



# Patient Reported Outcomes

Useful for Whom?  
A Consumers Perspective

Liz Helms  
President & CEO  
California Chronic Care Coalition

# Chronic Conditions



# Chronic Conditions

## An “Epidemic”?

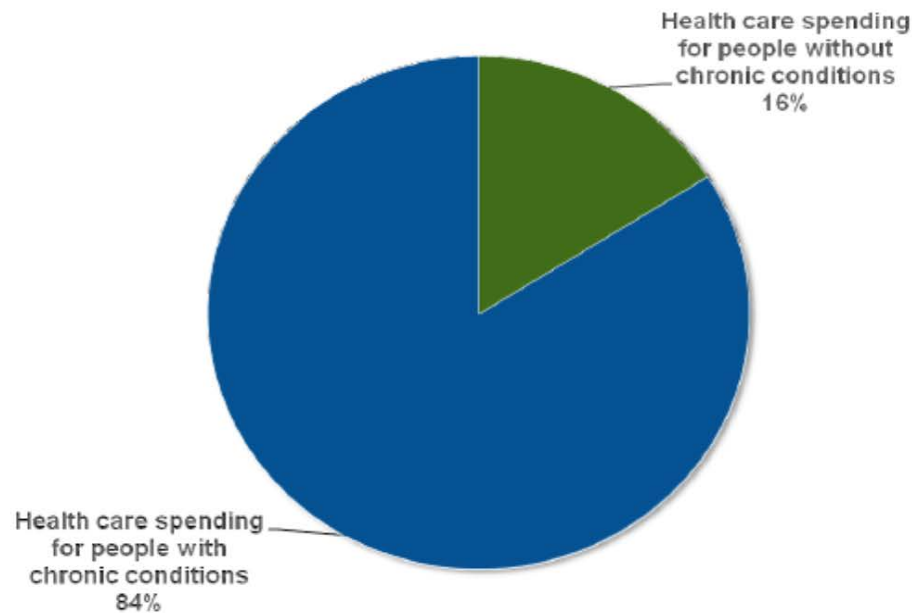
- In 2000, 125 million Americans had chronic conditions.
- By 2020, the number will increase to 157 million.



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# Chronic Conditions Rising Costs

## Caring for the Chronically Ill is Expensive



Source: Medical Expenditure Panel Survey, 2006

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# Chronic Conditions

## California Baby Boomers and Older Adults Health Status



- Many older Californians are plagued by health problems that require medical attention and case management.
- Over one quarter of Californians age 45–70 report having high blood pressure, arthritis or back problems.
- 2 in 5 Californians have at least one chronic condition/ 7 million Californians suffer from multiple chronic conditions (2007).

# Who We Are



- ❑ AARP
- ❑ Alzheimer's Association, California Council
- ❑ Arthritis Foundation, Pacific Region
- ❑ American Congress of Obstetricians and Gynecologists (ACOG), District IX
- ❑ California / American Cancer Society Action Network, Inc.
- ❑ American Chronic Pain Association
- ❑ American Diabetes Association
- ❑ American Heart Association
- ❑ Arthritis Foundation, Pacific Region
- ❑ Asthma & Allergy Found. of America, CA
- ❑ Breathe California of Sacramento Emigrant Trails
- ❑ California Academy of Family Physicians
- ❑ California Academy of Physician Assistants
- ❑ California Association of Alcohol and Drug Programs Executives, Inc.
- ❑ California Dental Association
- ❑ California Hepatitis C Task Force
- ❑ California Physical Therapy Association
- ❑ California Psychiatric Association
- ❑ California Society of Health-System Pharmacists
- ❑ Epilepsy California
- ❑ Foundation for Osteoporosis Research and Education (FORE)
- ❑ Hemophilia Council of California
- ❑ International Bi-Polar Association
- ❑ Mental Health America in California
- ❑ Mental Health Systems San Diego
- ❑ National Multiple Sclerosis California Action Network
- ❑ National Alliance for the Mentally Ill (NAMI) California
- ❑ National Fibromyalgia Association
- ❑ Neuropathy Action Foundation
- ❑ Project Inform
- ❑ Sickle Cell Disease Foundation of CA
- ❑ TMJ Society of California

