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# Consumers and Health Data in Maine

Ted Rooney, RN, MPH  
Health and Work Outcomes

Jess Maurer, Esq., Director  
Maine Assn. of Area Agencies on Aging

# Objective

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Asked to talk about

- What should the state's role be in making health care/medical care information available to consumers to help them make informed choices?
- How/why consumers should be involved in the design and governance of health data organizations?

# My Background

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- Maine Health Data Organization Board
  - 1997 to 2002, 2009 - present.
- Maine Health Information Center/Onpoint Board, 2003- 2010
- Maine Data Processing Board 2007-08
- Quality Counts Board, 2004- 2008
- Maine Health Management Coalition Board, 1994-1999
- Several NQF, AHRQ, NCQA and other national committees about health data
- Worked as contractor with
  - Maine Health Management Coalition since 2000
  - Quality Counts since 2008

# My Work with Consumers

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- Worked with consumers actively since 2002
- Thousands of hours with hundreds of consumers in
  - Focus groups
  - Website testing
  - Various committees and work groups in Maine
  - Various workshops and forums nationally

# Start with “Who are Consumers?”

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- The general public: (2003)
  - People as citizens of Scotland and consumers who have used or who have the potential to use the services of NHS Scotland, i.e. anyone in Scotland.
- Patients (or users):
  - People who are using services or have recently used services.
- The actively interested public:
  - People who take an active interest in services, particularly carers, and the family and friends of patients. This group may sometimes be integrated with ‘patients’.
- Patient interest groups:
  - People in organisations that can provide information about common and differing perspectives and needs of groups of patients.
- People who may not get involved without particular recognition and a sensitive approach to their individual needs, background and circumstances
  - (For example, people from deprived or remote or rural communities; people with mental health problems; people with learning, physical or sensory disabilities; frail older people; children and young people)

# RWJF-AF4Q

## Consumers- Patients- Public

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- **Consumers:**
  - individuals who have significant personal experience with the health care system.....most lack the ability to influence and communicate with a large network or constituency
- **Consumer Rep:**
  - individuals who work at nonprofit, mission oriented organizations that represent a specific constituency of consumers or patients. ...trusted source of information. Unlike individual consumers, they speak from a global perspective and have experience representing the diverse needs and wants of groups of consumers and patients.
  - they typically do not have a financial stake in the health care system.
- **Need Both !!**

# History of Consumer Involvement in Health Care Delivery in Maine

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- Examples of Consumer Involvement
  - Hospital Board of Directors
  - Hospital Auxiliary
  - FQHC Board of Directors
  - State Employee Health Commission
    - 14 union- 10 management members
    - Winner of first annual Quality Counts QI Award - 2011
- Journey of working with consumers, especially on labor- management groups, over last 10 years

# Institute of Medicine Report 1999:

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## ***To Err Is Human:***

### Annual Deaths:

- Medical Mistakes            44,000 - 98,000
- Motor Vehicle Accidents       43,458
- Breast Cancer                42,297
- AIDS                            16,516
- Workplace Accidents         6,000

# Institute of Medicine Report 2001

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- ***“Crossing the Quality Chasm:  
A New Health System for the 21<sup>st</sup> Century”***
  - “Chasm” not a “Gap”
- Rand: McGlynn 2004
  - Right Care 55% of time

