



Engagement Matters.

Jessie Gruman Health Engagement Award Master Lecture
2016 Annual Meeting, Society of Behavioral Medicine
March 31, 2016

Michael G. Goldstein, MD

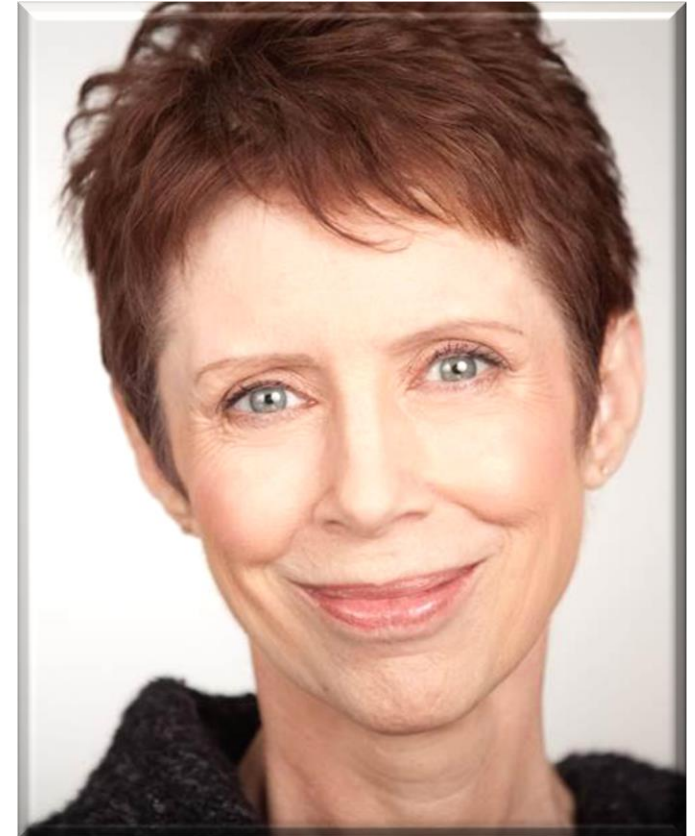
Associate Chief Consultant for Preventive Medicine

VHA National Center for Health Promotion and Disease Prevention

1

Jessie Gruman, Ph.D.

- Founder, President of *Center for Advancing Health*, the leading patient engagement policy institute, based in Washington, DC
- Spearheaded the development of the Engagement Behavior Framework
- Visionary, scientist, policy maker, patient, advocate, author, mentor, colleague, friend and more...



Outline & Objectives

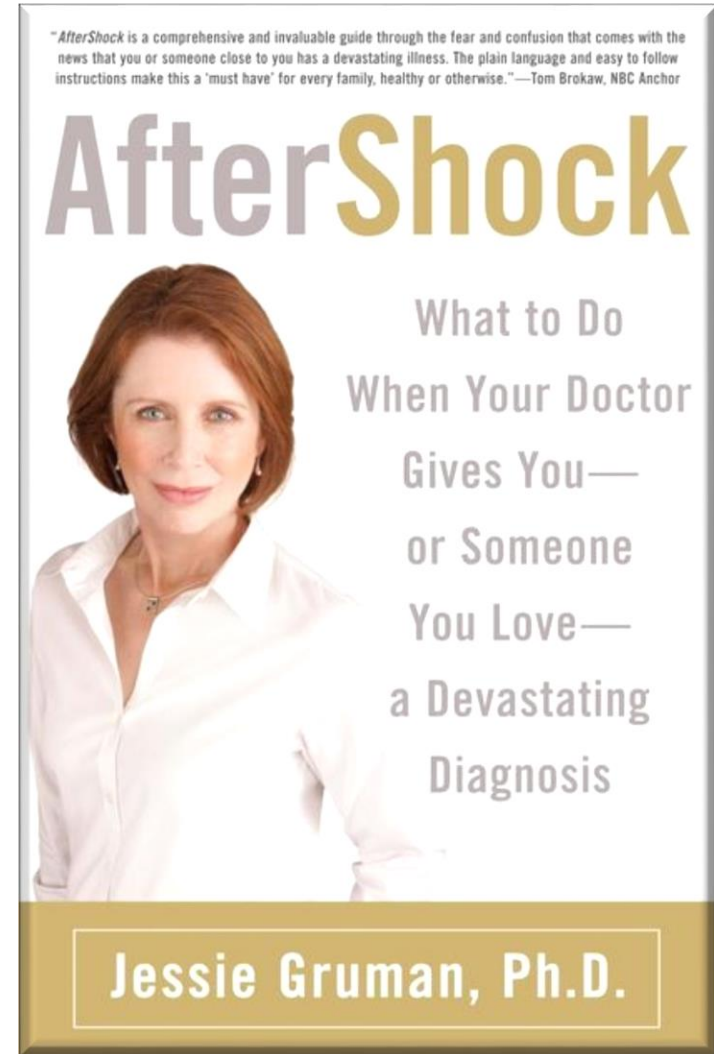
- **What is Patient Engagement?**
- **Why and How Does Engagement Matter?**
- **How Can Health Care Systems Support Patient Engagement?**

Engagement Matters

“People have the right to understand what is going on in their body, be given a realistic sense of how treatment might affect it, and the responsibility to make decisions informed by that knowledge.

We are, after all, the ones who will live with the consequences of our choices.”

**[Jessie Gruman, Introduction,
Aftershock, 2007]**



<https://itunes.apple.com/us/app/aftershock-facing-serious/id881103514?mt=8>

What do Veterans Want?

“Help me manage my medications”

“Let me see all my health records.”

“Help me understand my information.”

“Notify me.”

“Help me manage my appointments.”

“Help me care for myself.”

“Help me connect with other Veterans.”



VHA Voice of the Veteran Report (2011)

Definitions: Patient Activation & Patient Engagement

- **Patient activation:**

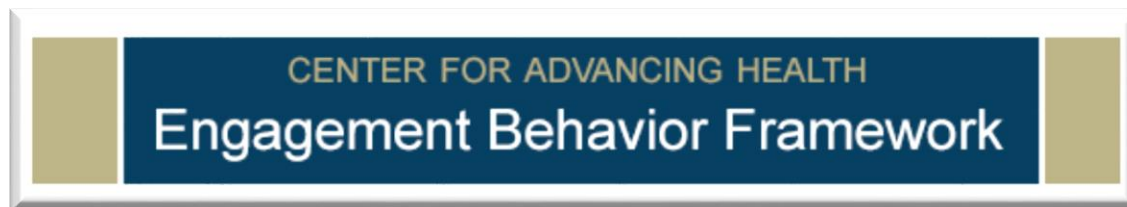
*“understanding one’s **role** in the care process and having the **knowledge, skill and confidence** to manage one’s health and health care”*

(Hibbard et al., HSR, 2004; Hibbard and Greene, Health Affairs, 2013)