# Patient Reported Outcomes For Consumers

## Pros

- ▶ Patient reports experience
  - Side effects, symptoms
- ▶ Patient view of their health
- ▶ Objectivity
- ▶ Better understanding
- ▶ Labeling
- ▶ Patient engaged and activated
- ▶ Increase knowledge
- ▶ Increases value – triple aim
- ▶ Personal responsibility

## Cons

- ▶ Not enough information
- ▶ Drug information may be hard to find
- ▶ Health literacy
- ▶ Label claims can add confusion
- ▶ During acute illness
- ▶ Increase discriminatory practices

# Patient-Reported Outcomes to Improve Health Care Quality

Did services provided actually improve personal care?

➤ Patient experience

❖ Patient centered

❖ Self-management

❖ Care delivery

❖ PROs in Clinical trials

- Help analyze personal quality

- Improved outcomes

- Performance and comparative effectiveness of different treatments



# PATIENT RELATED OUTCOMES



- ▶ **Improved quality and lowering overall costs**
  - Medication adherence
  - Compliance
  - Create tools for better understanding therapeutic class of drugs
  - Transparency of information
  - Improved CMM
    - Multiple chronic conditions coordination



# Patient Reported Outcome Measurement Information System – PROMIS

- ▶ Can we easily use our outcomes data for:
- ▶ clinical trial outcome evaluation?
- ▶ clinical decision-making?
- ▶ administrative and management purposes?
- ▶ health policy decision making?
- ▶ regulatory and market purposes?



# Re-engineering the Clinical Research Enterprise

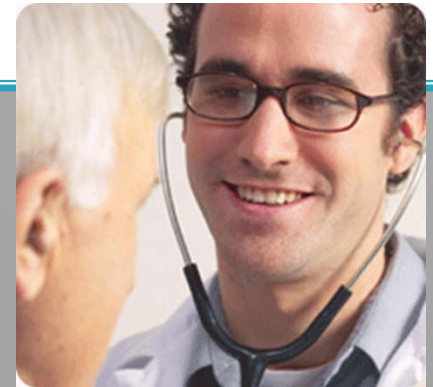
- ▶ To continue NIH's mission of successful medical research, it will need to recast its entire clinical research system
- ▶ Requires the development of new partnerships of research with organized patient communities, community-based health care providers, industry, and academic researchers.
- ▶ Need new paradigms in how clinical research information is collected, used, and reported.
- ▶ Includes the advances in information technology, psychometrics, and qualitative, cognitive, and health survey research.



# Patient Assessment Survey

**ConsumerReportsHealth**

Special Report for California Residents



## How Does Your Doctor Compare?

Exclusive: Patients rate more than 170 physician groups

How to get the best care

Quiz: Does your physician measure up?

GUIDE TO CALIFORNIA PHYSICIANS  
PAGE 8

### RATINGS

For information on whether you're getting the best care, ask your doctor or a trusted friend. You'll also want to know if you get your follow-up care.

For with all of your health care and from your doctor, you'll want to know if you get your follow-up care.

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### Health Care Reform One Year Later

California's health care landscape has shifted dramatically since the passage of the Affordable Care Act in October 2010. About 24 million people who did not have health insurance before now do. Thanks in part to Covered California, the state's health insurance Marketplace and its expanded Medicaid program Medi-Cal, as a result, more people than ever are looking for primary care doctors. Here are some other ways that the ACA has affected California.