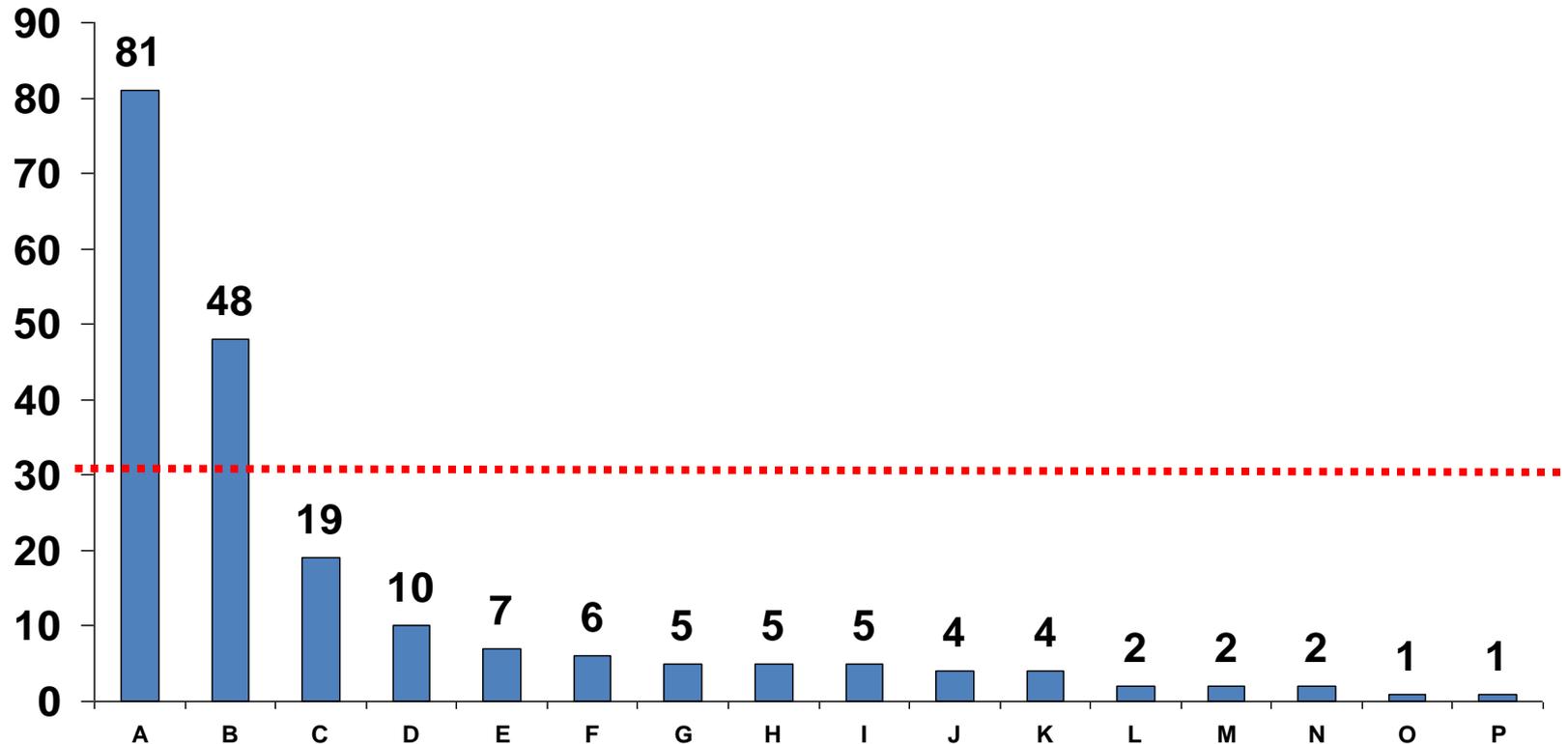
# IOM Framework

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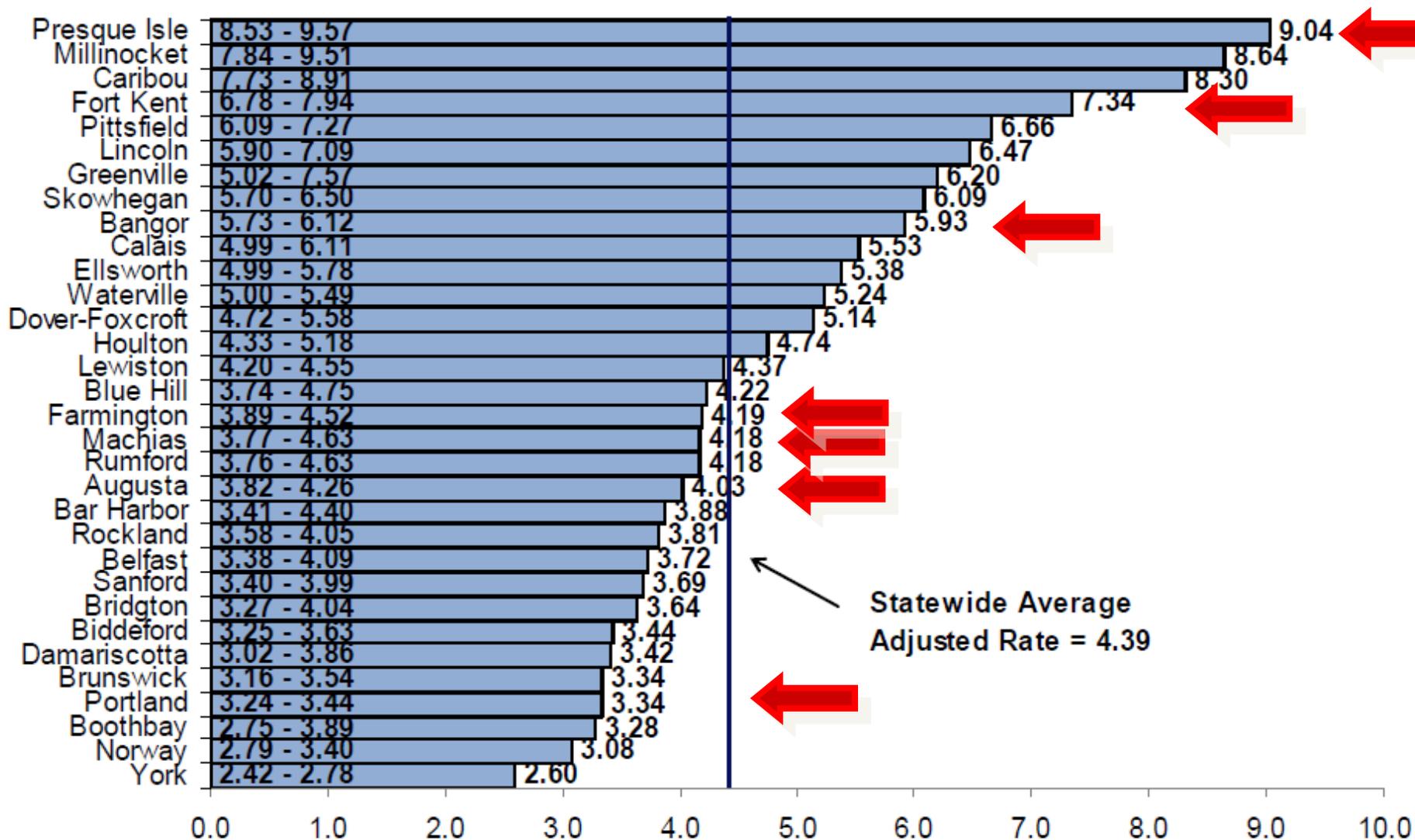
- Safe
- Timely
- Effective
- Efficient
- Patient Centered
- Equitable

# Abdominal Aortic Aneurysm - 2002

## Threshold Volume = 30/year



**Diagnostic Cardiac Cath (No AMI) - Inpatient & Outpatient  
Age and Gender Adjusted Rate per 1,000 Population  
Maine Hospital Service Areas, 2002-2006 Combined**



- Has committee looked at variation nationally and in Maine?

# Comparative Cost: Large Maine Hospitals 2010

Below State Average

Above State Average



# Problems With Safety Persist

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Don Berwick – November 2007:

- “The chances of being injured by hospital care is greater than one in 10, and accidental death due to mismanaged care is about one in 300.”
- 2007 Maine Discharges:

– Total Discharges in Maine	163,705
– Berwick: 1 in 300 result in death	546
– Berwick: 1 in 10 result in inj./ill.	16,371

