

Push Pull Model

NIH Roadmap

PROMIS

Users Needs

Lawrence J. Fine, MD, DrPH

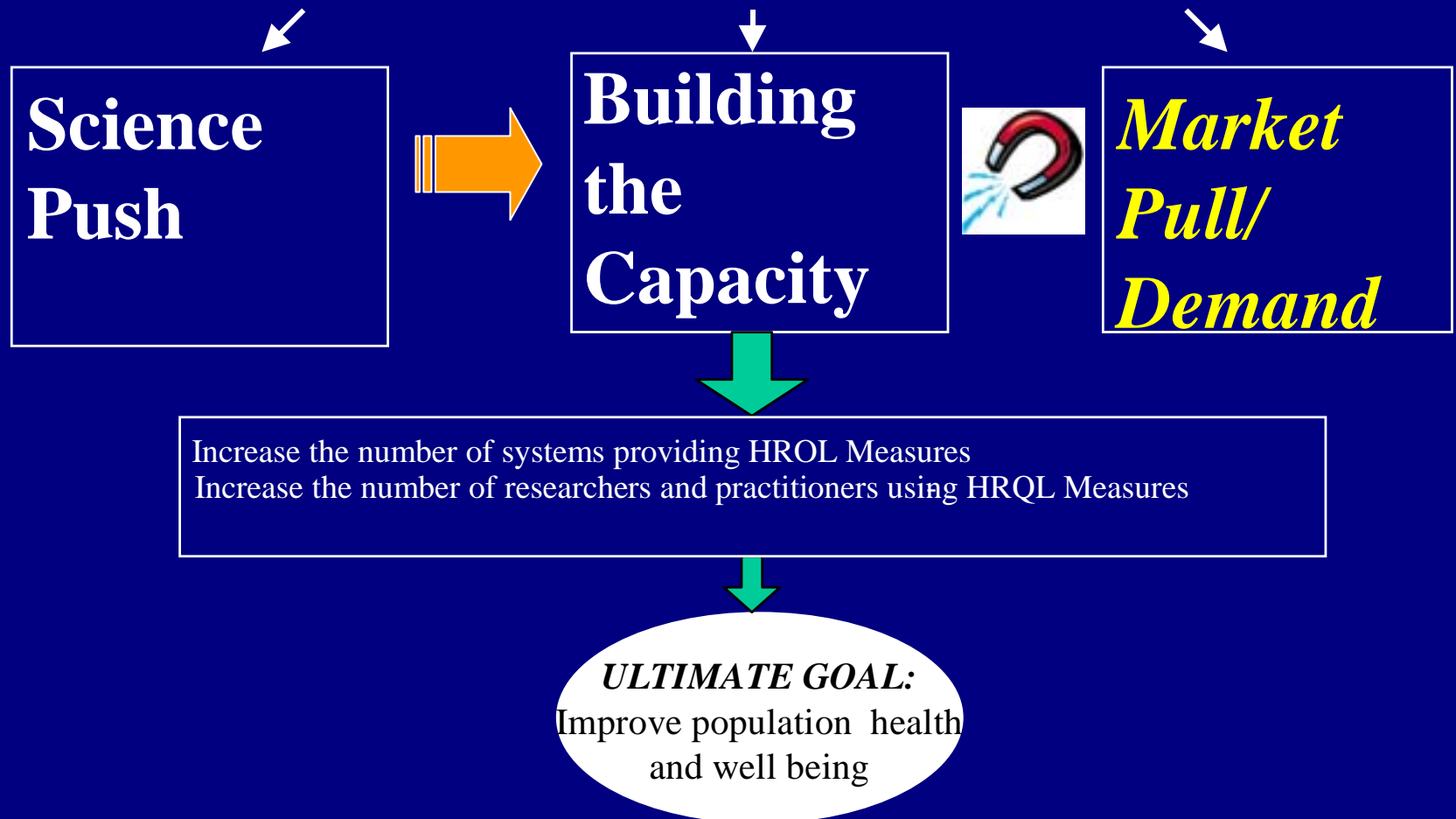
Medical Advisor

Office of Behavioral and Social Sciences

National Institutes of Health

Necessary Steps : A Synergistic Model

Getting H RQL Measures Into Research and Practice



If you want to change the world, be that change.

- Gandhi

NIH Roadmap

Relevant to Science Push, Delivery Capacity, and Market Pull/Demand

What is the NIH Roadmap?

