Patient Reported Outcomes

Useful for Whom?
A Consumers Perspective

Liz Helms
President & CEO
California Chronic Care Coalition
Chronic Conditions

84

84 cents of every health care dollar is being spent on chronic conditions.” It’s time for that to change.
Chronic Conditions

An “Epidemic”?  

- In 2000, 125 million Americans had chronic conditions.  
- By 2020, the number will increase to 157 million.
Caring for the Chronically Ill is Expensive

Health care spending for people without chronic conditions 16%

Health care spending for people with chronic conditions 84%

Source: Medical Expenditure Panel Survey, 2006
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

<table>
<thead>
<tr>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient reports experience</td>
<td>Not enough information</td>
</tr>
<tr>
<td>◦ Side effects, symptoms</td>
<td>Drug information may be hard to find</td>
</tr>
<tr>
<td>Patient view of their health</td>
<td>Health literacy</td>
</tr>
<tr>
<td>Objectivity</td>
<td>Label claims can add confusion</td>
</tr>
<tr>
<td>Better understanding</td>
<td>During acute illness</td>
</tr>
<tr>
<td>Labeling</td>
<td>Increase discriminatory practices</td>
</tr>
<tr>
<td>Patient engaged and activated</td>
<td></td>
</tr>
<tr>
<td>Increase knowledge</td>
<td></td>
</tr>
<tr>
<td>Increases value – triple aim</td>
<td></td>
</tr>
<tr>
<td>Personal responsibility</td>
<td></td>
</tr>
</tbody>
</table>

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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
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.
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

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

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.

- Head-to-head studies: 97%
- Randomized controlled clinical trial results: 84%
- Comparative effectiveness studies: 80%
- Real-world evidence: 79%
- Compendia or treatment guidelines: 68%
- Health economic data: 30%
- Retrospective database analyses: 26%
- Open-label prospective non-randomized studies: 15%
- Pharmaceutical manufacturer economic models: 7%
- Patient surveys: 1%

n=91
"If there's anything more we can do for you, don't hesitate to fill out the proper forms."

CALIFORNIA HEALTHCARE FOUNDATION
Stakeholders at the Decision Table
Most Useful PRO?

- Public Policy
  - Learning collaboratory
  - Open dialogue
  - Focus groups
  - Patient feedback in real time
## Patient Reported Outcomes: Useful for Whom?

<table>
<thead>
<tr>
<th>Type of PRO Measure</th>
<th>Example Coverage/Domains</th>
<th>PRO Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Symptoms</td>
<td>• Pain</td>
<td>0 – 10 numeric rating scale</td>
</tr>
<tr>
<td></td>
<td>• Fatigue</td>
<td>Fatigue Severity Scale</td>
</tr>
<tr>
<td></td>
<td>• Wheezing</td>
<td>Asthma Symptom Diary</td>
</tr>
<tr>
<td></td>
<td>• Depression</td>
<td>Beck Depression Inventory</td>
</tr>
<tr>
<td>✓ Functioning</td>
<td>• Emotional functioning</td>
<td>Hospital Anxiety and Depression Scale</td>
</tr>
<tr>
<td></td>
<td>• Productivity</td>
<td>Work Productivity and Activity Impairment Questionnaire</td>
</tr>
<tr>
<td></td>
<td>• Activities of daily living</td>
<td>Katz ADL</td>
</tr>
<tr>
<td>✓ Health status</td>
<td>• Multiple domains of functioning</td>
<td>SF-36</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sheehan Disability Scale</td>
</tr>
<tr>
<td>✓ Health-related quality of life</td>
<td>• Impact of health on a patient’s subjective sense of well-being</td>
<td>Cystic Fibrosis QoL Questionnaire</td>
</tr>
<tr>
<td>✓ Treatment satisfaction</td>
<td>• Satisfaction with medication</td>
<td>Treatment Satisfaction Questionnaire for Medication</td>
</tr>
<tr>
<td>Utility</td>
<td>• Health status for the purpose of computing QALYs</td>
<td>EQ-5D</td>
</tr>
</tbody>
</table>
Questions?

Thank You!

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