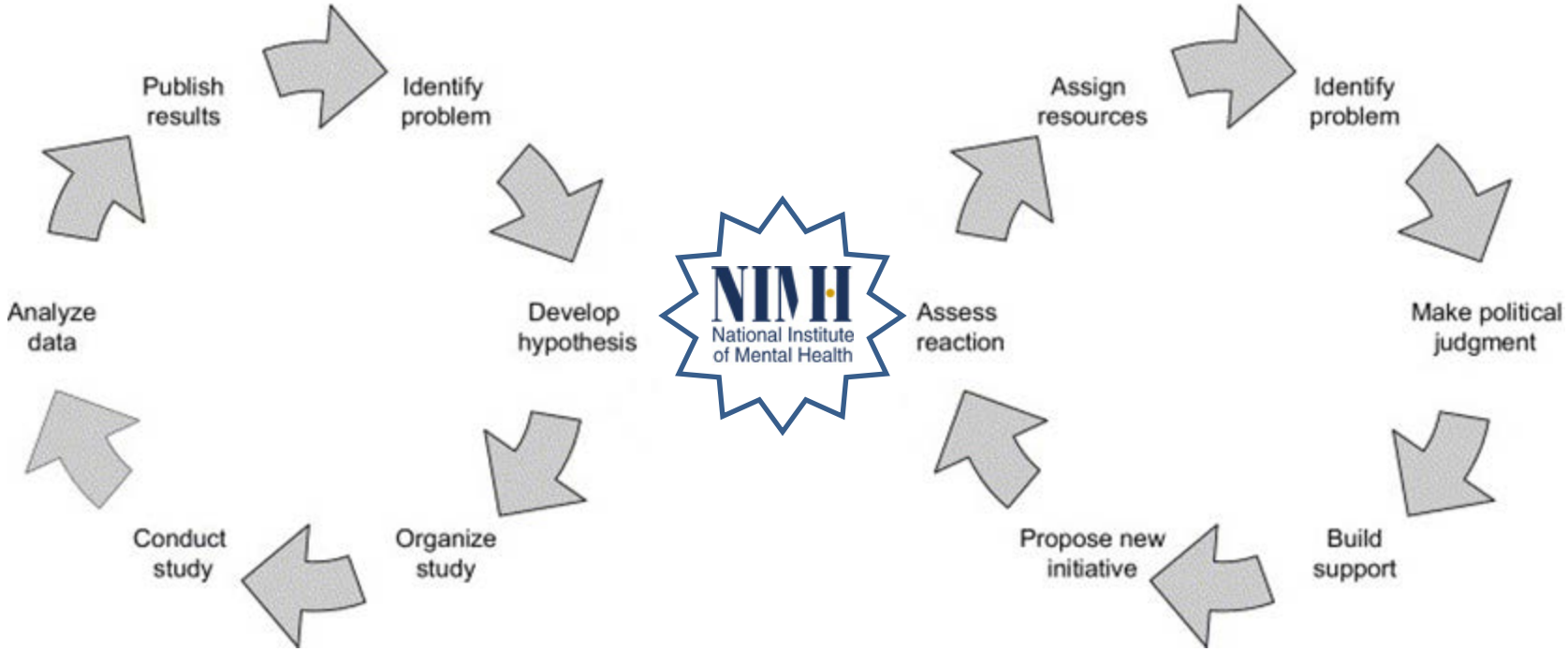


17 year odyssey from discovery to practice

Research and Policy Disconnect

Scientific decision making

Policy decision making



Ross Brownson et al., 2006, *American Journal of Preventive Medicine*

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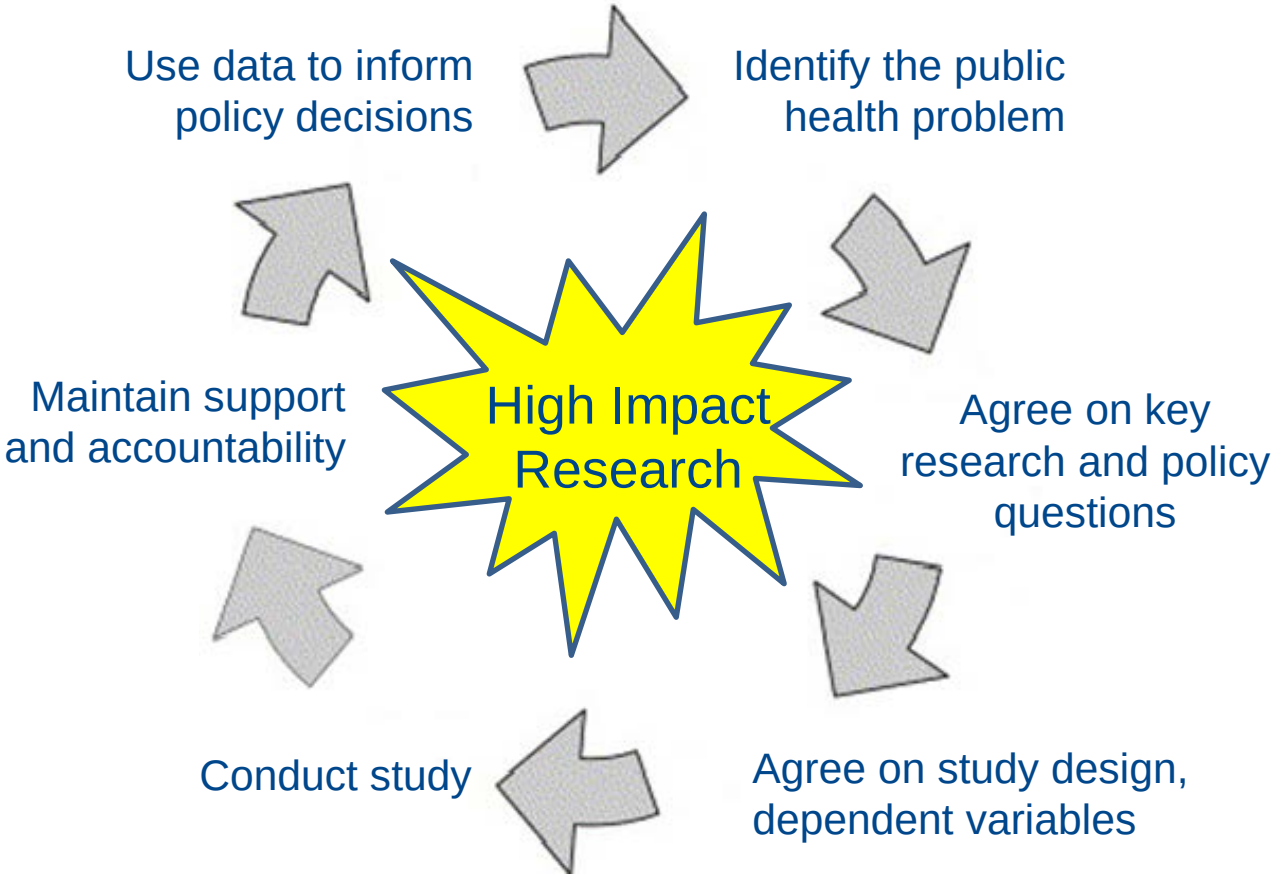
Hybrid Decision Making Model



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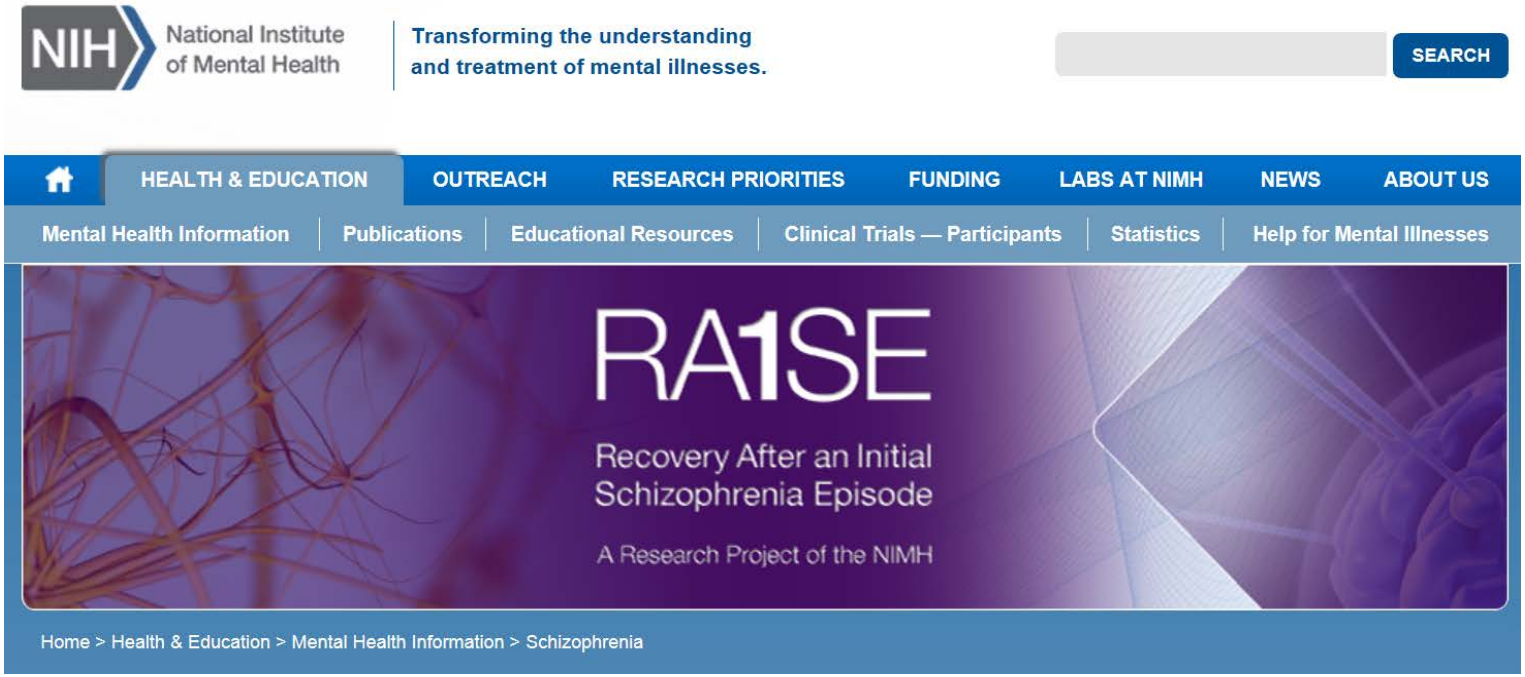
Case Study



The "Recovery After an Initial Schizophrenia Episode" initiative seeks to fundamentally alter the trajectory and prognosis of schizophrenia through coordinated and aggressive treatment in the earliest stages of illness.

Step 1

Identify the public health problem

Established Schizophrenia

- ~2.5 million adults in U.S. are affected
- Onset typically in late adolescence, early 20s
- High morbidity and mortality
  - Multiple episodes of psychosis over the lifetime
  - High unemployment, homelessness, incarceration
  - Shortened lifespan (suicide, medical co-morbidities)
- Economic cost of $62.7 billion in 2002
  - Direct health care costs of $22.7 billion

Early Intervention Matters

- Rapid remission of positive symptoms
- Lower rates of psychiatric re-hospitalization
- Decreased substance use
- Improved social and vocational functioning
- Increased quality of life

Ryan

Center for Practice Innovations℠
at Columbia Psychiatry
New York State Psychiatric Institute
Building best practices with you.