# Office of Inspector General DHHS - 2010

- **13.5 % of hospitalized Medicare beneficiaries experienced adverse events during their hospital stays** that resulted in prolonged hospitalization, required life-sustaining intervention, caused permanent disability, or death.
- An additional **13.5 percent experienced temporary harm** events that required treatment.
- Maine in 2010:
  - 61,385 Medicare patients discharged from Maine hospitals
  - **13.5% = 8,287 Medicare beneficiaries**
    - 22.7 per day

# Not All Preventable

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- “Although an adverse or temporary harm event indicates that the care resulted in an undesirable clinical outcome and may involve medical errors, adverse events do not always involve errors, negligence, or poor quality of care and may not always be preventable.”
- We don’t know how many adverse events occur in Maine, but I believe most Maine hospitals work very hard at patient safety.

# Maine Hospitals Tops

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- CMS
  - Quality in Maine hospitals on averages is highest in country
- Leapfrog
  - Maine hospitals on average are among safest in country

# Office of Inspector General

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Department of Health and Human Services **OFFICE OF  
INSPECTOR GENERAL**

*HOSPITAL INCIDENT REPORTING SYSTEMS DO NOT  
CAPTURE MOST PATIENT HARM*

Daniel R Levinson, Inspector General - **January 2012**

- All sampled hospitals had incident reporting systems to capture events, and administrators we interviewed rely heavily on these systems to identify problems.
- **Hospital staff did not report 86 percent of events** to incident reporting systems.

# Still Crossing The Quality Chasm—Or Suspended Over It?

- **Susan Dentzer, Editor Health Affairs, Quality Counts 2010**
- Rigorous chart-review methodology pioneered by the IHI disturbingly picked up 10X more confirmed significant adverse events than other methods—and determined that adverse events occurred in one-third of hospital admissions, even in hospitals that had instituted advanced patient safety programs.

# Susan Dentzer cont'd

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- One of the first major national success stories in quality improvement: the campaign to reduce preventable bloodstream infections, which began in Michigan and spread forty-five states.
- Number of patients in US intensive care units suffering a bloodstream infection declined by 63% between 2001 and 2009.
- But it requires doing things differently.

# Disturbing Information Continues

- **Diagnostic Errors Found in 1 of 4 ICU Patient Deaths**
- *HealthLeaders Media*, **August 28, 2012**
- As many as 40,500 American adults may die in hospital intensive care units each year because their critical care teams didn't accurately diagnose their illnesses, according to a [Johns Hopkins University School of Medicine](#) review of 30 international papers that examined autopsy results.

That's more people than die each year of breast cancer in the U.S. or from bloodstream infections acquired in the ICU, the researchers say. And many more patients suffer harm from care provided for the wrong condition.

"The bottom line is that these were misdiagnoses made by the ICU staff," says Bradford Winters, MD, associate professor of anesthesiology and critical care medicine at Johns Hopkins University School of Medicine and lead author of the paper.

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- If you are a consumer not connected with the health care system, at this point what are you thinking?
  - And how much confidence do you have that health care system will improve on its own?
  - And how do you know if it does?
  - Only answer is full and credible transparency.

# Need More and Deeper Metrics

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- on all aspects of the health care system that the state should help fund and produce on all aspects of the IOM framework
  - Safe
  - Effective
  - Timely
  - Patient Centered
  - Equitable
  - Efficient

# Consumers Need Trusted Intermediaries Focused on Delivery System

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And the state should work closely with trusted intermediaries to develop and disseminate this information to consumers:

- Multi-stakeholder health improvement collaboratives
  - MHMC Foundation
  - Quality Counts
- Labor – management groups
- Health oriented non-political consumer groups
  - Area Agencies on Aging
  - AARP
  - Others

# And We Need to Get Consumers Involved in All Aspects of Health Care System

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1. Improve one's own health / health of family member
  - Wellness offerings
  - Healthy eating
  - Meals on wheels, etc.
2. Get information to make informed choices about care
  - Promote GetBetterMaine
  - Help people access information
  - Articles in newsletters
  - Review at meetings, etc.
3. Work with others to help improve their health
  - Look at numbers Living Well and Matter of Balance are reaching vs. number needed to reach
  - Market to reach desired number