By now, you've seen a lot of different words, so use a picture or diagram to make it clearer, or just draw it. If you still have concerns when you go home, call and ask for a follow-up appointment, perhaps on the phone or with a nurse practitioner or a physician assistant. He or she might be able to spend

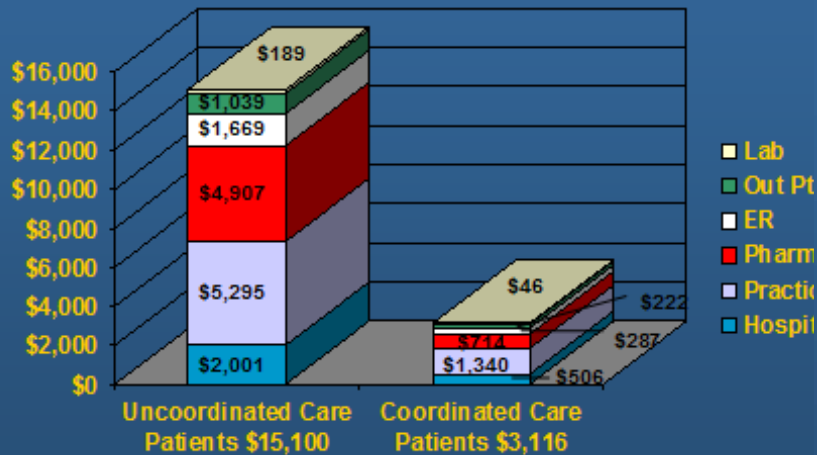
time with you to make sure that these procedures communicate with your primary care doctor, too. Ask for copies of letters or reports that the specialist plans to send to your primary care provider. Electronic health records

- California Doctor Ratings
- Q: Example: Did you and your doctor talk about a healthy diet and healthy eating habits?
- How often did your doctor seemed informed and up to date about care from your specialists?



# Can PROs Affect Total Cost of Care?

## State Medicaid Example: Average Contribution of Cost Components for Uncoordinated Care vs. Coordinated Care



IHIS

## SEC Published Study: Institute of Medicine\* National Cost Savings Estimates Per Year for Period 2010-2018

- ◆ Public Programs (Medicaid and Medicare)
  - ◆ Avg. of **\$133.5 billion** per year
- ◆ Private Programs
  - ◆ Avg. of **\$106.6 billion** per year
- ◆ Total Public and Private
  - ◆ Avg. of **\$240.1 billion** per year

\* Web Link: [The Healthcare Imperative: Lowering Costs and Improving Outcomes. The Institute of Medicine. 2010. Washington, DC: The National Academies Press. Owens, MK. Chapter 3: Inefficiently Delivered Services, Costs of Uncoordinated Care, pgs 131-138. http://books.nap.edu/openbook.php?record\\_id=12750&page=131](http://books.nap.edu/openbook.php?record_id=12750&page=131)