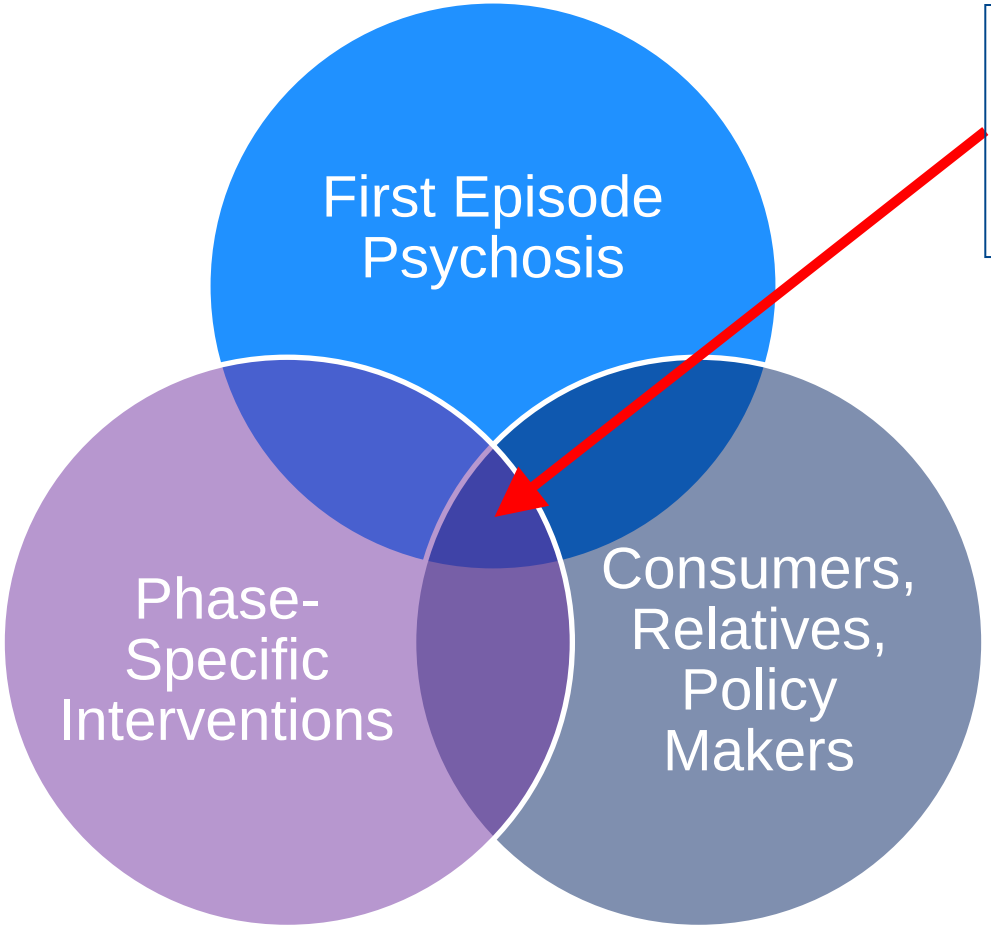
http://practiceinnovations.org/ConsumersandFamilies/ViewAllContent/tabid/232/Default.aspx

Coordinated Specialty Care Model

Step 2

Agree on key research and policy questions

Disability in Schizophrenia



Can coordinated specialty care, offered early on, improve long term-outcomes for schizophrenia in the US?

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Step 3

Agree on study design and dependent variables

NIMH RAISE Projects

- Comparative effectiveness trial
  - John Kane
  - Nina Schooler
  - Delbert Robinson

The Feinstein Institute for Medical Research
North Shore-Long Island Jewish Health System
North Shore LIJ

- Implementation study
  - Lisa Dixon
  - Susan Essock
  - Howard Goldman

RFMH Research Foundation for Mental Hygiene, Inc.
New York State Psychiatric Institute

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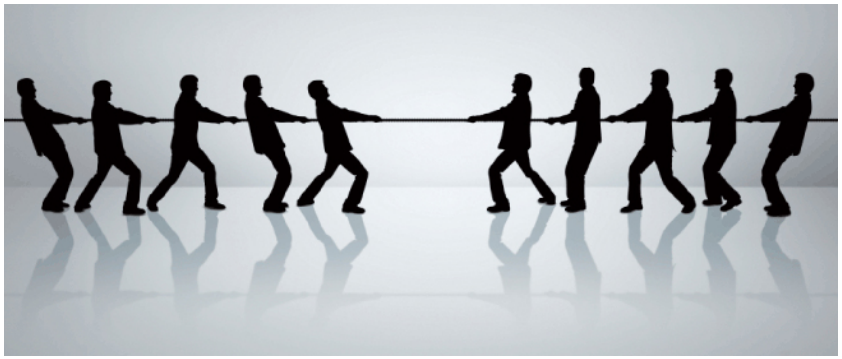
Policy Makers' Interests

U.S. Federal Stakeholders	Dependent Variables
Substance Abuse and Mental Health Services Administration (SAMHSA)	Recovery, functioning, quality of life
National Institute of Drug Abuse (NIDA)	Substance abuse, tobacco dependence
Centers for Medicare and Medicaid Services (CMS)	Psychiatric relapse, re-hospitalization, cost of medical and specialty care
Social Security Administration (SSA)	School completion, early vocational milestones, competitive employment

Brokering Agreement on Measures

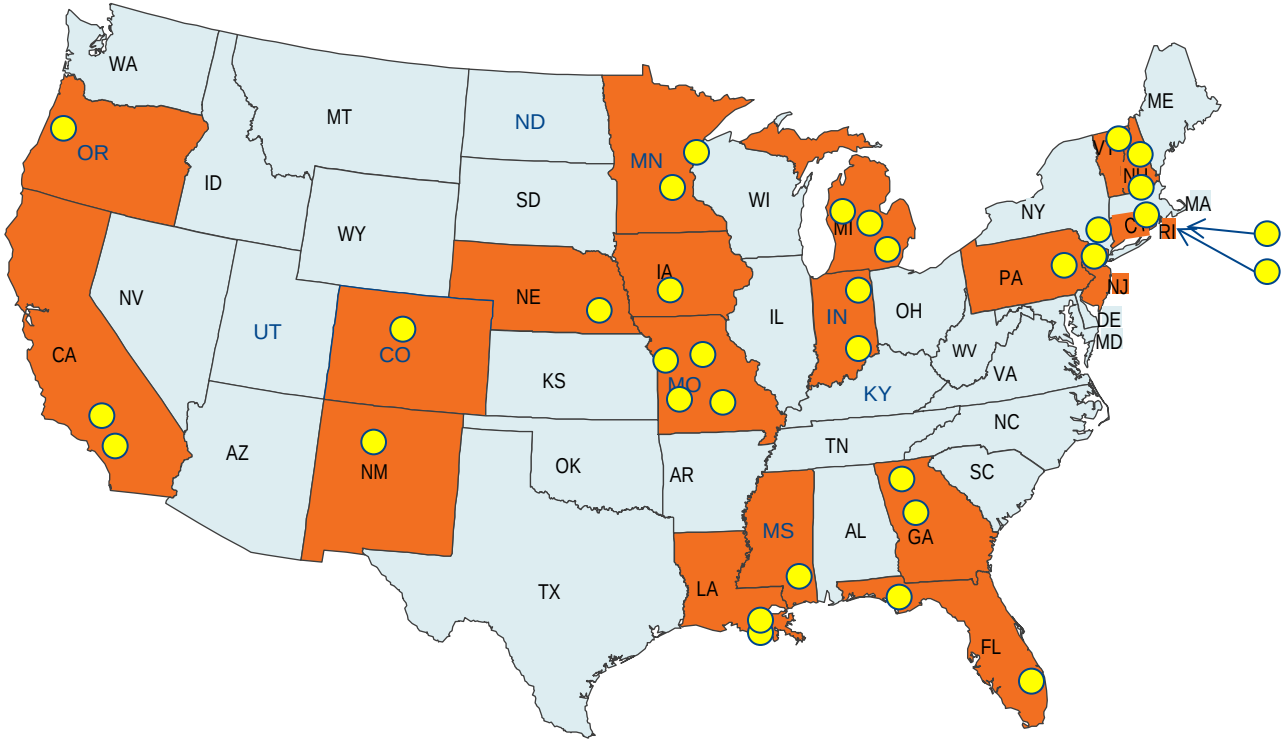


“The Social Security Administration figures its annual budget in terms of U.S. dollars, not Quality Adjusted Life Years.”

Step 4

Conduct study

RAISE Clinical Trial



- Phase-specific specialty care for First Episode Psychosis vs. TAU
- Representative patients (N=404) and community clinics (N=34)
- Focus on clinical and functional recovery, cost of care, societal benefits

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RAISE Implementation Study

- *State Officials as Research Partners*

  - NYS Office of Mental Health
  - MD Mental Hygiene Administration

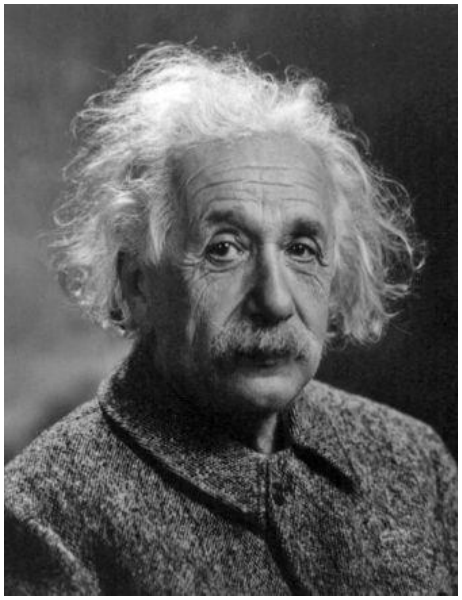
- *"Turn Key" Solutions for State Administrators*

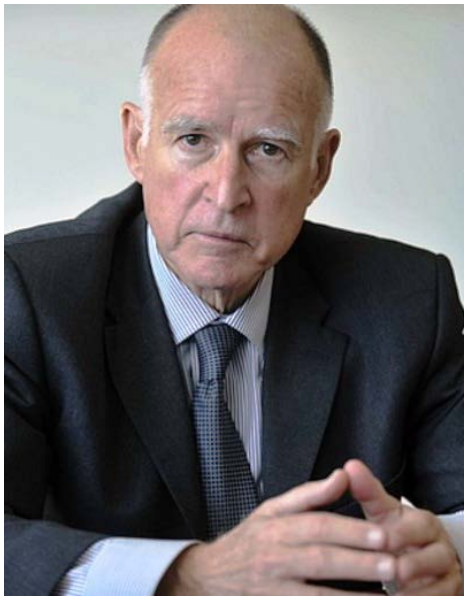
  - Training and supervising existing staff
  - Assertive outreach and client engagement