- **Patient engagement:**

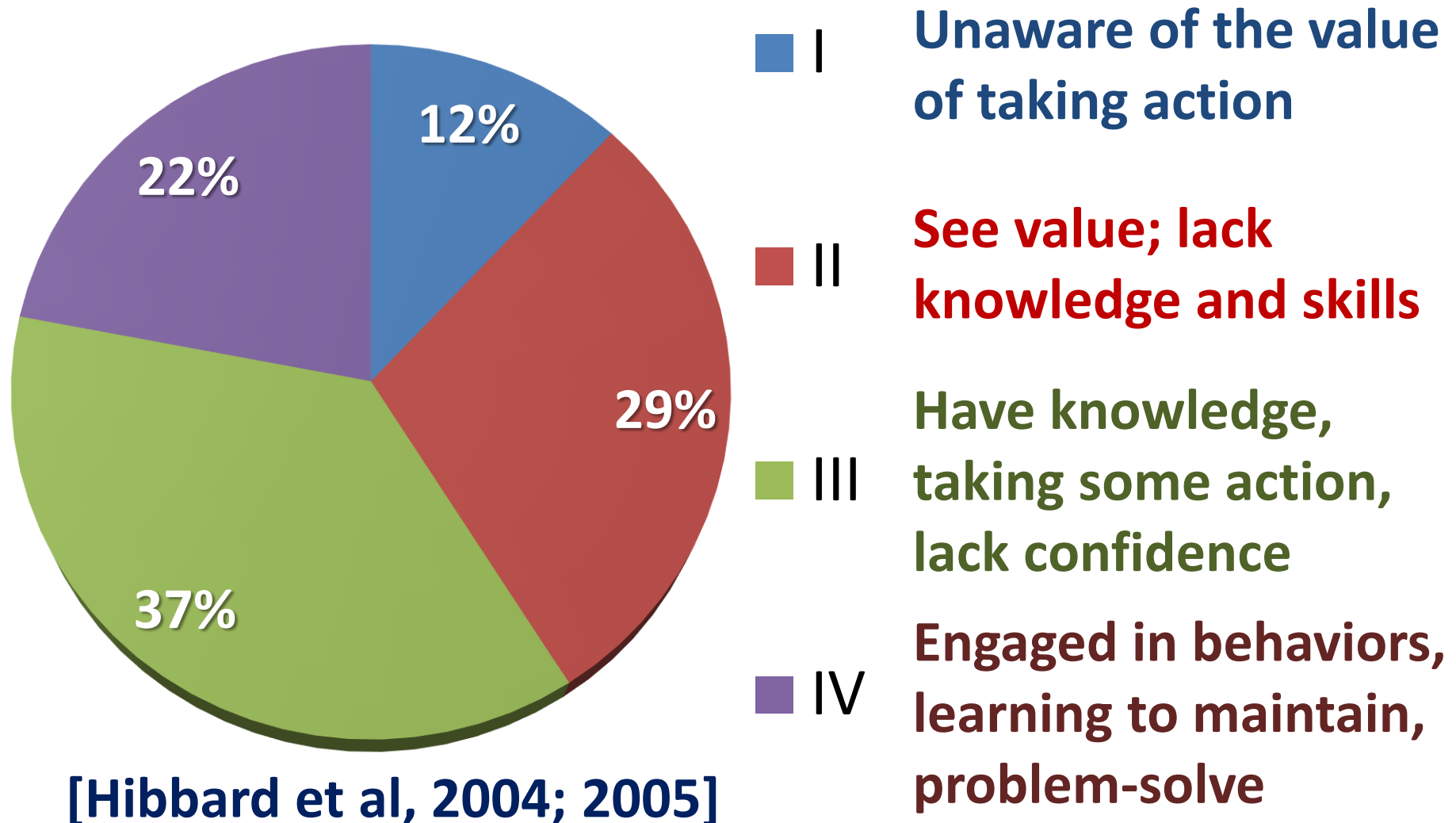
*“**actions** individuals must take to obtain the greatest benefit from the health care services available to them.”*

(CFAH Whitepaper, 2010; Gruman et al, 2010)



<https://youtu.be/AO-YwwISrul>

Levels of Patient Activation



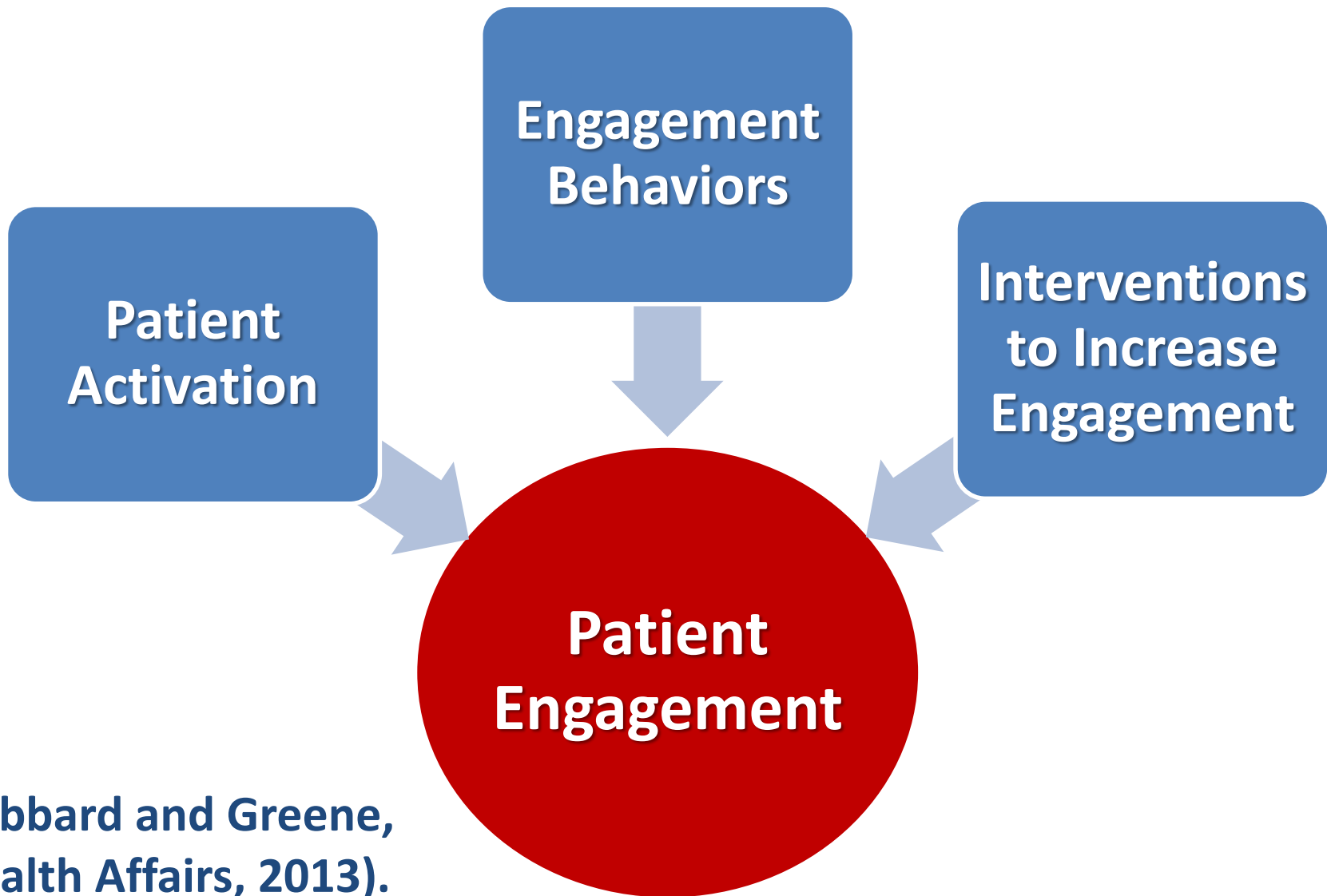
Patient Activation

Higher Patient Activation scores are associated with:

- Engaging in healthy behaviors; not engaging in health damaging behaviors
- Engaging in preventive visits, screening, immunizations
- Engaging in self-management behaviors, taking medications, visits
- Preparing for health care visits
- Seeking information about health, quality
- Higher quality interpersonal exchanges with clinicians
- Less delay in seeking care

(Hibbard & Greene, Health Affairs, 2013)

Patient Engagement



(Hibbard and Greene,
Health Affairs, 2013).