IHIS

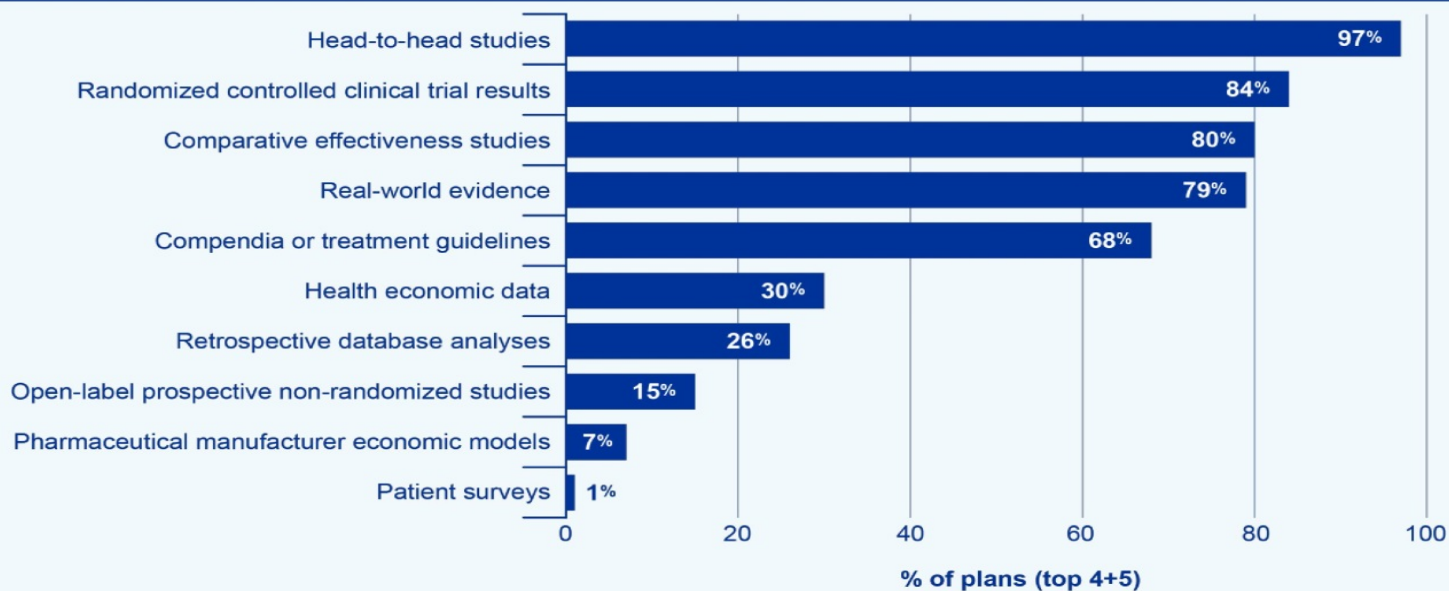


# Collaborative Roadmap to Success

## PROs score low

### Data Sources for Formulary Decision Making

When reviewing specialty drugs for formulary decision making, what data sources influence your decision making the most? Please rate each source on a scale of 1 to 5, where 1= not at all influential and 5 = extremely influential.



n=91

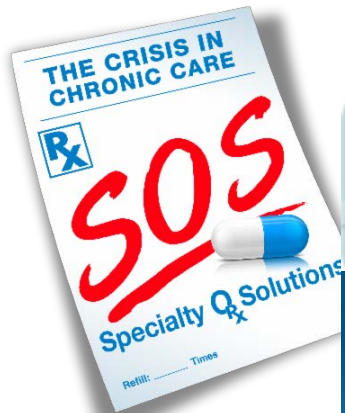


*"If there's anything more we can do for you, don't  
hesitate to fill out the proper forms."*

# Stakeholders at the Decision Table

## Most Useful PRO?

- ▶ Public Policy
  - Learning collaboratory
  - Open dialogue
  - Focus groups
  - Patient feedback in real time



Stakeholders  
Specialty Medication  
Collaboratory

# Patient Reported Outcomes: Useful for Whom?

Type of PRO Measure	Example Coverage/Domains	PRO Measures
✓ <b>Symptoms</b>	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Fatigue</li> <li>• Wheezing</li> <li>• Depression</li> </ul>	0 – 10 numeric rating scale Fatigue Severity Scale Asthma Symptom Diary Beck Depression Inventory
✓ <b>Functioning</b>	<ul style="list-style-type: none"> <li>• Emotional functioning</li> <li>• Productivity</li> <li>• Activities of daily living</li> </ul>	Hospital Anxiety and Depression Scale Work Productivity and Activity Impairment Questionnaire Katz ADL
✓ <b>Health status</b>	<ul style="list-style-type: none"> <li>• Multiple domains of functioning</li> </ul>	SF-36 Sheehan Disability Scale
✓ <b>Health-related quality of life</b>	<ul style="list-style-type: none"> <li>• Impact of health on a patient's subjective sense of well-being</li> </ul>	Cystic Fibrosis QoL Questionnaire
✓ <b>Treatment satisfaction</b>	<ul style="list-style-type: none"> <li>• Satisfaction with medication</li> </ul>	Treatment Satisfaction Questionnaire for Medication
Utility	<ul style="list-style-type: none"> <li>• Health status for the purpose of computing QALYs</li> </ul>	EQ-5D





# Questions?

## Thank You!

California Chronic Care Coalition  
Liz Helms  
909 12<sup>th</sup> Street, 201  
Sacramento, CA 95814  
[lizhelms@chroniccareca.org](mailto:lizhelms@chroniccareca.org)  
916.444.1985  
[www.chroniccareca.org](http://www.chroniccareca.org)