Step 5

Maintain stakeholder support, promote accountability

Time is Relative





Instill productive urgency

Early Data from Clinical Trial

Median duration of untreated psychosis is 74 weeks in community clinic settings

Addington et al., 2015, *Psychiatric Services*

Only 61% of FEP patients receive medications in line with PORT recommendations

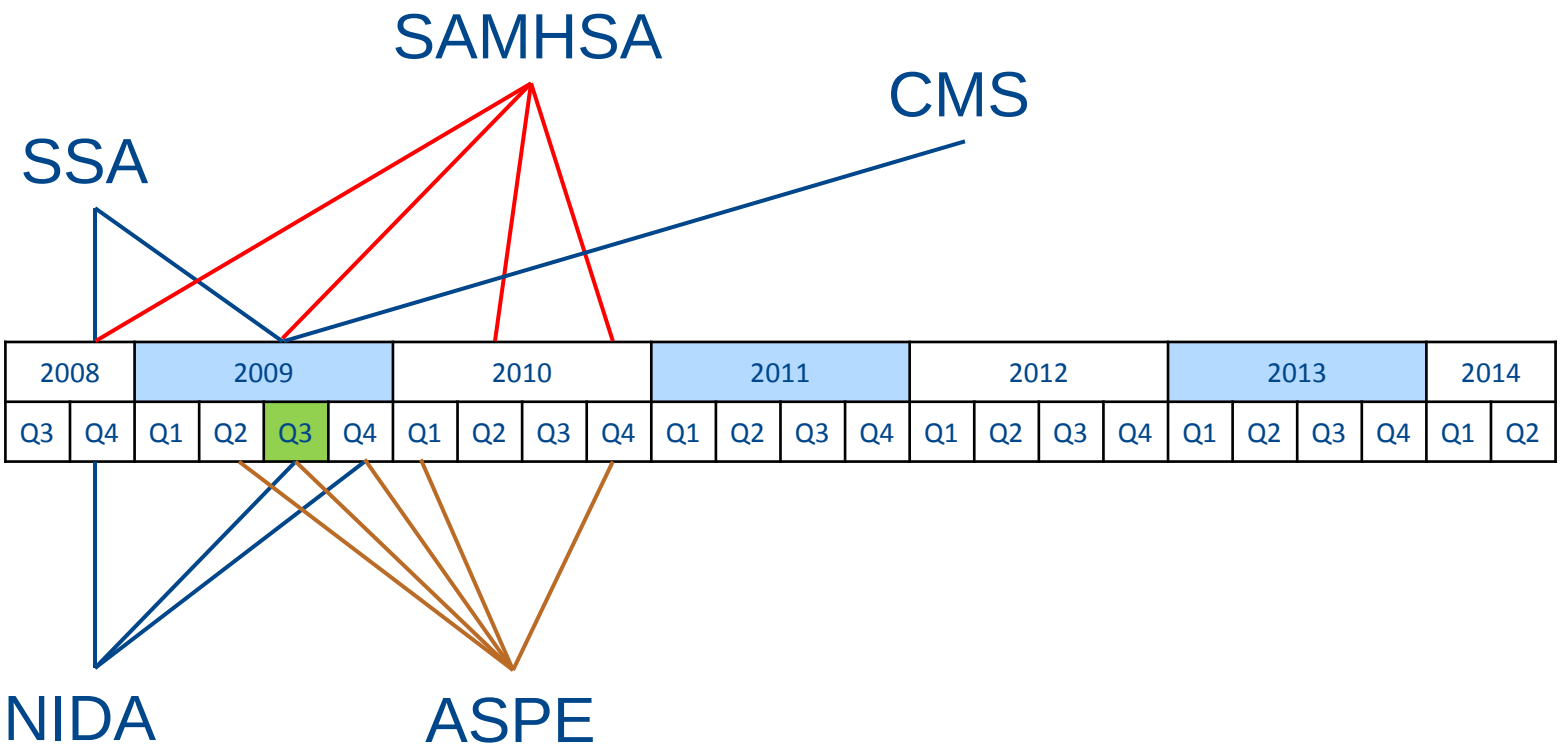
Robinson et al., 2014, *American Journal of Psychiatry*

<5% of FEP patients with cardio-metabolic risk factors receive appropriate medical care