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4. Work directly with health care providers to help improve the delivery, quality, experience of care
    - Participate in provider committees (with training)
  5. Work with stakeholders to drive system, policy, payment changes to transform care
    - Meetings with local providers
    - Community forums on quality-cost
    - State work groups

# Do You Get Quality Health Care?

How would you grade each of the following?	A	B	C	D	F	Don't know/ Refused
The quality of health care in the country as a whole	11	22	38	17	11	2
The quality of health care YOU receive	31	34	19	6	7	3

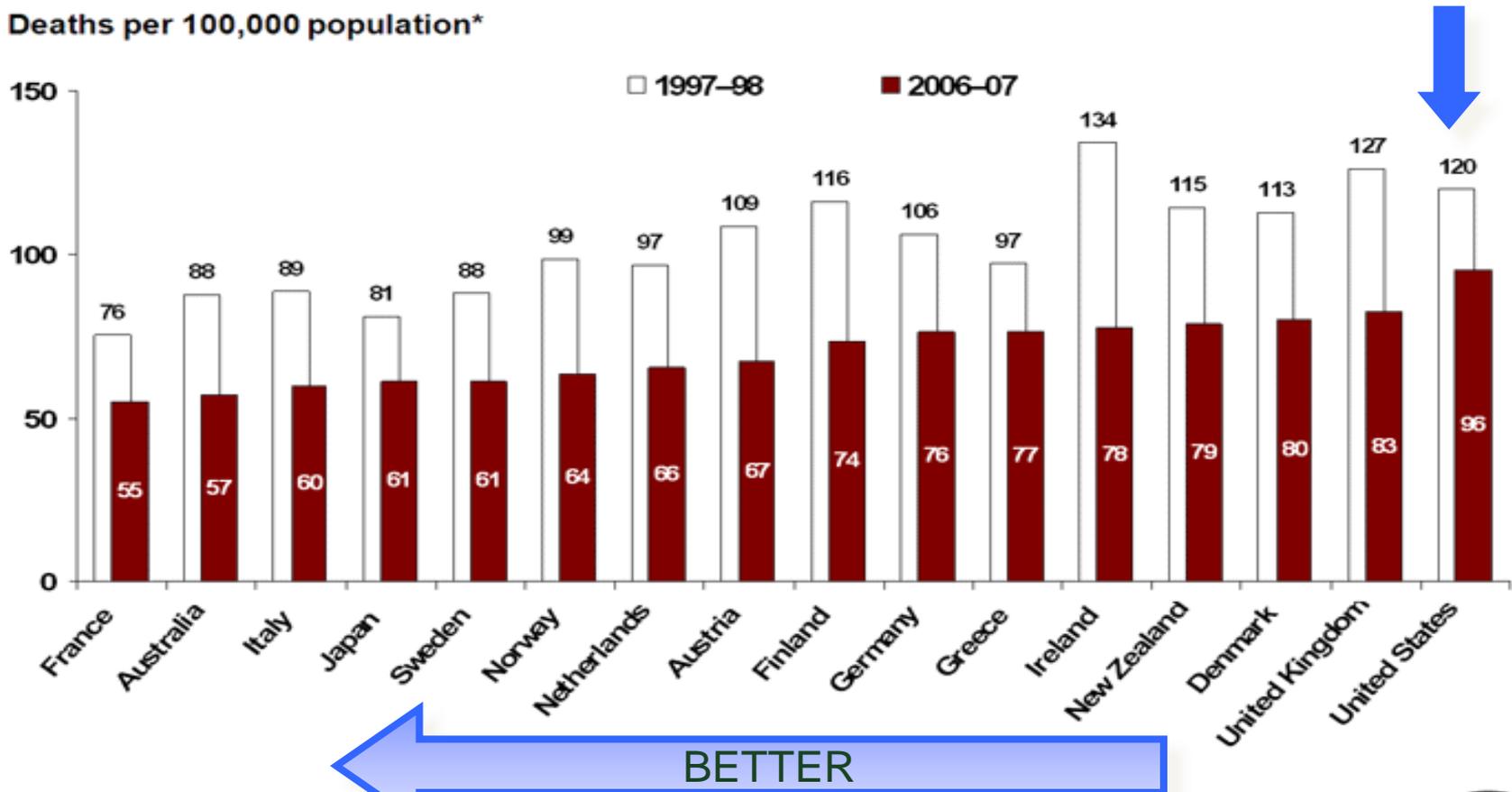
Robert Wood Johnson Foundation/Harvard School of Public Health poll from March 9-18, 2011

- As a consumer, there is a fundamental difference between looking out for yourself and looking out for 20,000 people.