ENGAGEMENT

The Center for Advancing Health listens to patient perspectives. We translate what we learn into resources that help all of us participate fully in our health care and that enable policy makers and clinicians to support us in doing so.

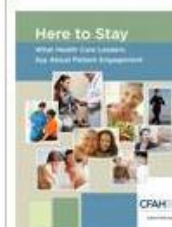
WHAT IS PATIENT ENGAGEMENT?



ENGAGEMENT BEHAVIOR FRAMEWORK

CFAH defines patient engagement as "the actions we take to support our health and to

SUPPORTING ENGAGEMENT



Here to Stay: What Health Care Leaders Say About Patient Engagement
More



Snapshot of People's Engagement in Their Health Care
More



Getting Tools Used: Lessons for Health Care from Successful Consumer Decision Aids
More

<http://www.cfah.org/engagement/>

CENTER FOR ADVANCING HEALTH Engagement Behavior Framework

Methodology

- Items from Patient Activation Measure (Hibbard)
- 210 Interviews with patients and caregivers
- Literature review
- 57 key informant interviews: consumer & advocacy groups, purchasers, health care representatives, researchers, clinicians
- External review panel helped to refine final list

[CFAH Whitepaper, 2010; Jessie Gruman et al, 2010]

CENTER FOR ADVANCING HEALTH

Engagement Behavior Framework

**Find Good
Health Care**

**Communicate
with Health Care
Professionals**

**Organize Health
Care**

**Pay for Health
Care**

**Make Good
Treatment
Decisions**

**Participate in
Treatment**

Promote Health

**Get Preventive
Health Care**

**Plan for the End
of Life**

**Seek Health
Knowledge**

[CFAH Whitepaper, 2010; Jessie Gruman et al, 2010]

Communicate with Health Care Professionals

- Prepare a *list of questions and issues* for discussion
- Bring a *list of all current medications* and alternative products and be prepared to discuss their benefits and side effects
- *Report* physical and mental *symptoms*
- *Ask questions* when any explanations or next steps are not clear
- *Express any concerns* about recommendations or care experiences



[CFAH Whitepaper, 2010; Jessie Gruman et al, 2010]

Make Good Treatment Decisions

- Gather and share *additional expert opinions* on any serious diagnosis prior to beginning treatment
- *Ask about the evidence* for the benefits and risks of recommended treatment options
- *Negotiate a treatment plan* with providers



[CFAH Whitepaper, 2010; Jessie Gruman et al, 2010]

Participate in Treatment

- *Learn about medications and devices*, including side effects or interactions
- Fill prescriptions, *monitor effectiveness* and share discontinuation plans
- *Maintain devices*
- Review and *evaluate tests in discussion* with health care providers
- *Monitor symptoms and conditions*, including danger signs that require urgent attention



[CFAH Whitepaper, 2010; Jessie Gruman et al, 2010]

Promote Health

- *Set and act on priorities for changing behavior** to optimize health and prevent disease
- *Secure services that support changing behavior** to maximize health and functioning and maintain those changes over time
- Manage symptoms by *following agreed-upon treatment plans*, including diet, exercise and substance use



[CFAH Whitepaper, 2010; Jessie Gruman et al, 2010]

Self Care: VHA Healthy Living Messages

- ★ Get involved in your health care.
- ★ Be tobacco free.
- ★ Eat wisely.
- ★ Be physically active.
- ★ Strive for a healthy weight.
- ★ Limit alcohol.
- ★ Get recommended screening tests & immunizations.
- ★ Manage stress.
- ★ Be safe.



What is Self-Management?

*“Self-management is broadly defined as **all** that a patient does to manage their chronic condition and live their lives as fully and productively as possible.”*



[Bodenheimer et al, 2002; Lorig et al, 2003]

Self-Management Domains



- To take care of the illness
(medical management)
- To carry out normal activities
(role management)
- To manage emotions, coping
(emotional management)

[Corbin & Strauss, 1998; Bodenheimer et al, 2002; Lorig et al, 2003]

Self-Management Tasks for Diabetes



Monitoring



Diet and healthy eating



Physical activity



Medication taking



Medical and dental visits



Coping with emotions



Foot care



Managing Weight



Managing symptoms and blood sugars

AHRQ Patient Engagement Framework

Care for the individual patient

- Communication and Information Sharing
- Self-Care
- Decision Making
- Safety

Practice improvement

Policy design and implementation

[Scholle et al, AHRQ, 2010;]

HHS/AHRQ National Quality Strategy Priorities

1

Make care safer by reducing harm caused in the delivery of care

2

Ensure that each person and family members are engaged as partners in their care

3

Promote effective communication and coordination of care

4

Promote the most effective prevention and treatment practices for the leading causes of mortality, starting with CVD