Correll et al., 2014, *JAMA Psychiatry*

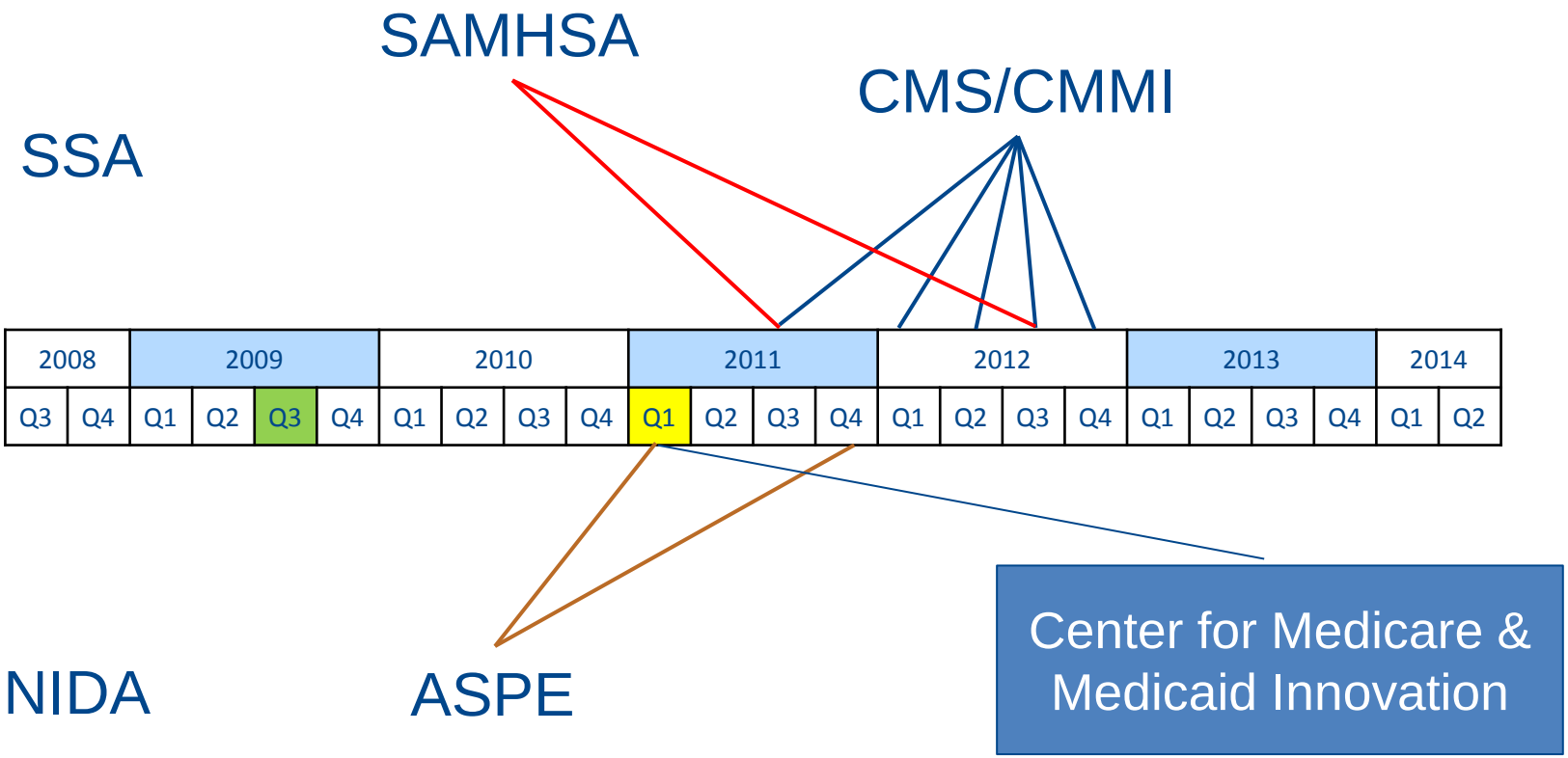
Engineer accountability

NIMH Engagement Activities



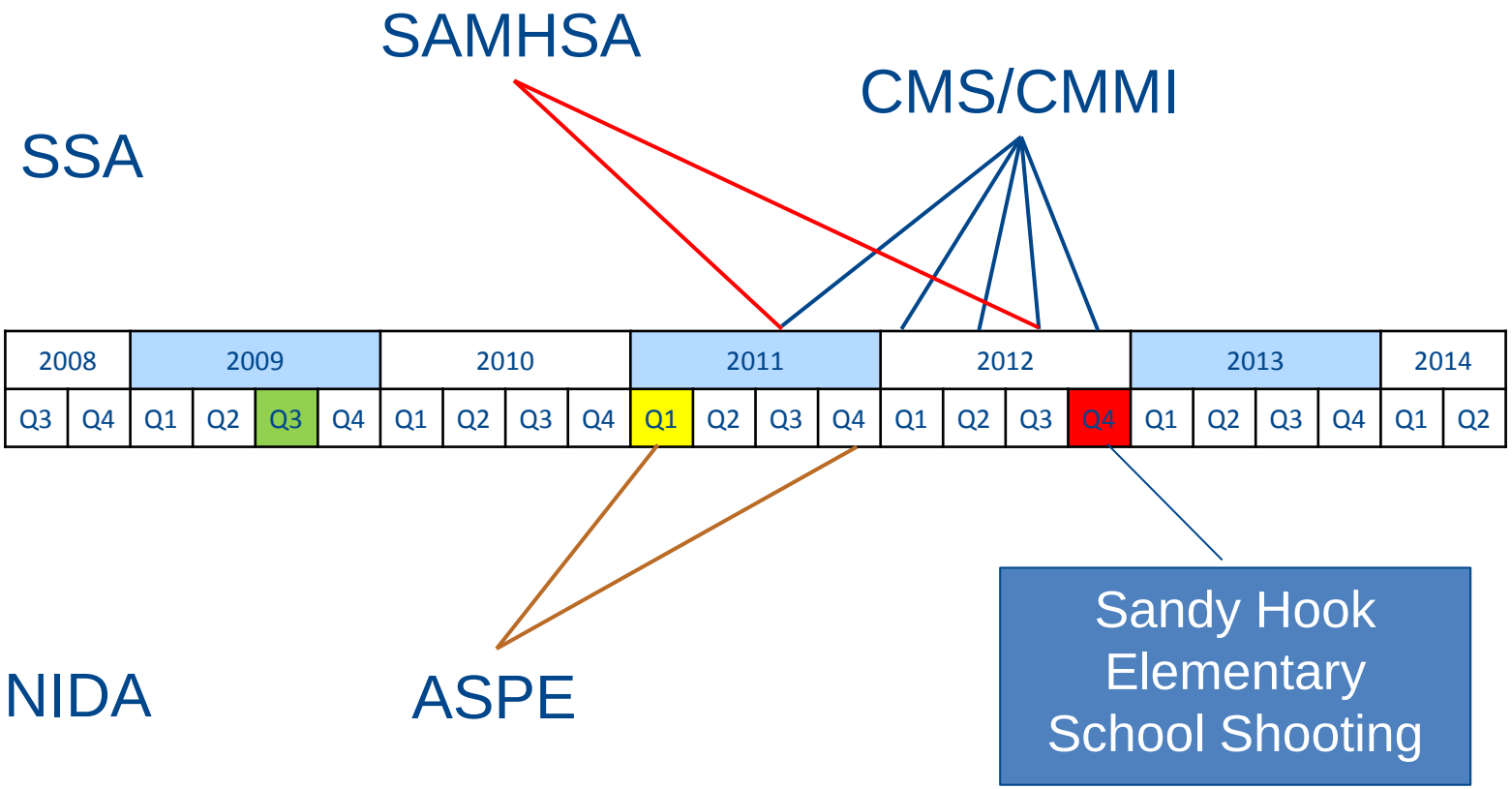
2008 - 2010

NIMH Engagement Activities



2011 - 2012

NIMH Engagement Activities



2011 - 2012

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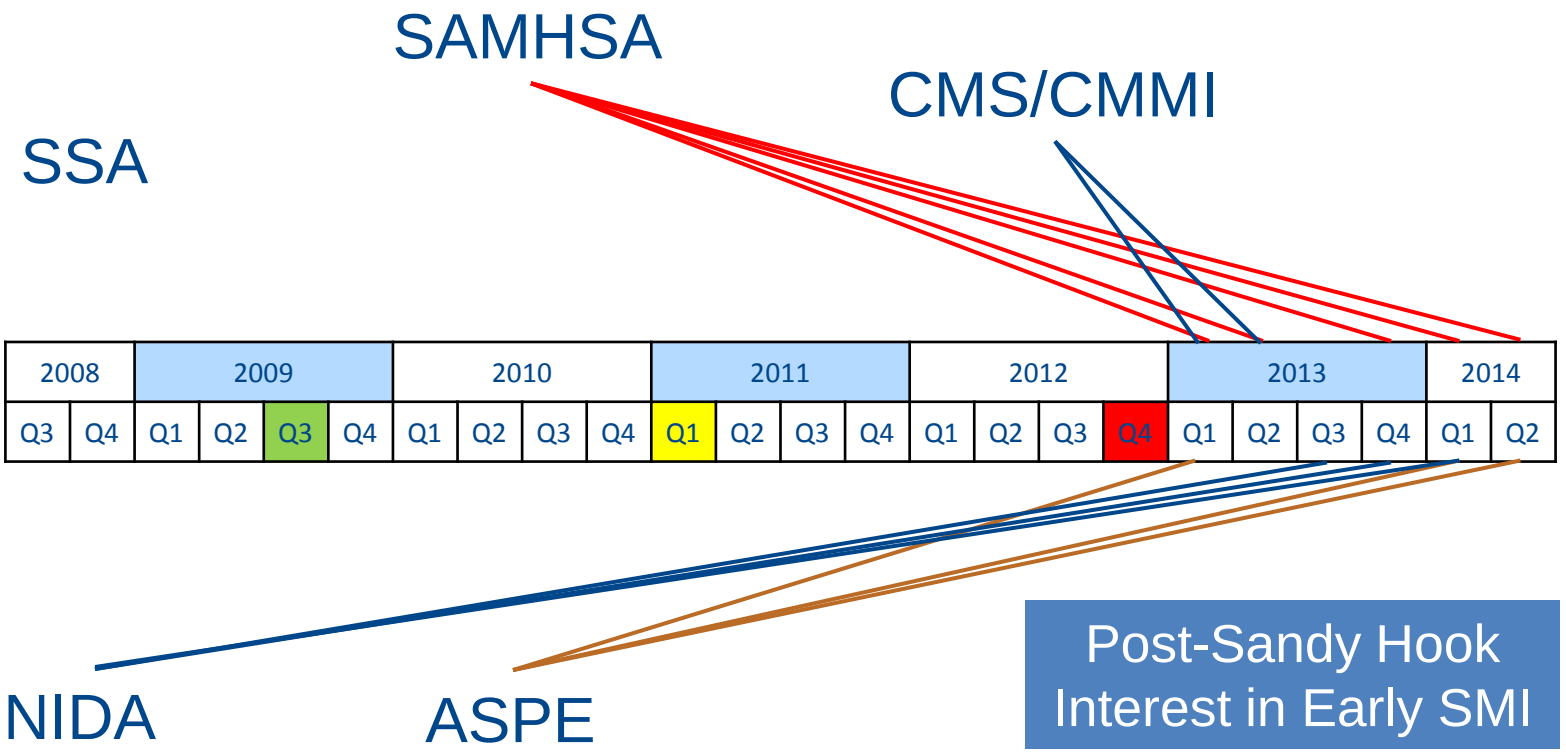
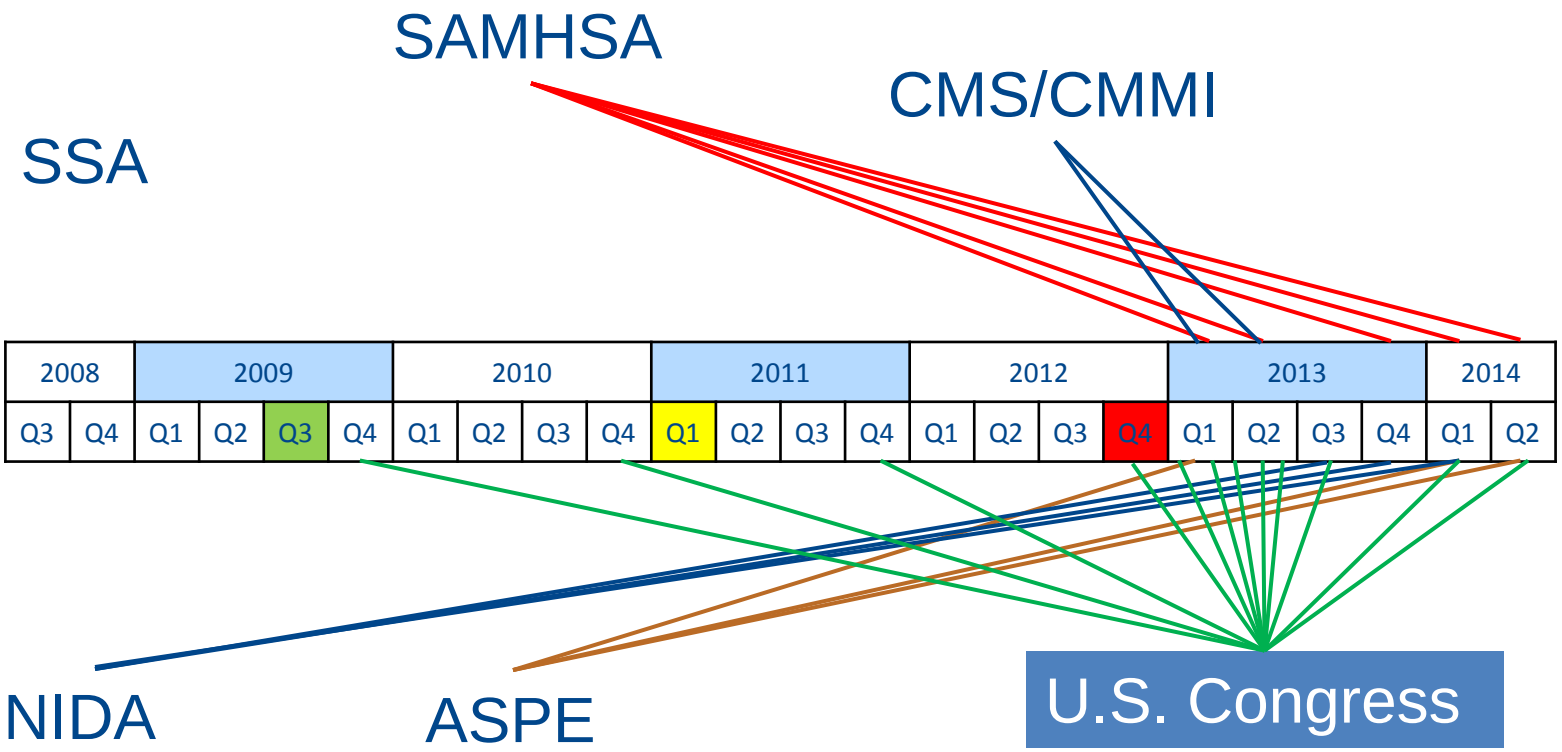


2013 - 2014

NIMH Engagement Activities



2013 - 2014

Step 6

Use data to inform policy decisions

Early Actions from Implementation Study

- *RAISE → OnTrackNY*

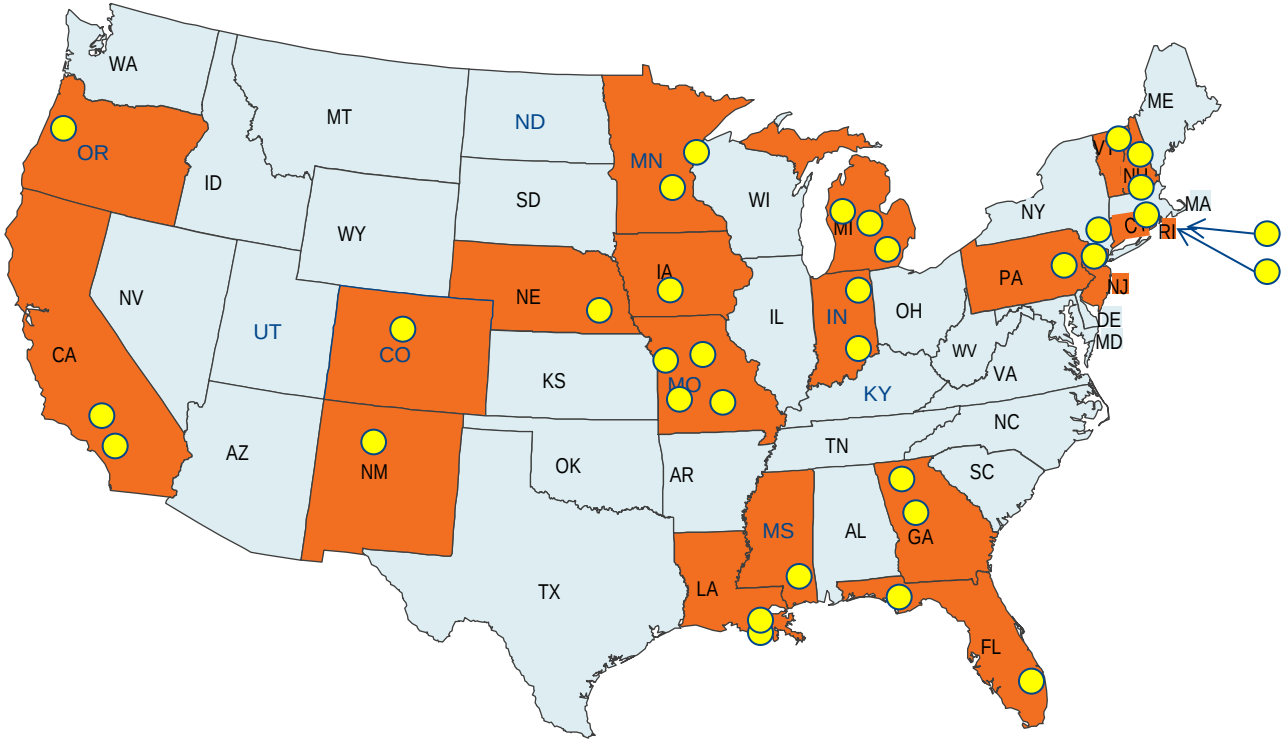
  - NYS Office of Mental Health
  - 4 new clinics for FEP
  - June 2013

- *RAISE → Maryland Early Intervention Program*

  - MD Mental Hygiene Administration
  - 4 new clinics for FEP/CHR
  - October 2013

- *In both cases, state officials accepted feasibility data before articles were accepted for publication!*

RAISE Clinical Trial



- Phase-specific specialty care for First Episode Psychosis vs. TAU
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- Focus on clinical and functional recovery, cost of care, societal benefits

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Impact of Coordinated Specialty Care