- A framework of priorities the NIH as a whole must address in order to optimize its entire research portfolio.

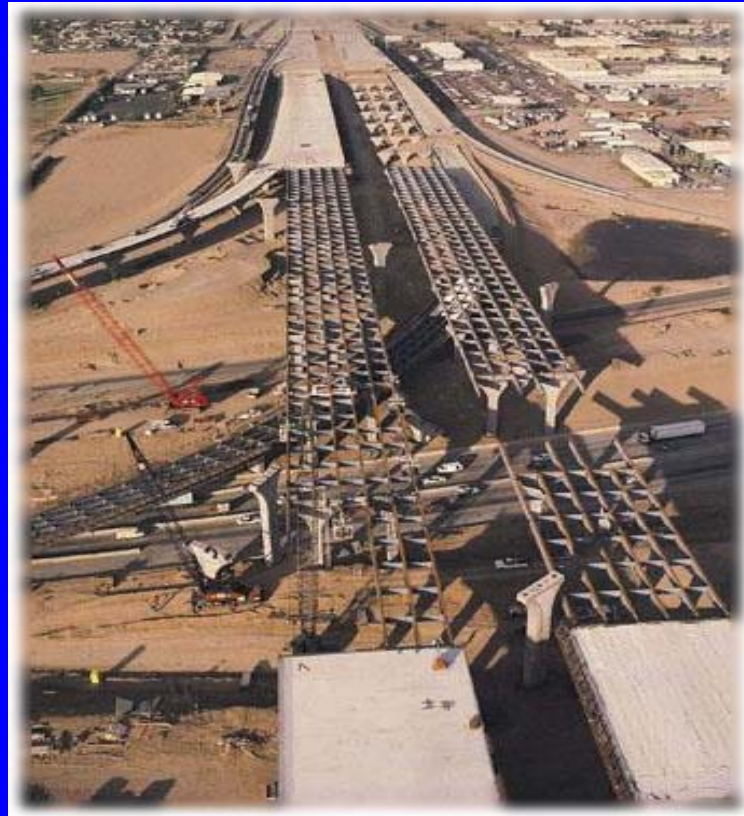
Roadblocks



NIH Roadmap: three themes emerged

- New Pathways to Discovery
- Research Teams of the Future
- Re-engineering the Clinical Research Enterprise – Science Push and Market Demand

The NIH Roadmap: *A Work in Progress*



PROMIS – Patient-Reported Outcomes

Measurement Information System:

A collaborative network of investigators charged to develop and implement a publicly available system of a large item bank and a CAT for more efficient testing of major chronic disease symptoms and functioning.

Relevant to science push, initial steps in building a delivery system, and a vision of market demands

Item Banking and CAT Activities within NIH

- National Institute for Child Health and Human Development (NICHD)
 - RFA (R21): *Dynamic Health Assessments for Medical Rehabilitation Outcomes* (Eight applications awarded with four focusing on developing CATs)
 - Dynamic Assessment of Pediatric Assessment of Pediatric Health and Functioning
 - Quality Metric Inc. (PI: Dr. John Ware)
 - Developing a Computer Adaptive TBI Cognitive Measure
 - University of Florida (PI: Dr. Craig Velozo)
 - A Dynamic Specific Physical Activity Scale
 - University of Illinois at Chicago (PI: Dr. Barth Riley)
 - Rehabilitation Outcomes, Community Participation and ICF
 - Washington University (PI: Dr. David Gray)

Item Banking and CAT Activities within NIH

- National Institute of Neurological Disorders and Stroke (NINDS)
 - Contract: *Quality of Life In Neurological Disorders*
 - Not awarded at this time.
- National Cancer Institute (NCI)
 - R01: Item Banking and CAT for Quality of Life Outcomes
 - Evanston Northwestern Healthcare (PI: David Cella)
 - R21: A Fatigue Item Bank for Children with Cancer
 - Evanston Northwestern Healthcare (PI: Jin-shei Lai)
- National Institute of Mental Health (NIMH)
 - R01: Mental Health Computerized Adaptive Testing
 - University of Illinois at Chicago (PI: Robert Gibbons)

Agency for Healthcare Research and Quality (AHRQ)

- Extramural Projects
 - Computer-adaptive testing of post-acute care functioning (Jette)

PROMIS: Science Push and Delivery Capacity

- **Develop a core set of questions:**
 - Primarily from existing items
 - Develop common metrics
 - With clear domains/constructs