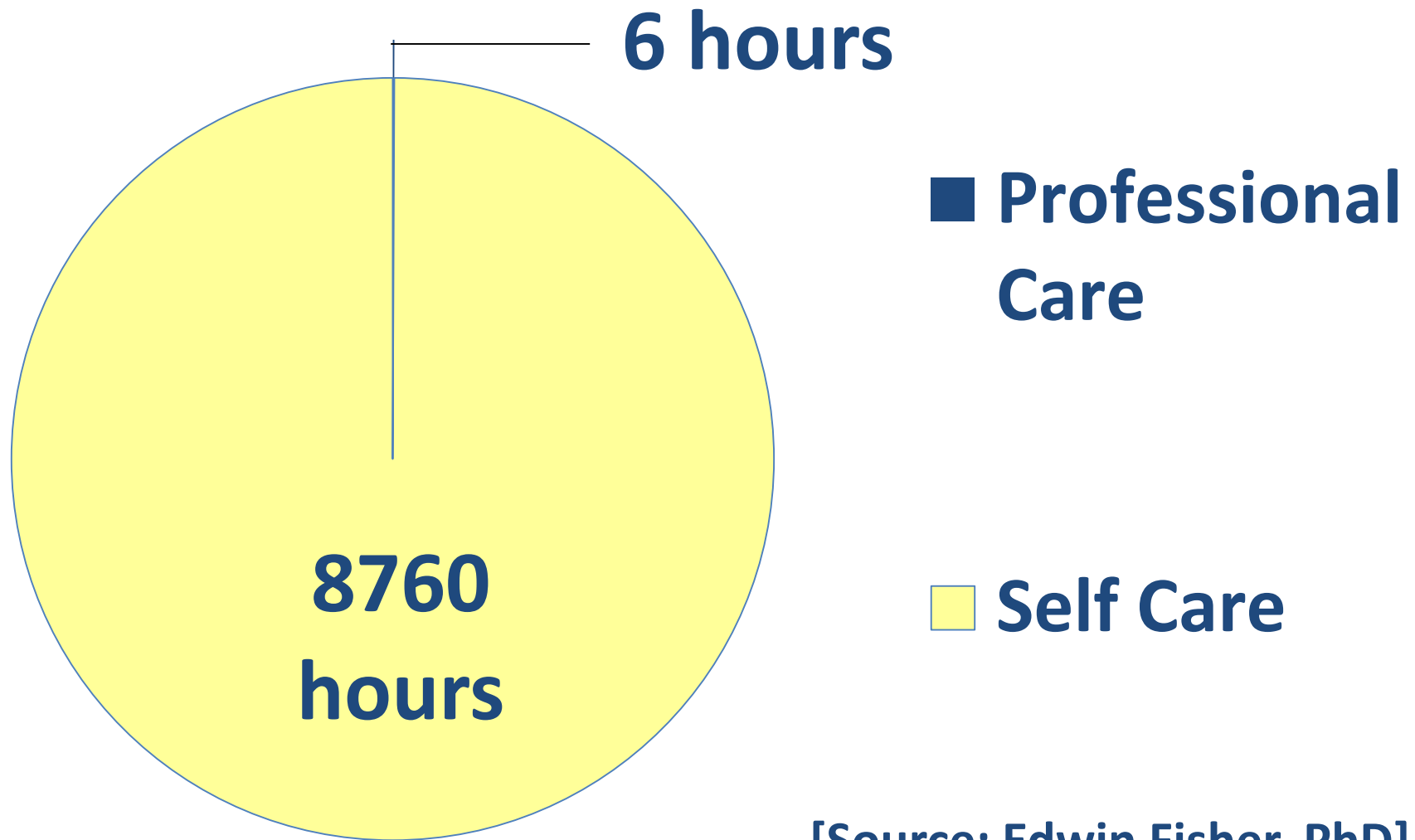
5

Work with communities to promote wide use of best practices to enable healthy living

6

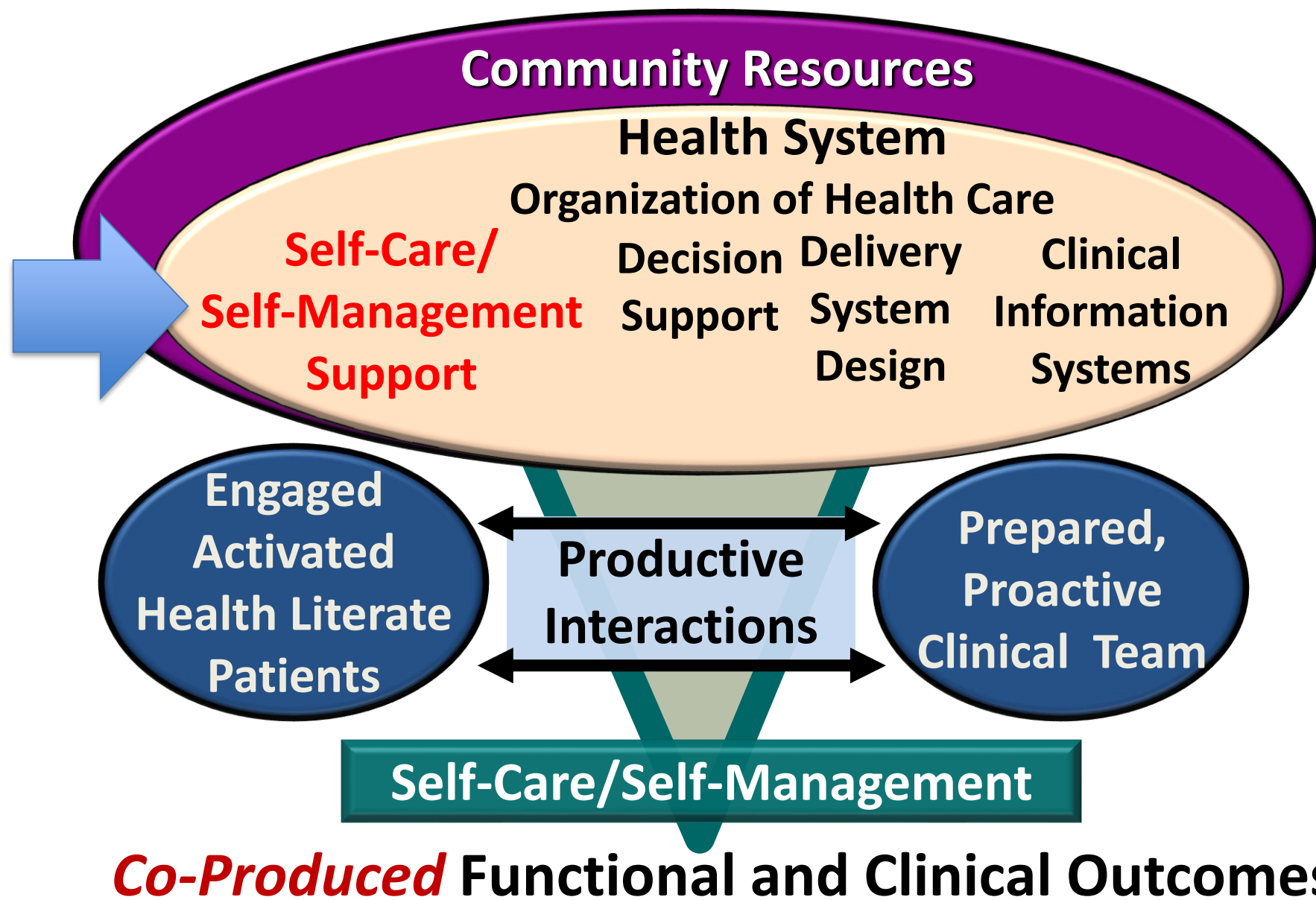
Make quality care more affordable for individuals, families, employers and governments by developing and spreading new health delivery models

Self-Care Hours Vs. Professional Care Hours



[Source: Edwin Fisher, PhD]

The Planned Care Model (Wagner et al, 1998)



What is Self-Management Support?

Institute of Medicine Definition:

- “The *systematic* provision of *education* and *supportive* interventions
- to increase patients’ *skills and confidence* in managing their health problems,
- including regular *assessment* of progress and problems, *goal setting*, and *problem-solving support*.”

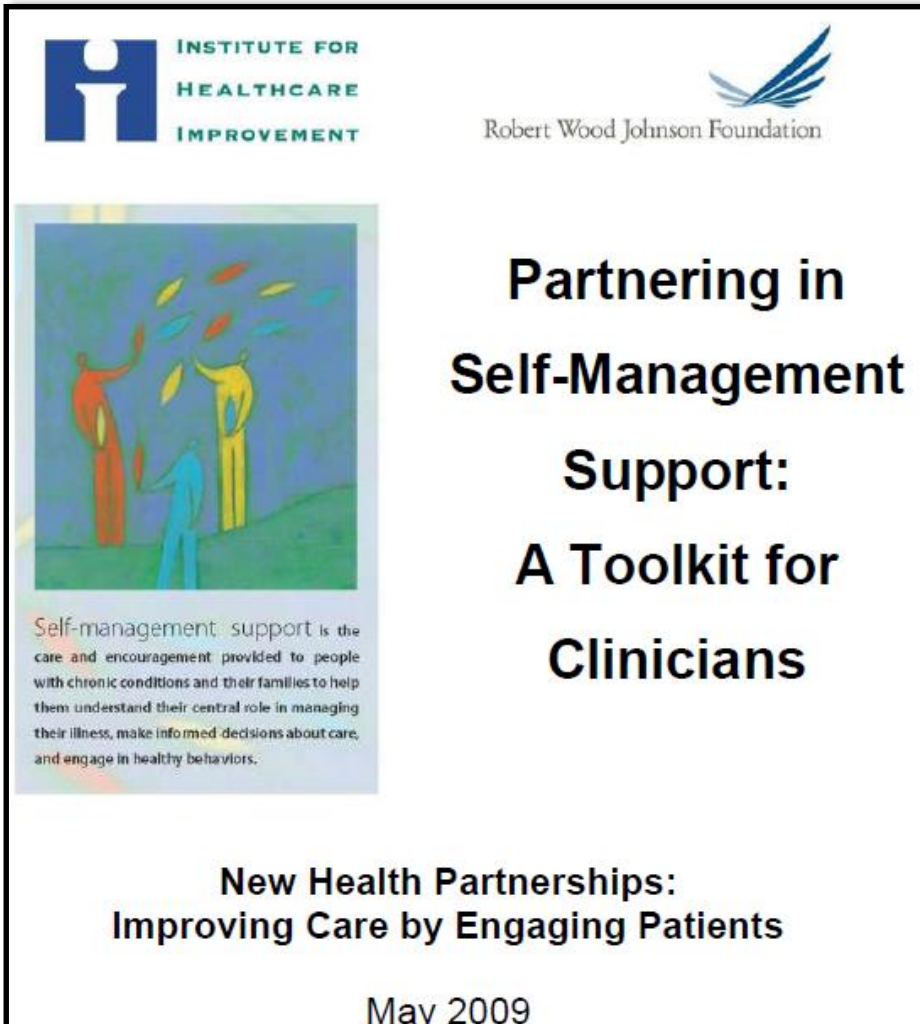
[Adams, IOM, 2003; Pearson, AHRQ, 2007]