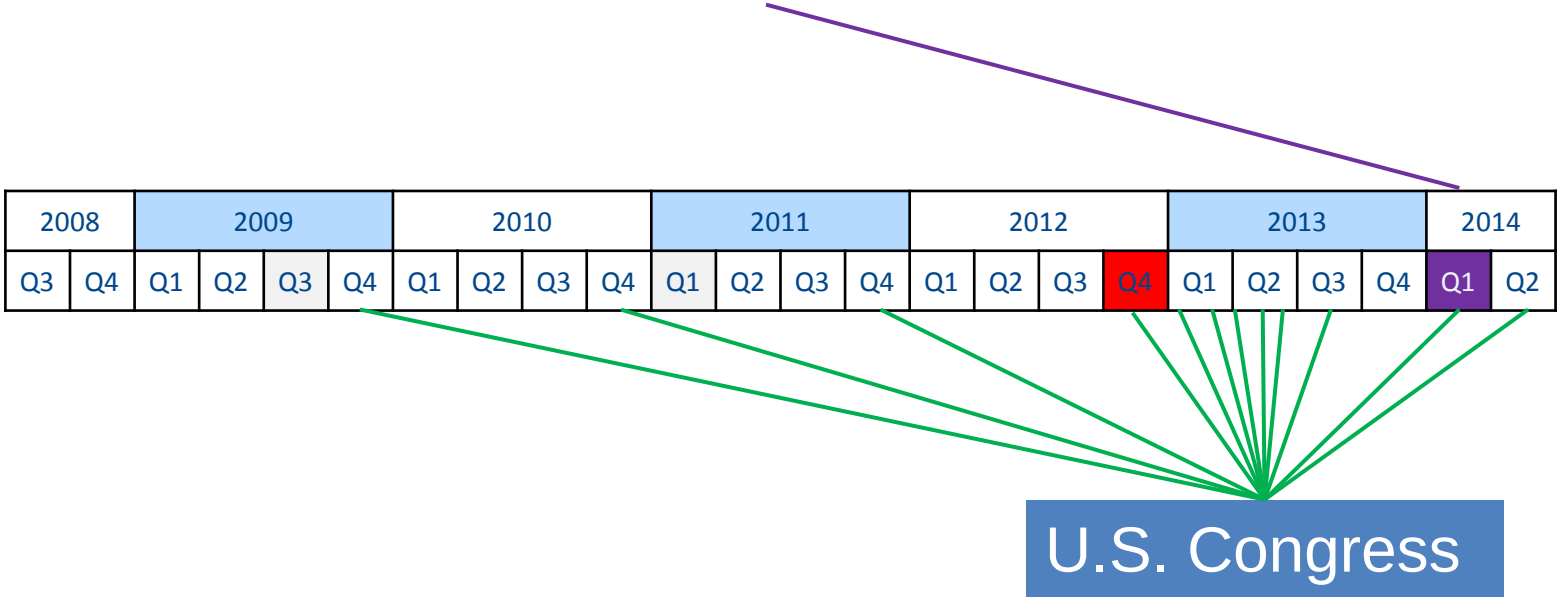
- CSC participants remain in treatment longer
- CSC improves outcomes over 24 months
  - overall quality of life
  - measures of symptoms
  - interpersonal relations
  - involvement in work or school
- Participants with shorter duration of untreated psychosis derive substantially more benefit from CSC

Kane et al., in press, *American Journal of Psychiatry*

Do the right things,
at the right time.

Congressional Action

Consolidated Appropriations Act of 2014

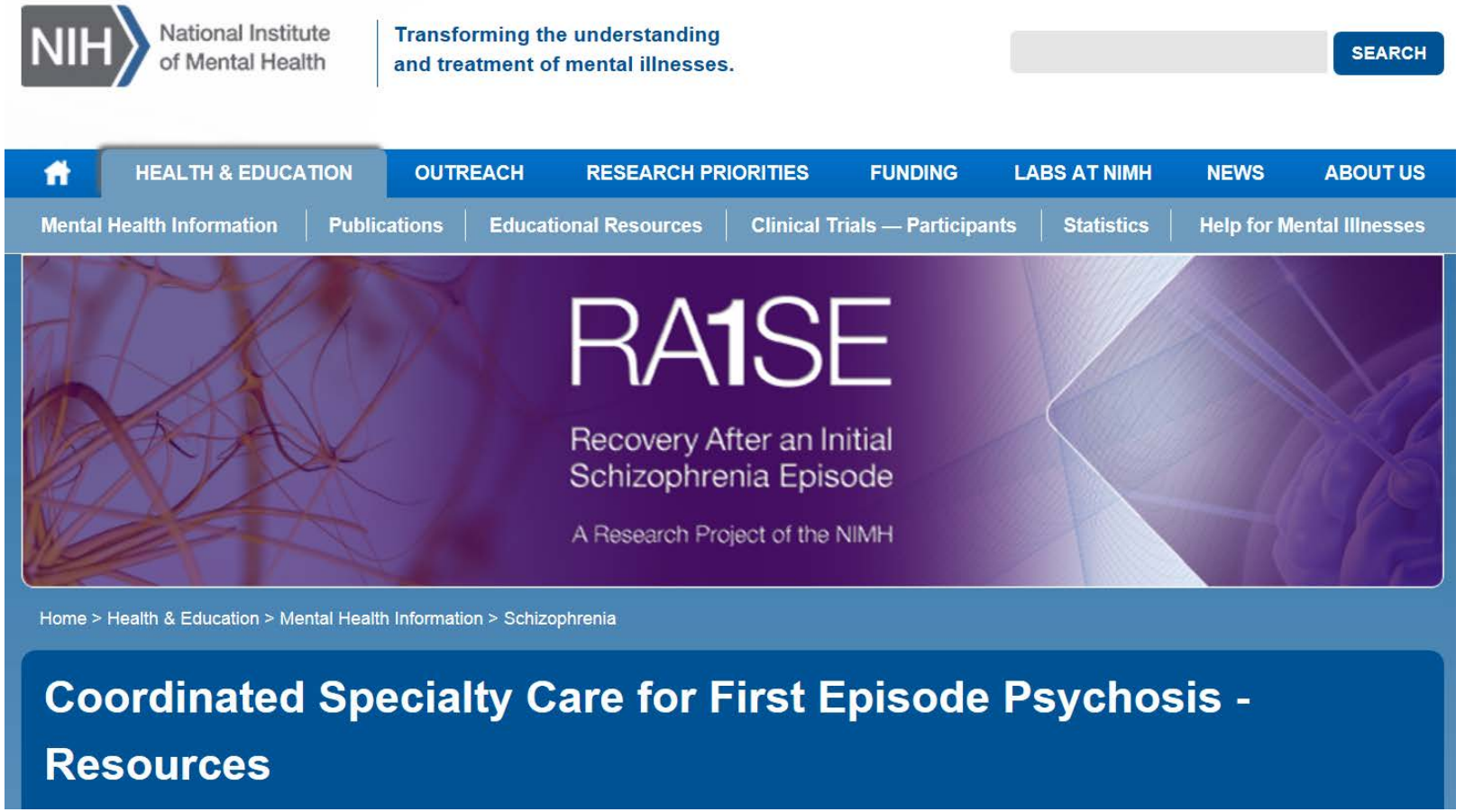


2013 - 2014

H.R. 3547, 113th Congress

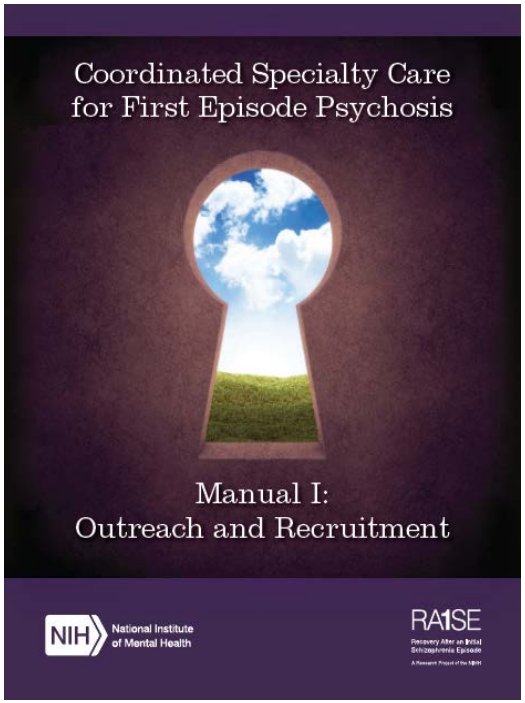
January 17, 2014

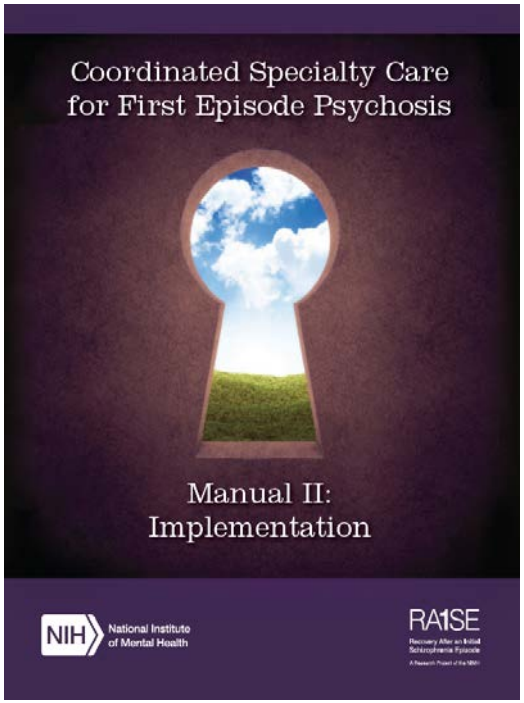
- Increased Community Mental Health Block Grant (CMHBG) program by $24.8M
- Funds allocated for first episode psychosis (FEP) programs
- NIMH and SAMHSA to develop guidance for States regarding effective programs for FEP



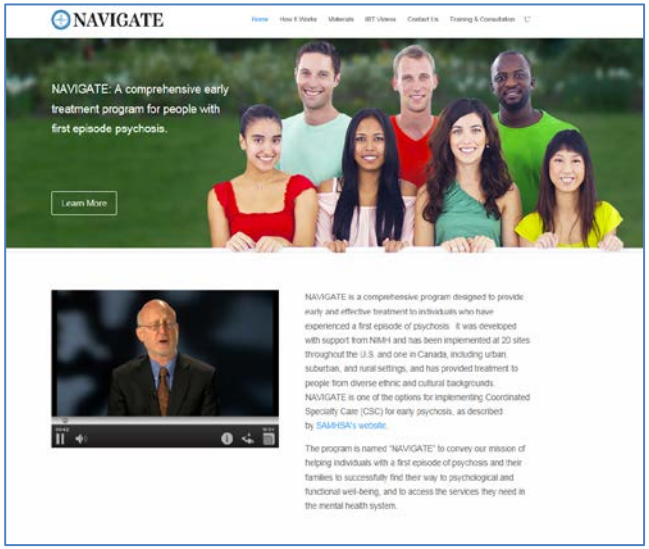
- **Evidence-based Treatments for First Episode Psychosis: Components of Coordinated Specialty Care**
- **RAISE Coordinated Specialty Care for First Episode Psychosis Manuals**
- **RAISE Early Treatment Program Manuals and Program Resources**
- ***OnTrackNY* Manuals & Program Resources**
- **Voices of Recovery Video Series**

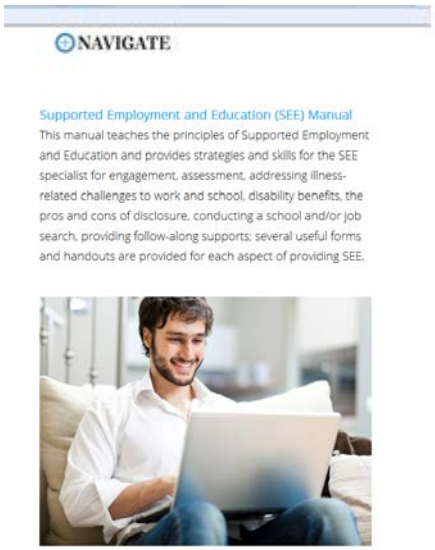
http://www.nimh.nih.gov/health/topics/schizophrenia/raise/coordinated-specialty-care-for-first-episode-psychosis-resources.shtml