Science Push and Delivery Capacity

- Based on testing in a large diverse sample – wide range of severity and conditions, health literacy, and other important sources of variability
- *Relationship between HRQL and health preferences*
- *Changes in HRQL over time*

Market Demand

- Adaptable to different purposes:
 - different research objectives
 - different information collection systems
 - new items, domains, technologies

Market Demands

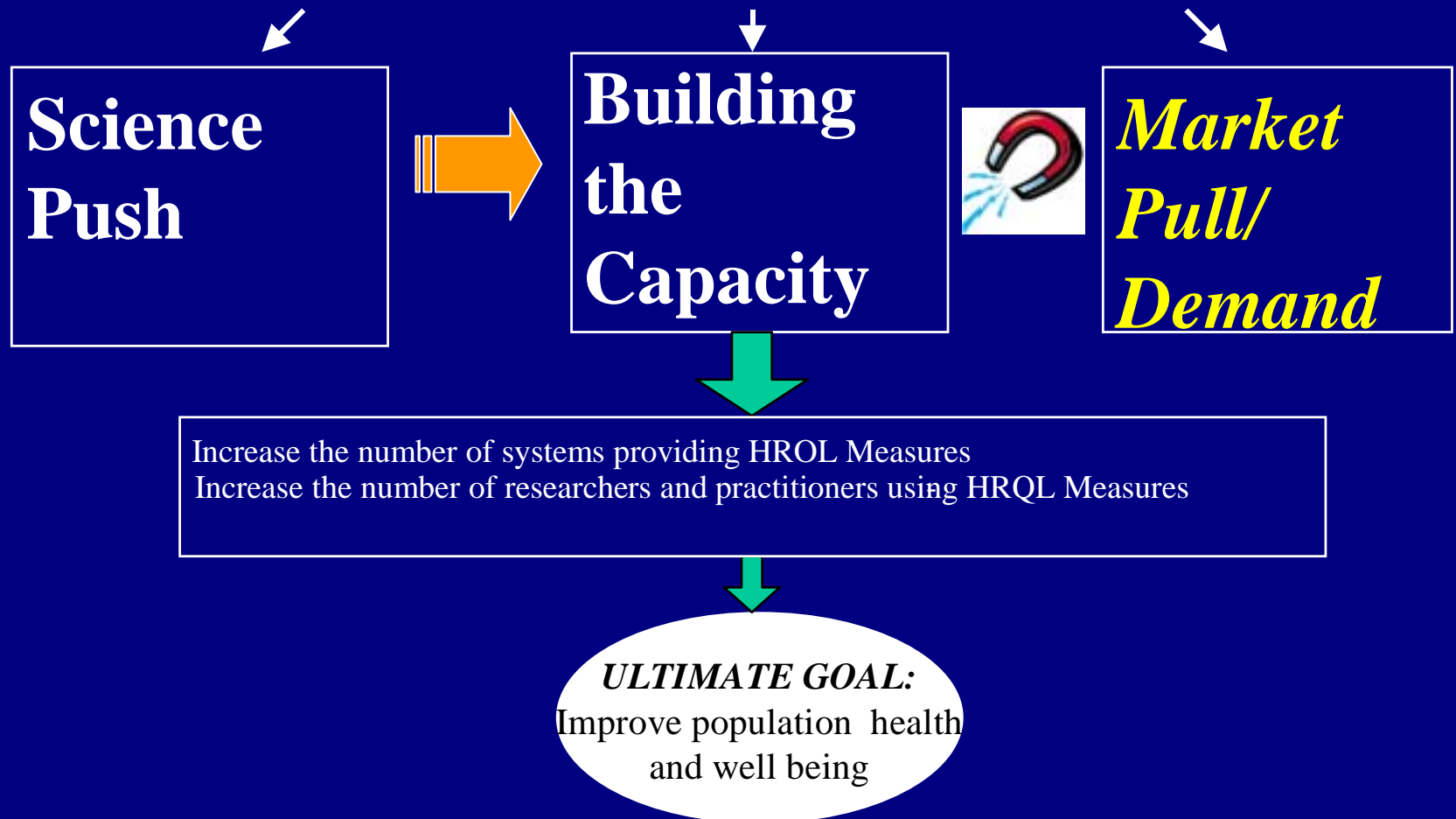
- Linked to information on minimum detected clinical differences or other features to assist in use in clinical trials
- Similarly features to enhance utility for measuring quality of health care

Market Demands

- utility for clinical practice - can it be used to alter treatment plans ?
- Evidence that there is substantial reduction in respondent burden, elimination of floor and ceiling effects and other potential benefits and few disadvantages and reasonable costs

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Thank you

QUESTIONS?