What is Self-Management Support?

New Health Partnerships Definition:

“the care and encouragement provided to people with chronic conditions and their families to help them:

- ***understand their central role in managing their illness,***
- ***making informed decisions about care, and***
- ***engage in healthy behaviors.”***



The image shows the front cover of a report. At the top left is the logo for the Institute for Healthcare Improvement, featuring a stylized 'H' and the text 'INSTITUTE FOR HEALTHCARE IMPROVEMENT'. At the top right is the logo for the Robert Wood Johnson Foundation, featuring a stylized bird and the text 'Robert Wood Johnson Foundation'. In the center is a colorful illustration of three stylized human figures (one red, one yellow, one blue) standing on a green hill and reaching up towards several colorful fish-like shapes floating in the air. Below the illustration is a text box with the definition of self-management support. To the right of the illustration, the title 'Partnering in Self-Management Support: A Toolkit for Clinicians' is written in large, bold, black font. At the bottom, the subtitle 'New Health Partnerships: Improving Care by Engaging Patients' is written in bold, black font, followed by the date 'May 2009'.

INSTITUTE FOR
HEALTHCARE
IMPROVEMENT

Robert Wood Johnson Foundation

**Partnering in
Self-Management
Support:
A Toolkit for
Clinicians**

Self-management support is the care and encouragement provided to people with chronic conditions and their families to help them understand their central role in managing their illness, make informed decisions about care, and engage in healthy behaviors.

**New Health Partnerships:
Improving Care by Engaging Patients**

May 2009

[Schaefer J, et al. Available at: <http://www.improvingchroniccare.org>]

The **Process** of Patient-Centered Self-Management Support



[Glasgow et al., 2002; Schaefer J, et al. 2009; Battersby et al, Jt Comm Qual Patient Saf. 2010]

Core SMS Competencies & the 5As

- Relationship Building
- Exploring patients' needs, expectations and values
- Information Sharing
- Collaborative Decision Making, Goal Setting
- Action Planning, Problem Solving, Skill Building
- Follow-up on progress

Assess

Advise

Agree

Assist

Arrange

Evidence: Impact of Self-Management Support Interventions

Across multiple studies, improved:

- Knowledge and understanding
- Confidence and coping ability
- Health behaviors
- Social support

Limited evidence:

- Increased medication taking and follow-through
- Reduced hospitalizations (CHF)
- Improved illness outcomes (DM)

[Coulter, A. Patient Engagement—What Works?, 2012]

Low Health Literacy: Barrier to Engagement

**1 of 4 adults have
extremely limited literacy
skills.**



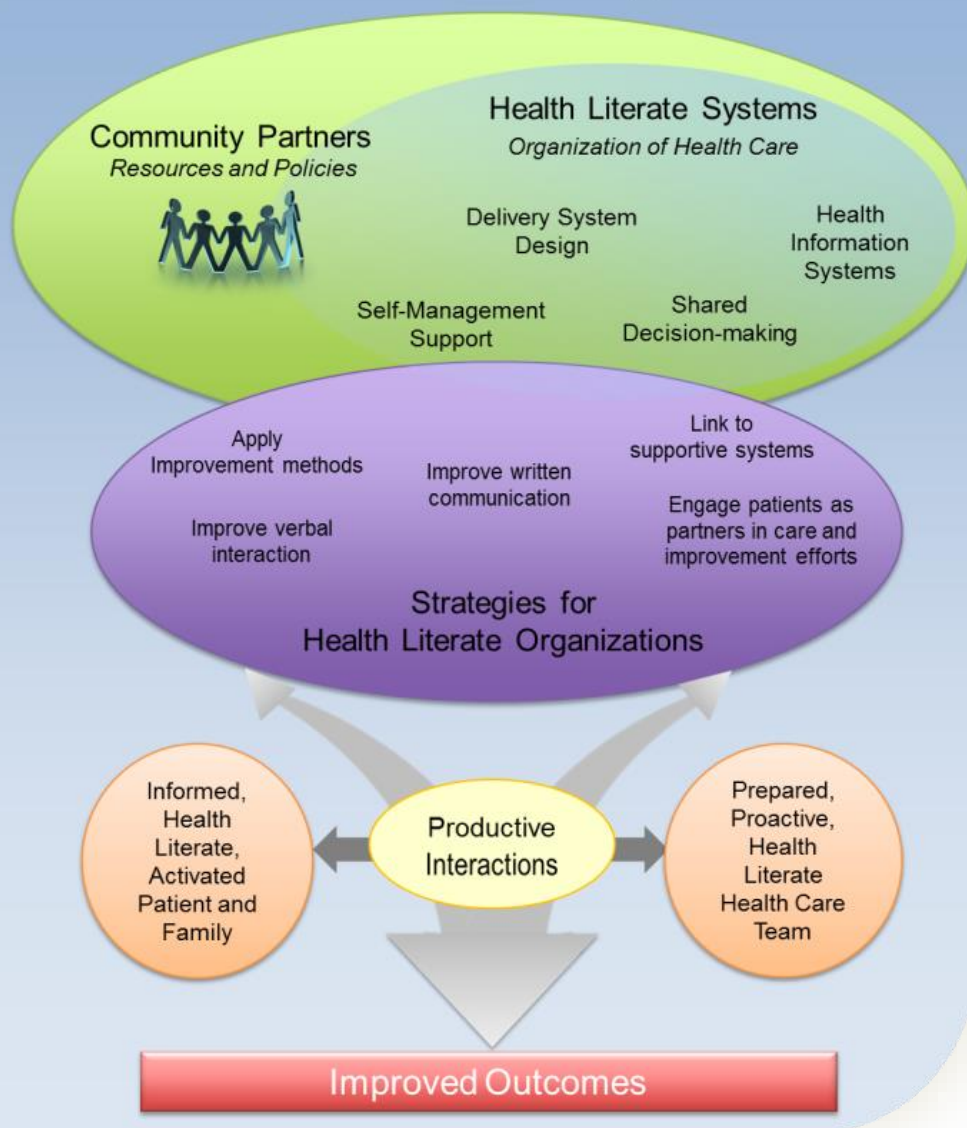
**Those with
low literacy
skills**

- Less self-management
- Less use of preventive services
- Lower medication-taking
- More unnecessary admissions or ER visits

[Koh, et al, Health Affairs, 2013]

Health Literate Care Model

A Universal Precautions Approach



Universal Precautions:

Structuring the delivery of care as if everyone may have limited health literacy

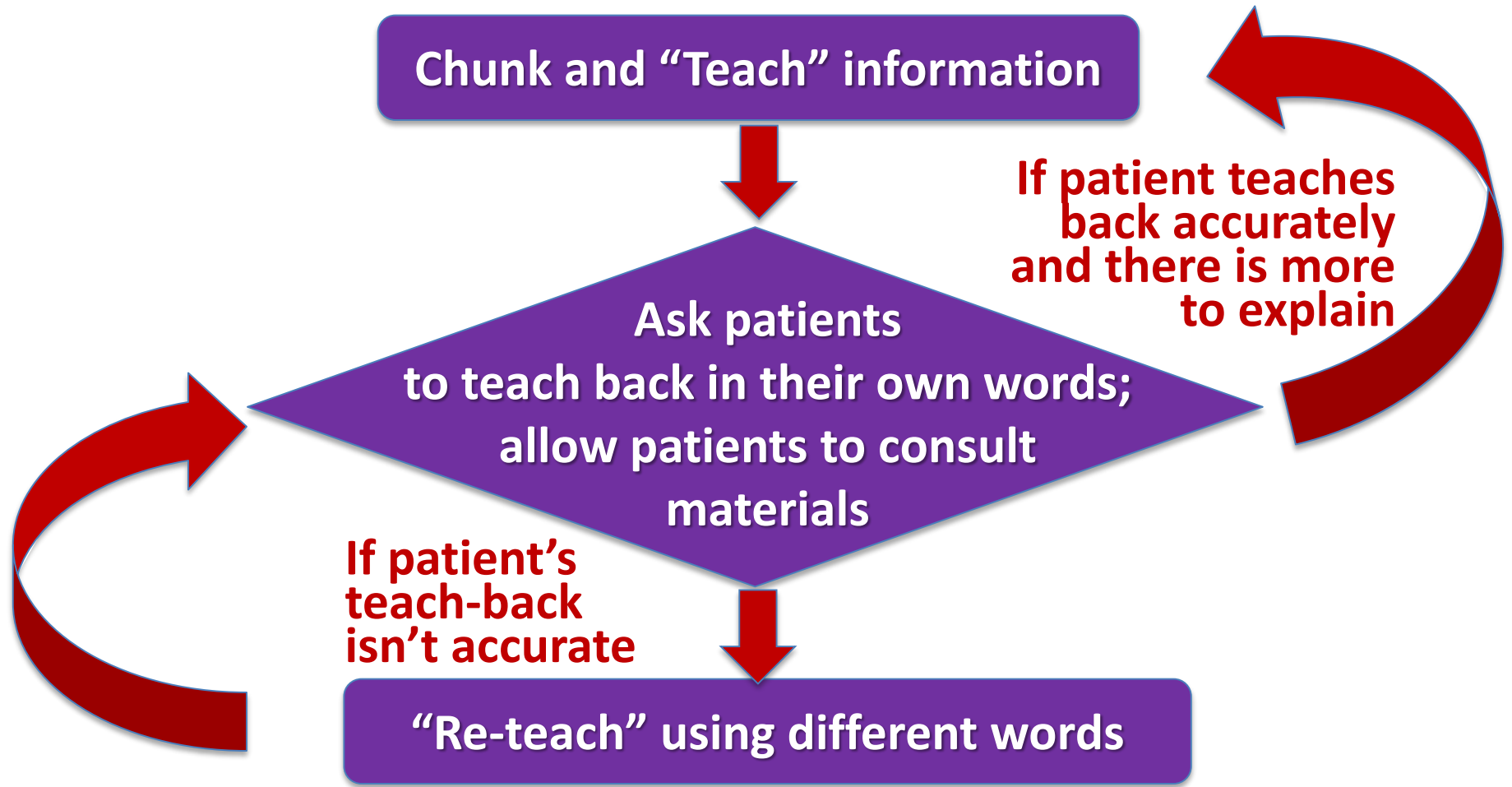
- You can't tell by looking
- Higher literacy skills \neq understanding
- Health literacy is a state not a trait
- Everyone benefits from clear communication

“Health literacy is the currency for everything we do.”

Howard K. Koh, MD, MPH, Former Assistant Secretary for Health

[Koh, et al, Health Affairs, 2013]

Improve Verbal Communication: The Teach-Back Method



[Koh, et al, Health Affairs, 2013; Schillinger et al 2003]

Systems to Support Patient Engagement

Peer Support

Training

**Tools,
Resources**

**System
innovations
(e.g., SMAs)**

**Links to
Community
Resources**

**Information
Systems/
Telehealth**

Leadership Support

**Patient/Family
Engagement in System,
Policy Improvement**

Training Clinicians in Veteran-Centered Communication

Veteran-Centered Communication Training:

**Support Self-Care/
Self-Management**

**Proactively engage
Veterans**

Personalize care

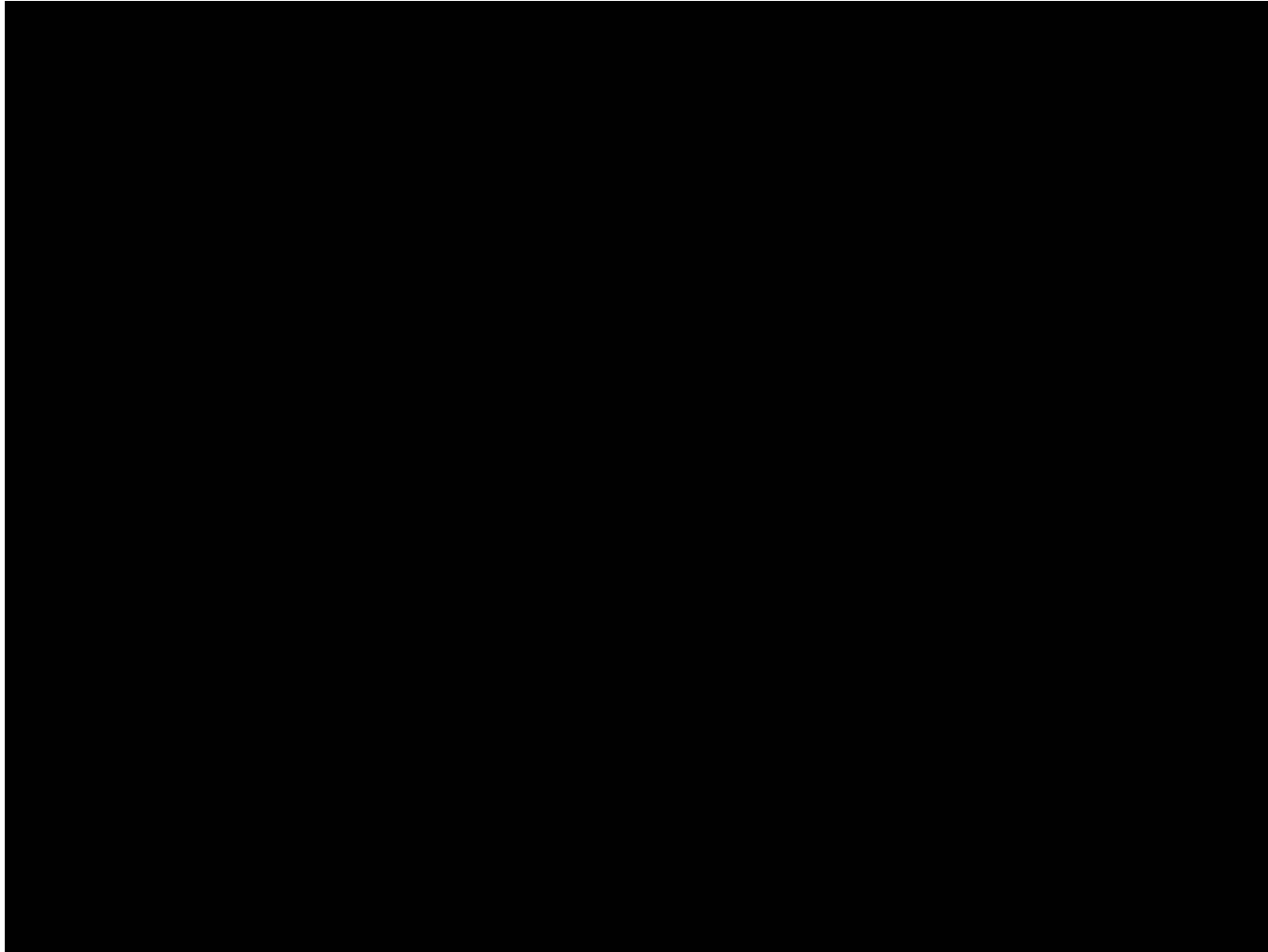
**Enable shared
decision making**

**Evidence-based,
Veteran-centered**

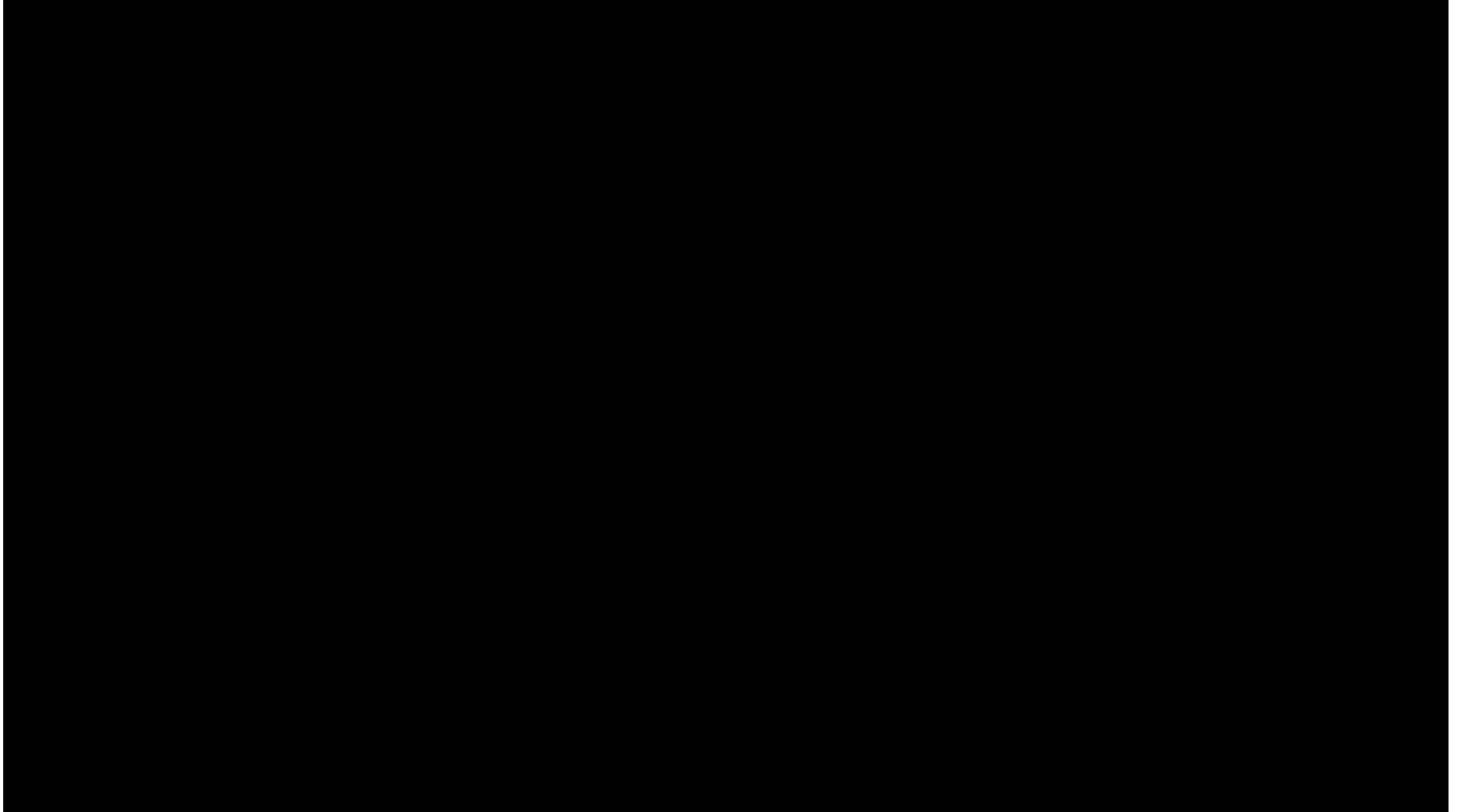
**Build trust,
shared understanding**

**Build healing
relationships and
healthy partnerships**

Demonstration: Veteran-Centered Communication in a VA Primary Care Clinical Encounter



Training Matters.



Clinical Tools to Support Engagement

My Health Choices



Circle your choice below.