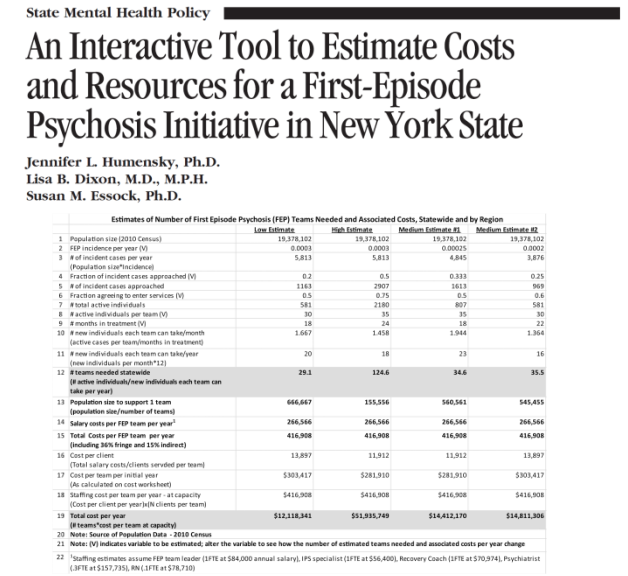




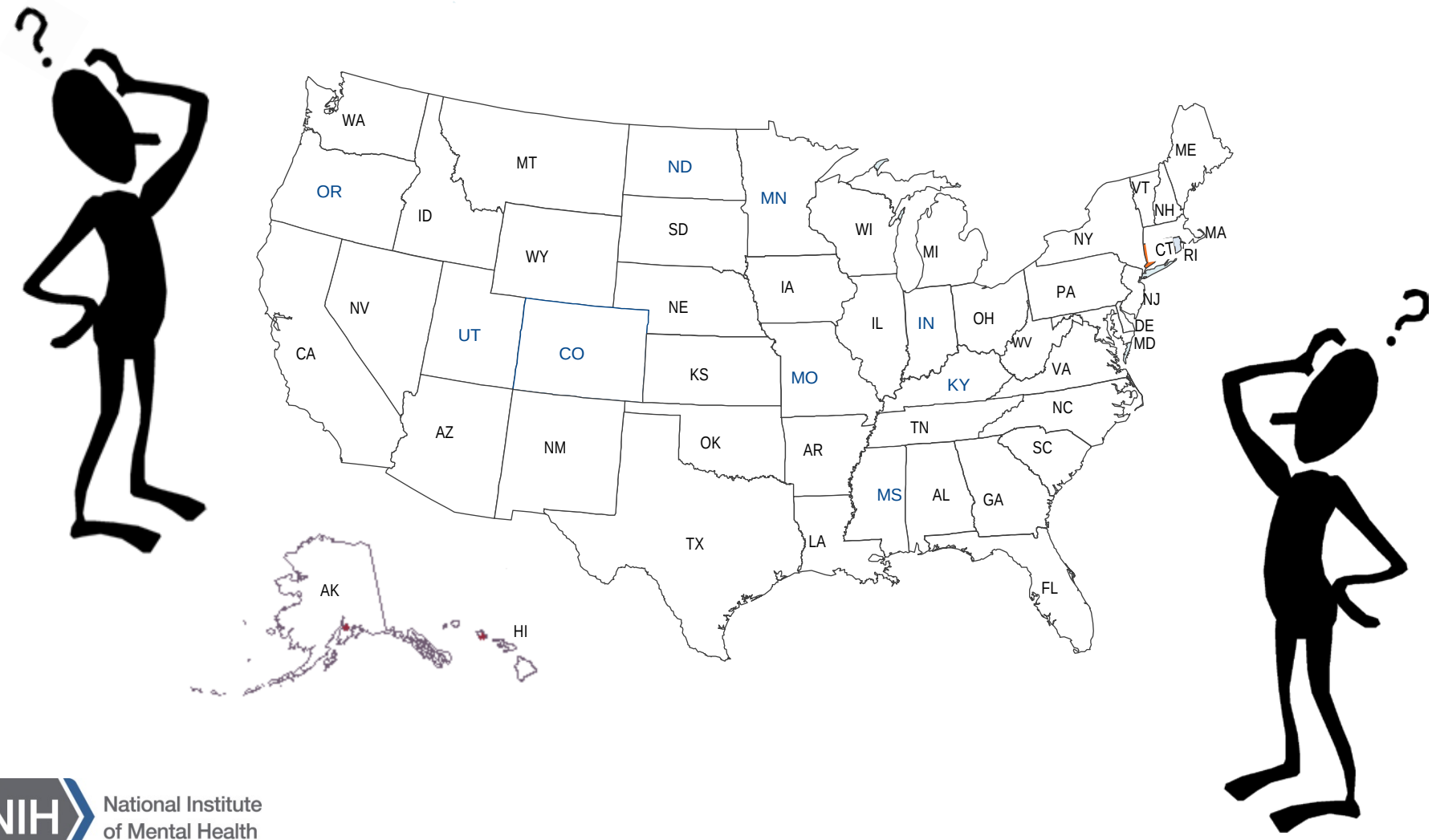
Corey – Another Door Opens







Potential Impact of H.R. 3547



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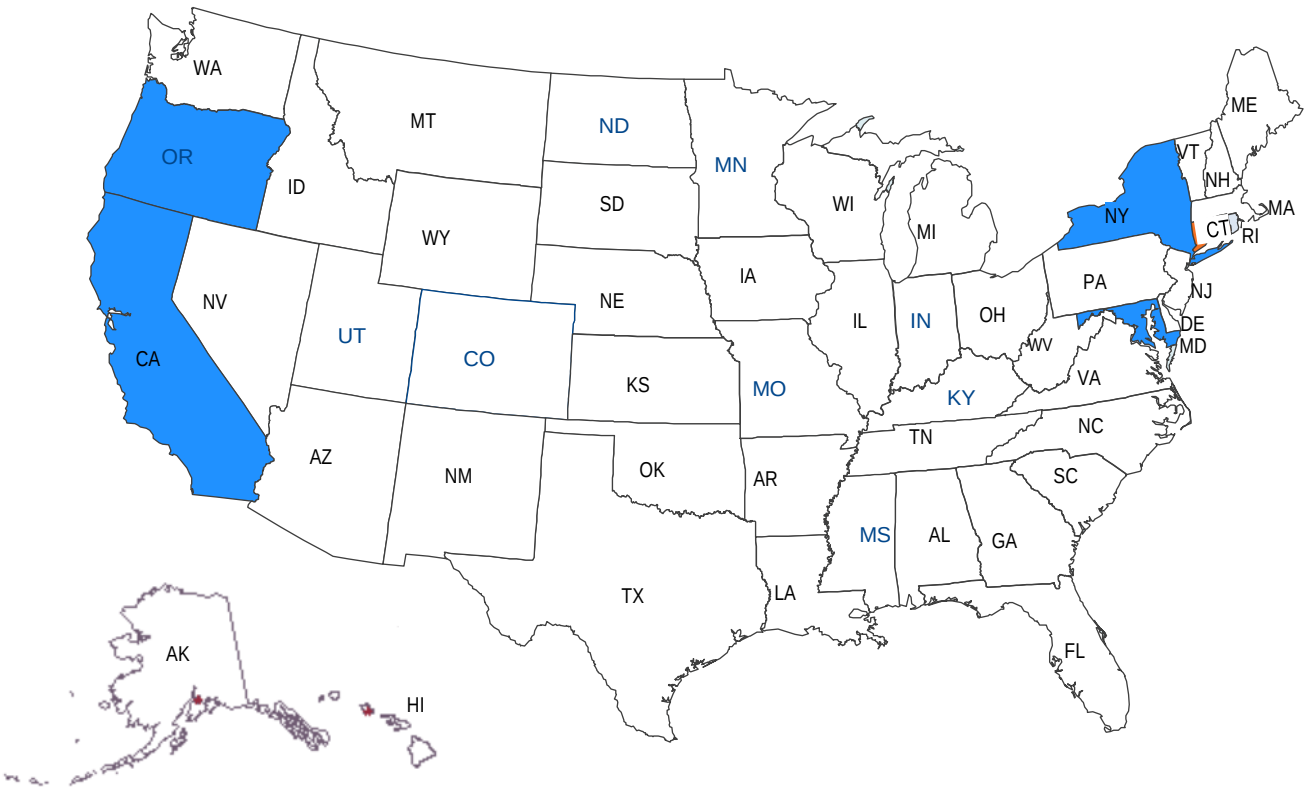
Innovators and Early Adopters, 2013



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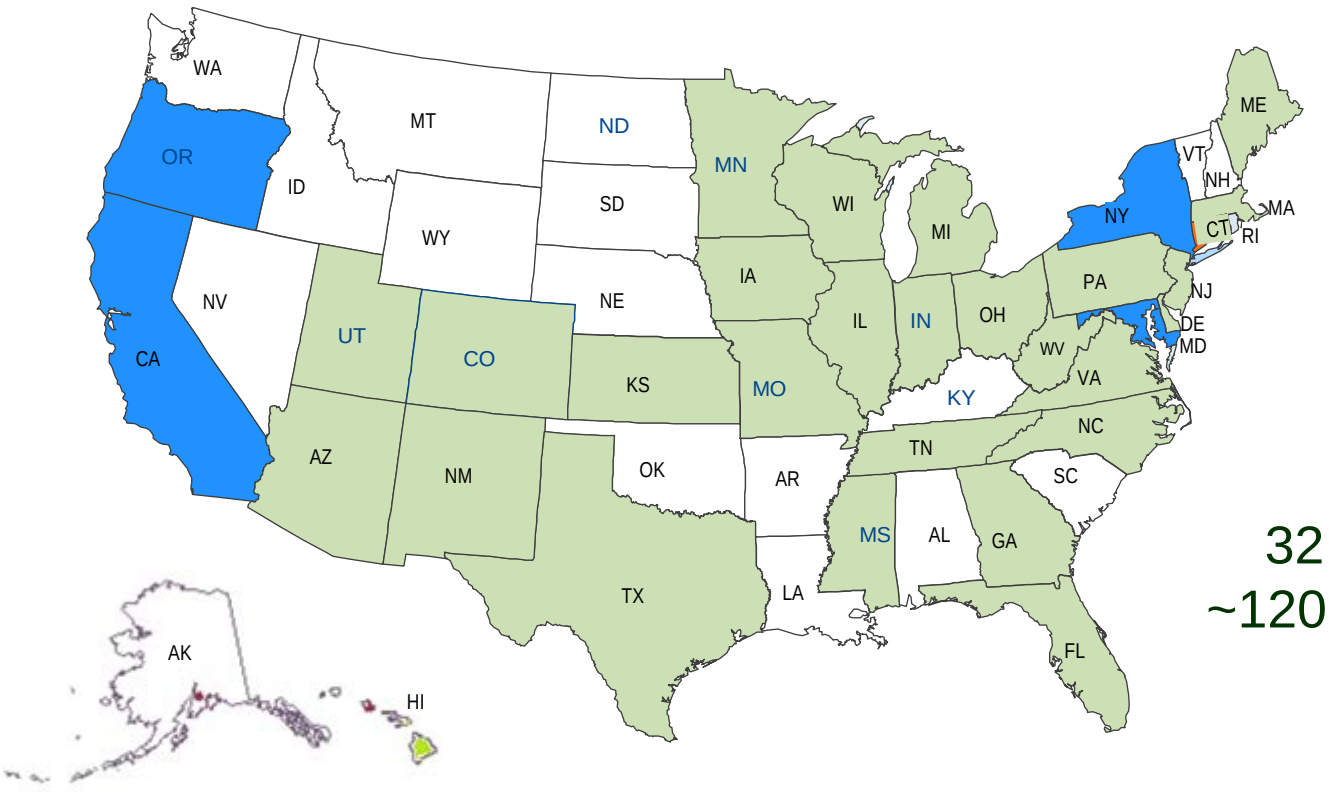
Early Majority, 2015