Deborah N. Ader, Ph.D., NIAMS

Aderd@mail.nih.gov

Larry Fine, M.D., DrPH, OBSSR

Finel@mail.nih.gov

Call-in: (888) 566-5788

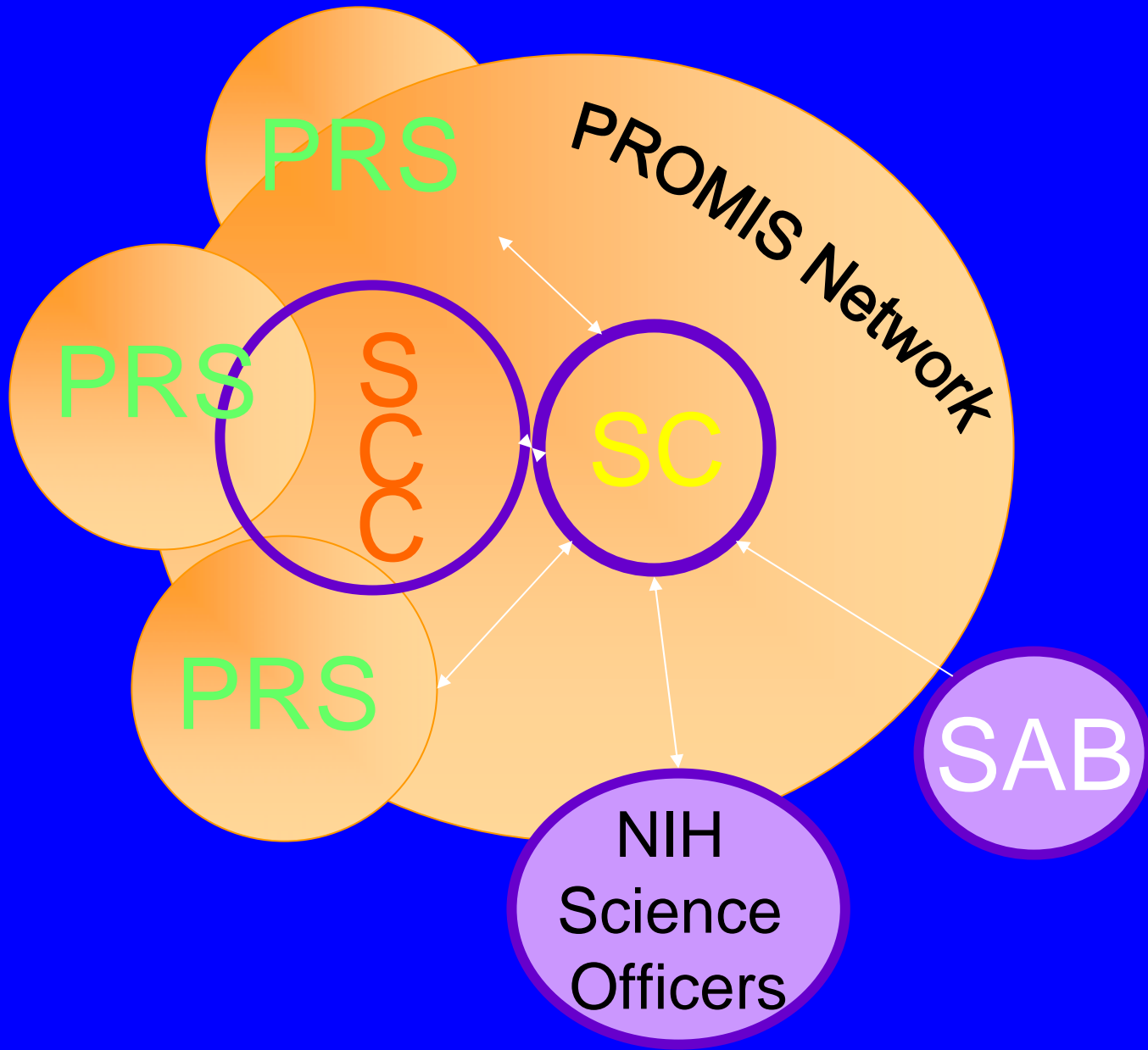
STRUCTURE

**Collaborative agreement network -
Patient Reported Outcomes
Measurement Information System
(PROMIS) consisting of:**

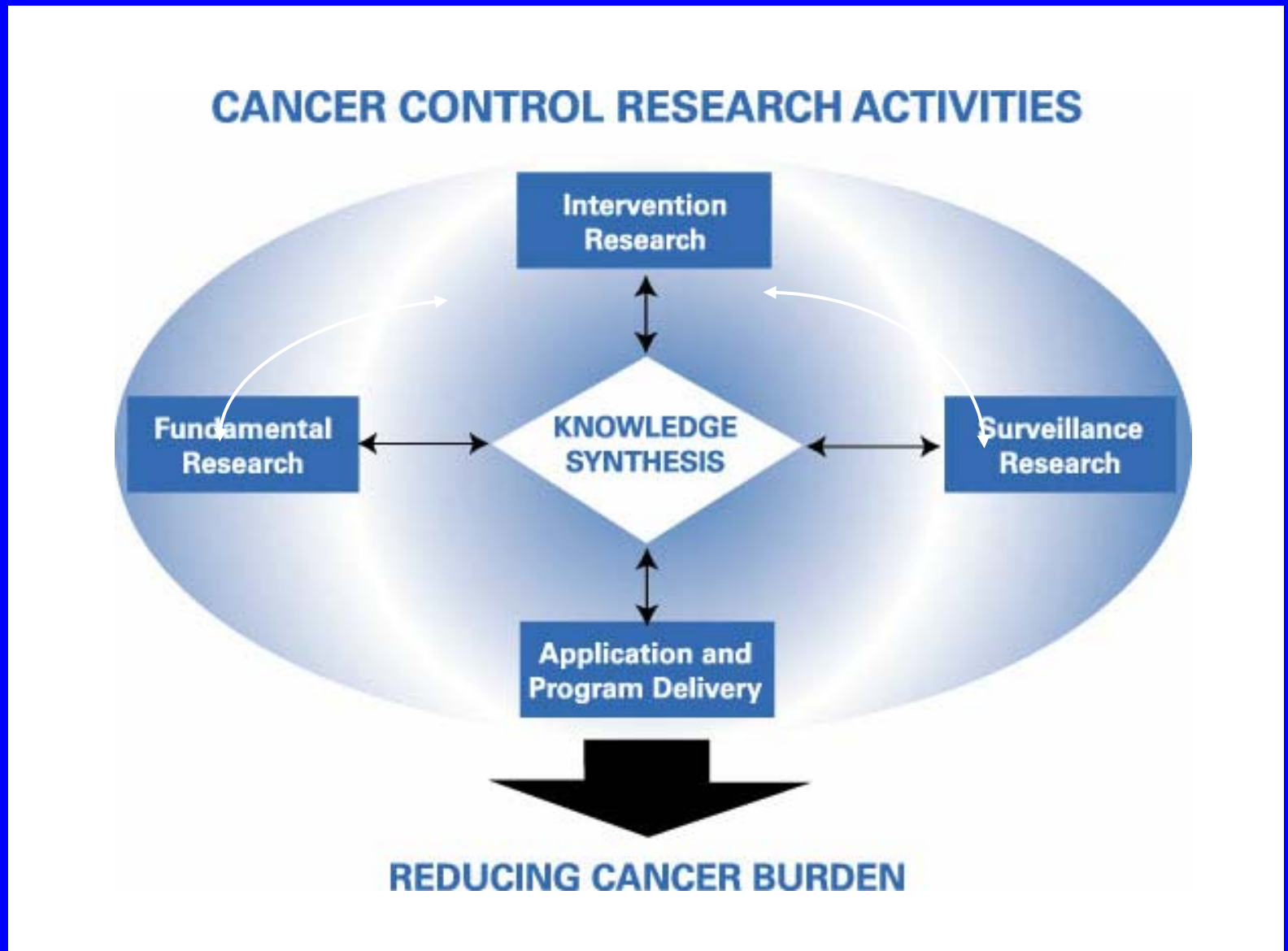
- **3-6 Primary Research Sites**
- **A Statistical Coordinating Center**
- **Steering Committee**
- **Scientific Advisory Board**

Primary Research Sites

- Identify and define key PRO constructs
- Contribute expertise to design PROMIS
- Collect data from specified populations
- Conduct independent studies that will complement PROMIS



Dynamic Model of Cancer Control Research



Working Together To Make the Whole Greater Than the Sum of Its Parts