Be Involved in
Your Health Care



Be Tobacco Free



Eat Wisely



Be Physically
Active



Strive for a
Healthy Weight



Limit Alcohol



Get Recommended
Screening Tests &
Immunizations



Manage Stress



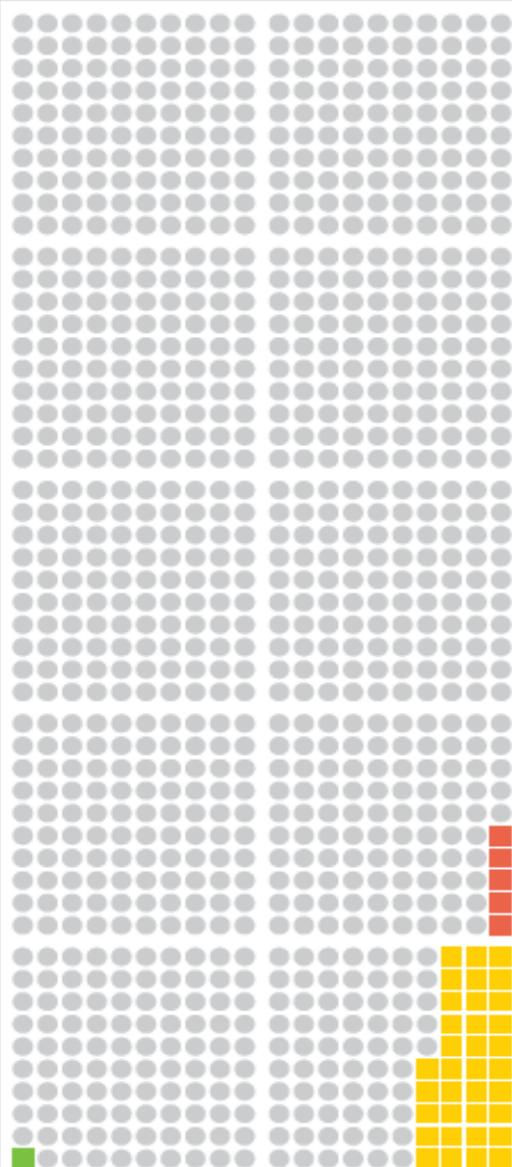
Be Safe



Benefits of Prostate Cancer Screening

0–1 fewer men in 1000
will DIE from **PROSTATE CANCER**

1000 MEN



Harms of Prostate Cancer Screening

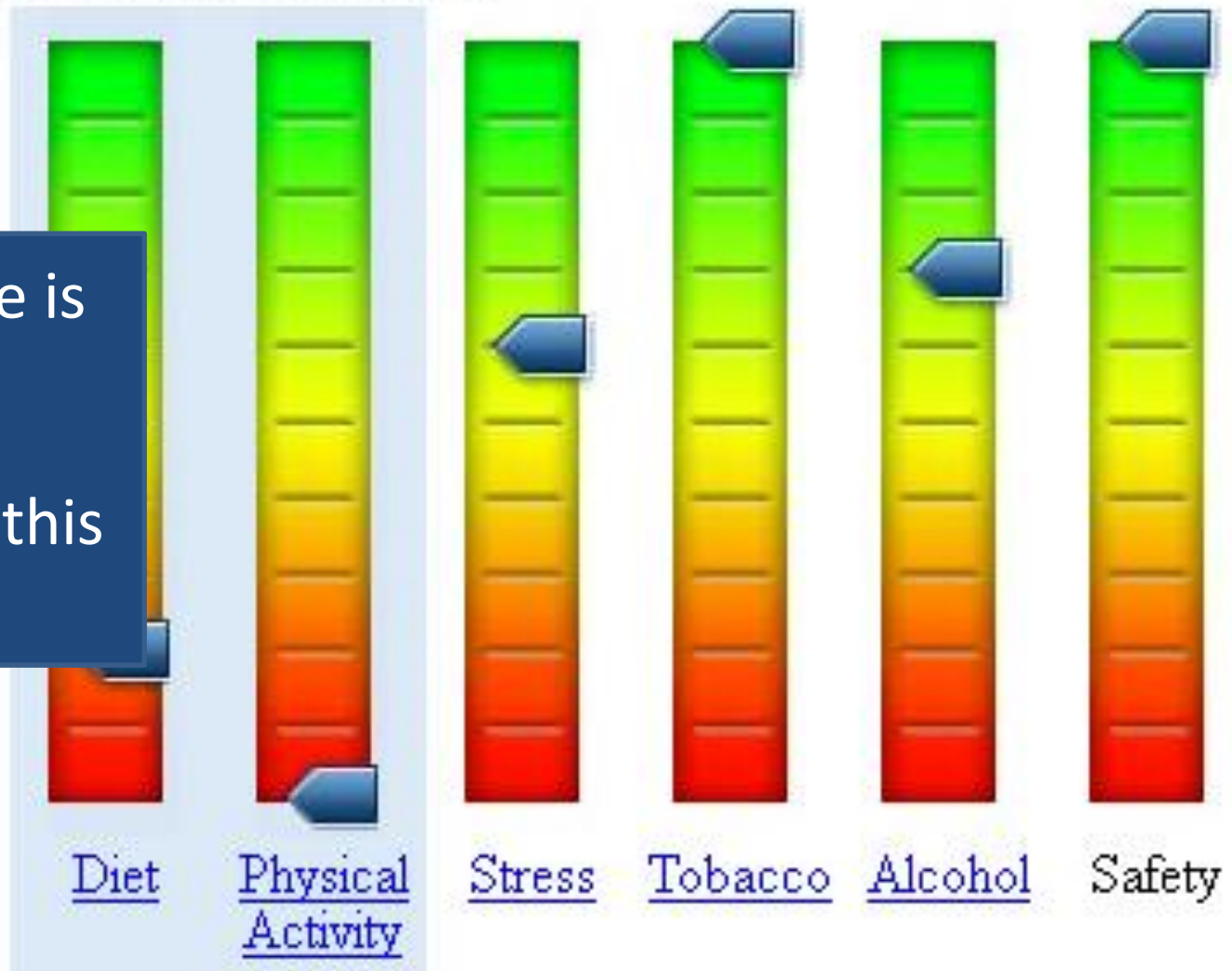
4–5 more men in 1000
will experience a **SERIOUS HARM**
from testing and treatment:

- 1–2 more men in 1000
will be **HOSPITALIZED** from
INFECTION received during
biopsy
- 3 more men in 1000
will experience a **HEART
ATTACK** or **BLOOD CLOT**
because of treatment
- Less than 1 in 1000
will **DIE** from complications of
biopsy or treatment

35 more men in 1000
will develop problems with
SEXUAL FUNCTION or **BLADDER
CONTROL** from treatment

Your Health Choices

Excellent



Your Health Age is

67

You can reduce this
by 20 years

Many
Changes
Possible

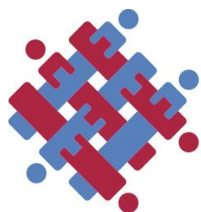
Where you stand



What you are interested in working on



Peer Support: 4 Key Functions



Peers for Progress

Peer Support Around the World

University of North Carolina at Chapel Hill

www.peersforprogress.org

Peer Support Interventions: Diabetes

- **Prediabetes: DPP** lay leaders as effective as professionals [Ali et al, 2014]
- **Diabetes:** significant reductions in A1c [Qi et al, 2015; Zhang, 2016]
- **Diabetes: Reciprocal peer support** model, more effective than nurse care management in improving glycemic control, other outcomes (Heisler et al, 2010)
- Heisler et al. testing a model for integrating **reciprocal peer support with** Shared Medical Appointments (SMAs) in VHA.



Heisler, M. Building Peer Support Programs to Manage Chronic Disease: Seven Models for Success, California Health Care Foundation, 2006



California Health Care Foundation
HEALTH CARE THAT WORKS FOR ALL CALIFORNIANS

Engagement Matters

“A lot of old people with diabetes like us sit around at home and look out the window. We feel sick and pretty useless. I learned things I could be doing to take care of my diabetes from [my peer partner]. But I also felt that I helped him. I enjoyed talking to him on the phone, and it made me feel inspired to do more.”



**Peer participating in Reciprocal Peer Support Calls.
From M. Heisler et al, Ann Int Med 2010.**

Engagement Matters




Ron Whitcomb, Vietnam Veteran, Vet2Vet Peer Facilitator

Engagement Matters

“The work we do is part of our ongoing recovery from PTSD and it is a blessing to have the ability, been given the opportunity by the VA, and to be able to help others.”

“The most profound statement anyone makes to us is ‘thank you guys for helping me come home’.”




ABOUTFACE

PTSD TREATMENT CAN TURN YOUR LIFE AROUND

For more information visit
www.ptsd.va.gov/AboutFace

NCPTSD 10-13C



Ron Whitcomb, Vietnam Veteran, Vet2Vet Peer Facilitator

What Can We Do to Support Patient Engagement?

- Patients
- Peers/Caregivers
- Clinicians/Teams
- Health Care System Leaders/Organizations
- Community Organizations
- Researchers/Innovators
- Advocates
- Government/Policy Makers

Engagement Matters

“I am, however, encouraged by the creativity and determination that people display as we take on the responsibilities of being patients – in effect, reluctant tourists in the foreign land of health care.

With help from our parents, children, spouses, siblings and friends, many of us are able to overcome formidable barriers within the current health system, even while we are ill and anxious.

We point our attention like a laser to find a reasonable pathway to recovery and then, day after day, take the actions that can help us and the people we love find our way home”



**Jessie C. Gruman,
Health Affairs, February, 2013**