32 States
~120 Clinics

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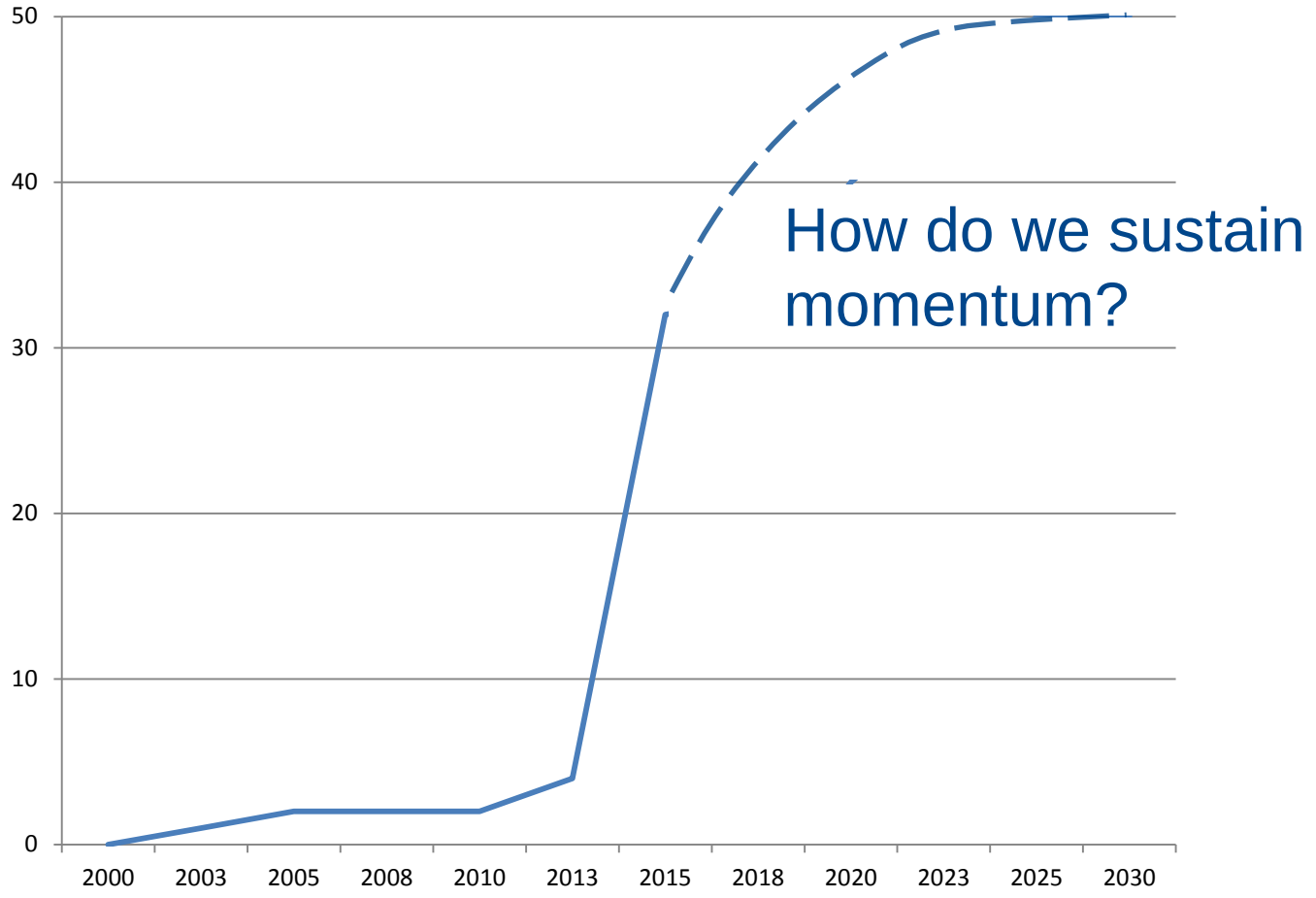
Early Services S-Curve

States with CSC Plans



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Beyond RAISE:

Creating an early psychosis learning community in the United States

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Early Psychosis Intervention Network (EPINET)

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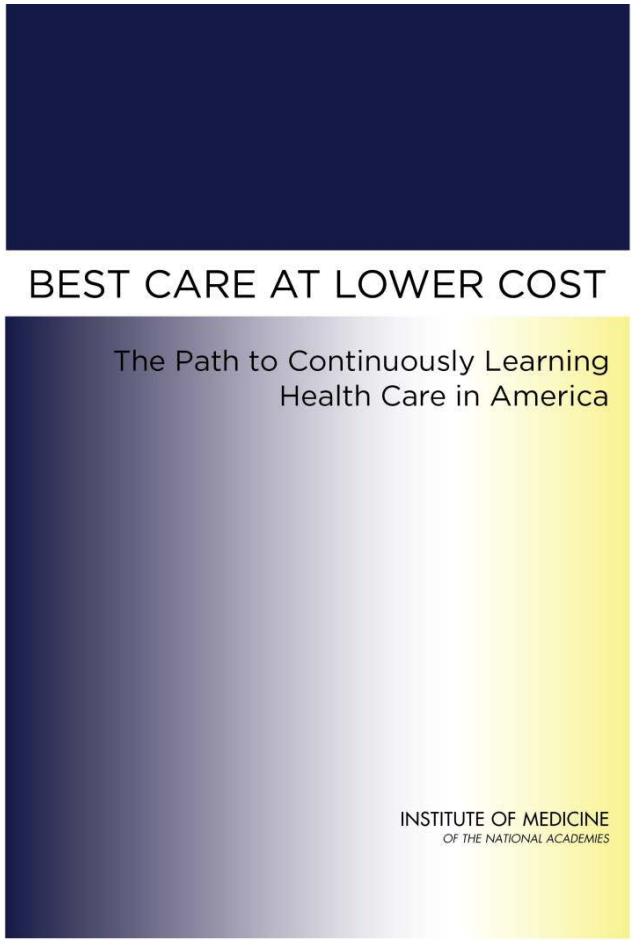
Strategic Objective 4 – Learning Healthcare Systems

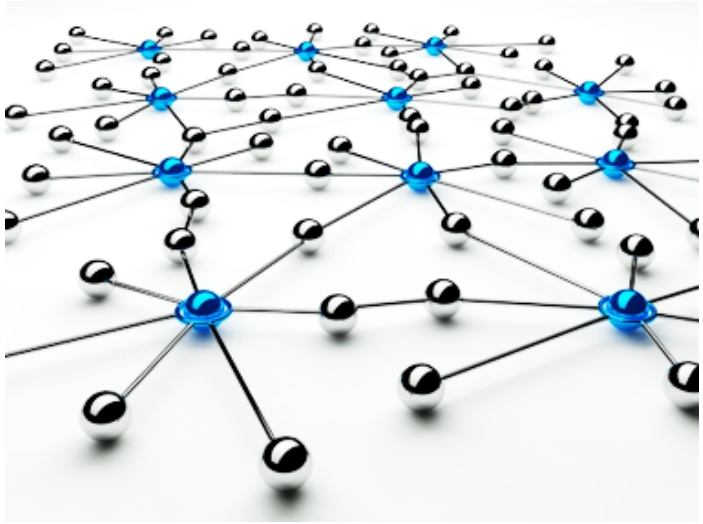


FY2015

- Practice-based research model
- Common data elements, data sharing, big data analytics
- Feedback loops for ongoing system improvement
- Culture of continuous learning
- Clinical data drive scientific discovery

EPINET Goals

- Establish a national learning healthcare network among early psychosis clinics
- Standardize measures of clinical characteristics, interventions, and early psychosis outcomes



- Adopt a unified informatics approach to study variations in treatment quality, clinical impact, and value
- Cultivate a culture of collaborative research participation in academic and community early psychosis clinics

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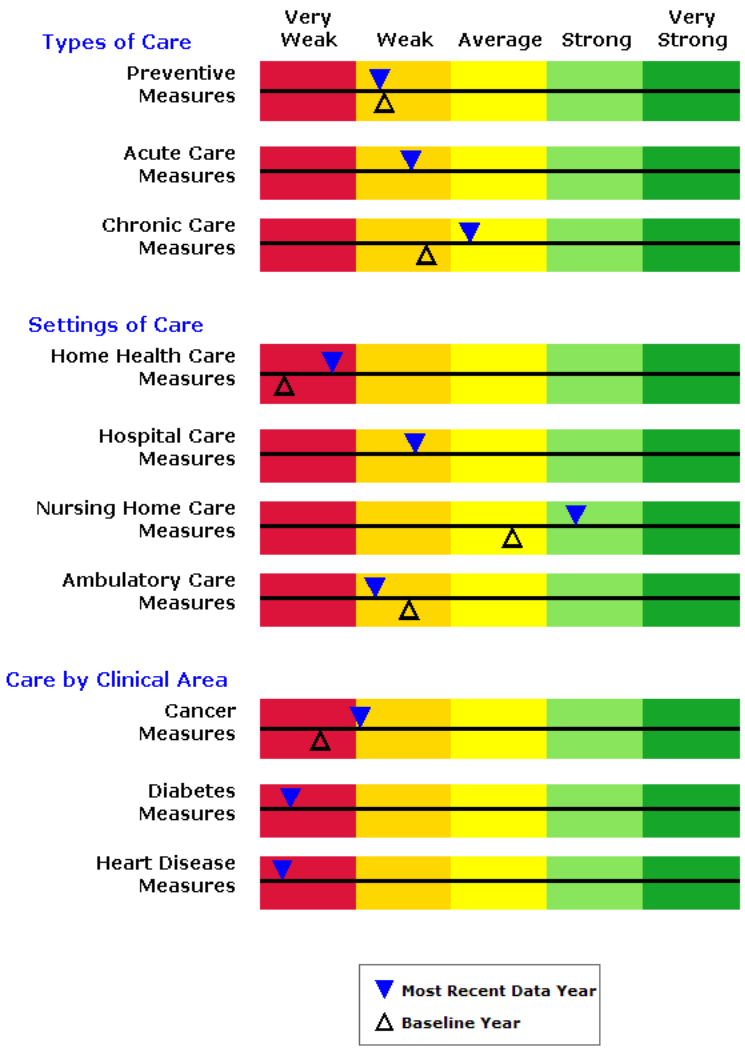
How can EPINET improve treatment?

- Fidelity to CSC model
- Monitor key outcomes
- Continuous quality improvement
- Evaluate rare events with statistical power
- Rapid piloting or fielding of new approaches



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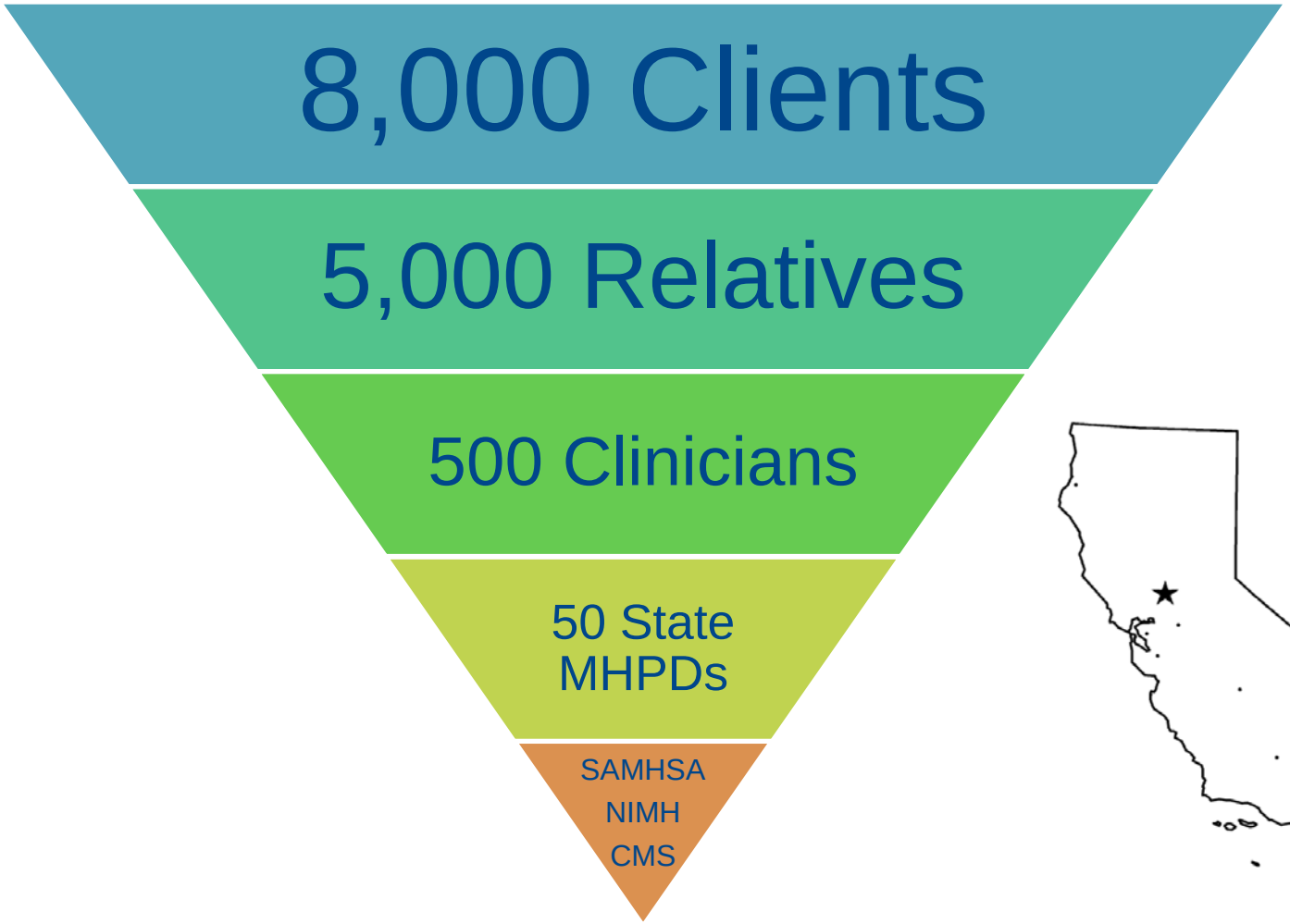
http://nhqrnet.ahrq.gov/snaps11/dashboard.jsp?menuId=4&level=0&state=FL

Who has a stake in EPINET?



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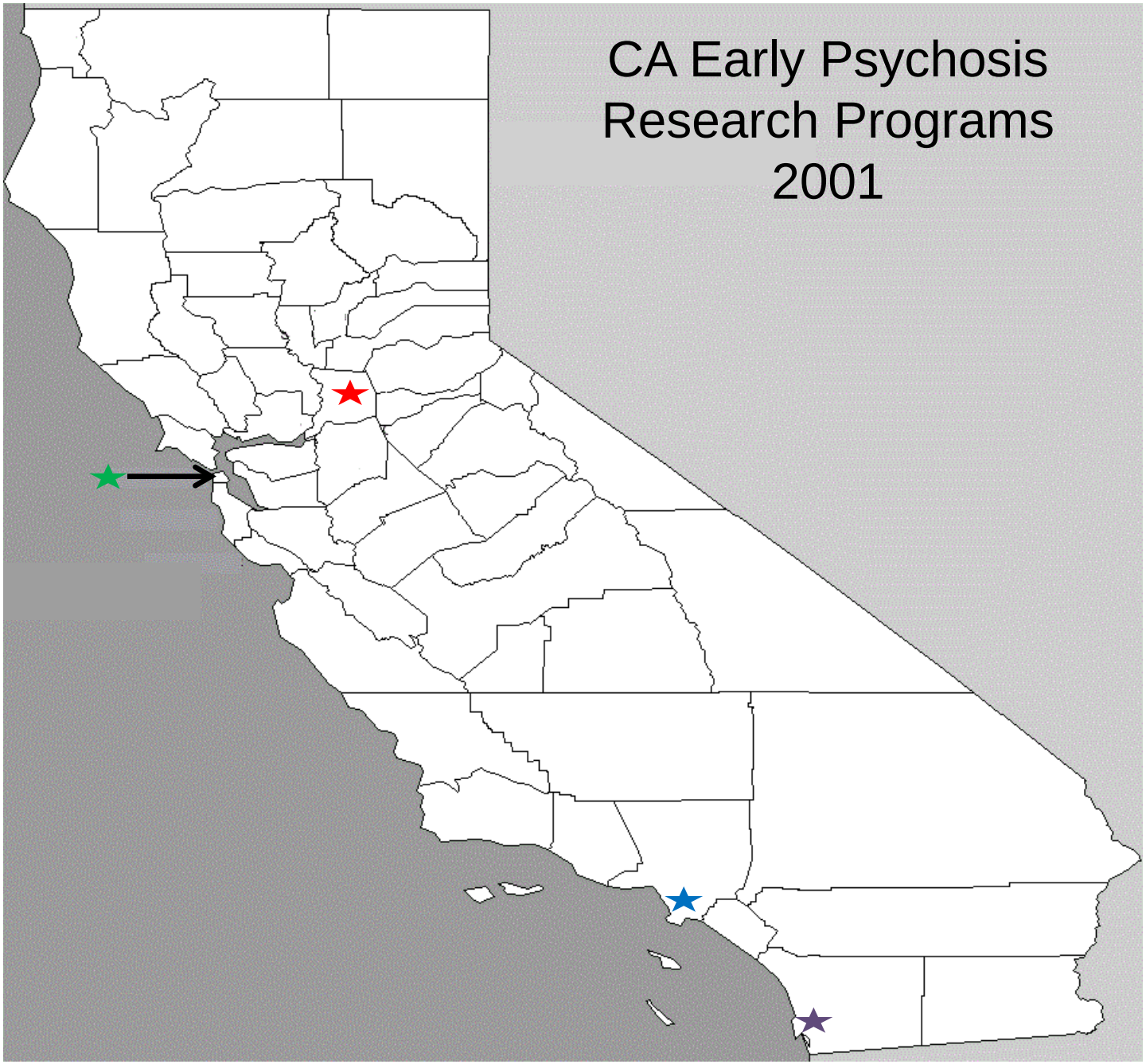
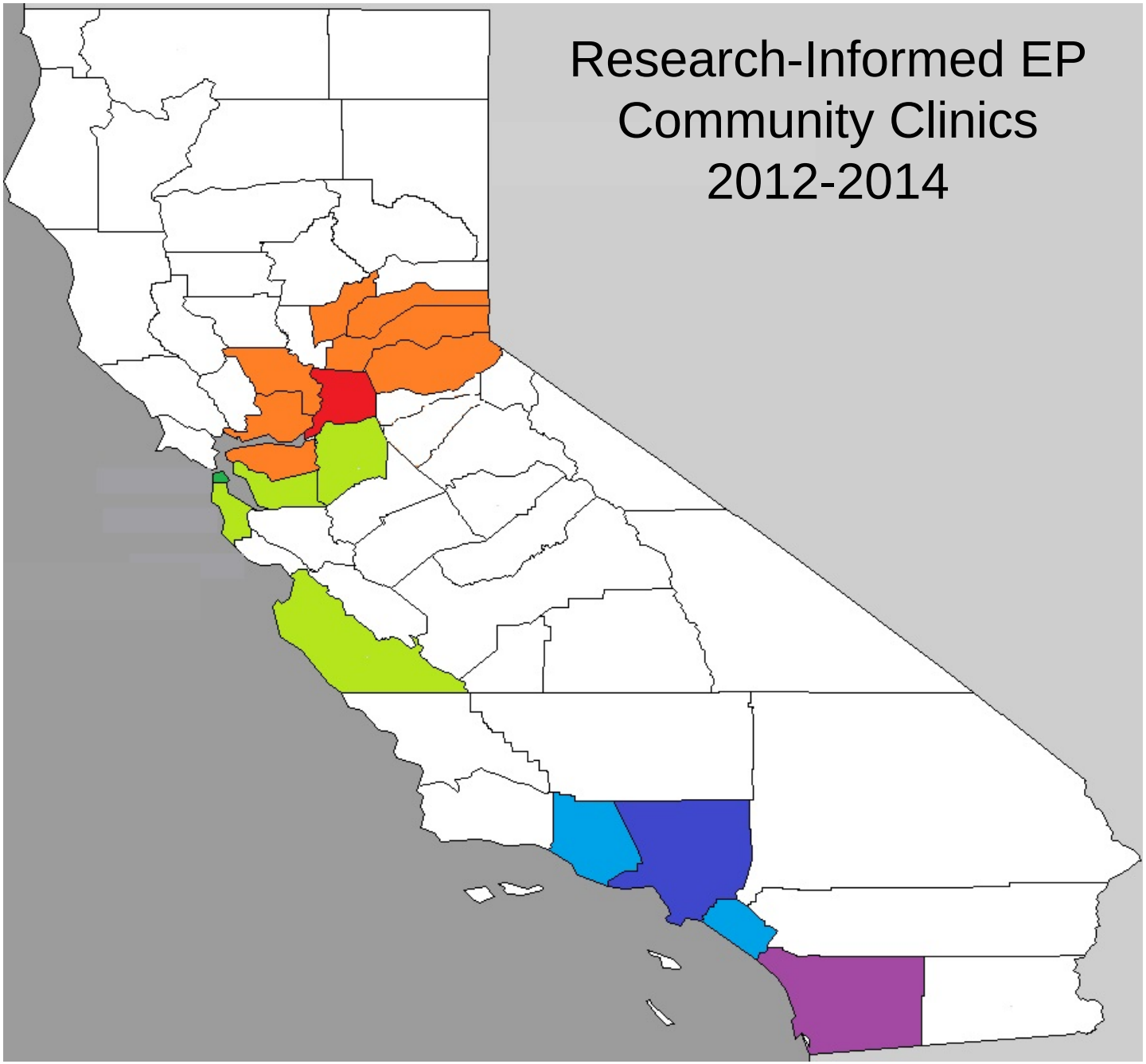

CA Early Psychosis
Research Programs
2001

Early Psychosis Research Clinics 2005


Research-Informed EP
Community Clinics
2012-2014

EPIC-CAL??

(Early Psychosis Intervention Consortium of California)

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Take Home Messages

- Scientists and policymakers often travel in “parallel universes[1]”
- Bridging this gap requires active engagement to find common interests, shared goals, and meaningful outcome measures
- Time matters – convey “productive urgency” to scientists; help policy makers see beyond immediate needs
- Recognize that stakeholders come and go, so talk to everyone, all the time.
- Big data may help us to improve the quality of care and drive scientific discoveries

[1] Brownson et al., 2006, *American Journal of Preventive Medicine*

For more information

rheinsse@mail.nih.gov

Thank you!