# Our Quality Is Less.....

## U.S. Lags Other Countries: Mortality Amenable to Health Care

Deaths per 100,000 population\*



\* Countries' age-standardized death rates before age 75; including ischemic heart disease, diabetes, stroke, and bacterial infections. Analysis of World Health Organization mortality files and CDC mortality data for U.S.

Source: Adapted from E. Nolte and M. McKee, "Variations in Amenable Mortality—Trends in 16 High-Income Nations," *Health Policy*, published online Sept. 12, 2011.

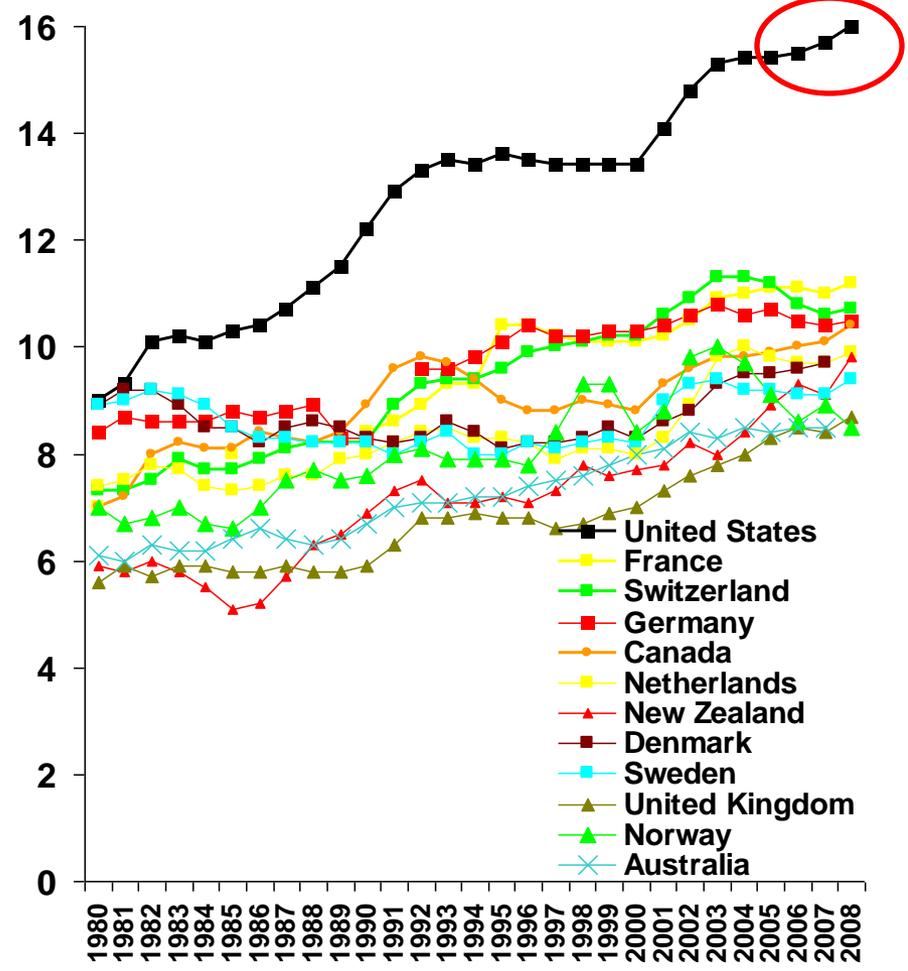
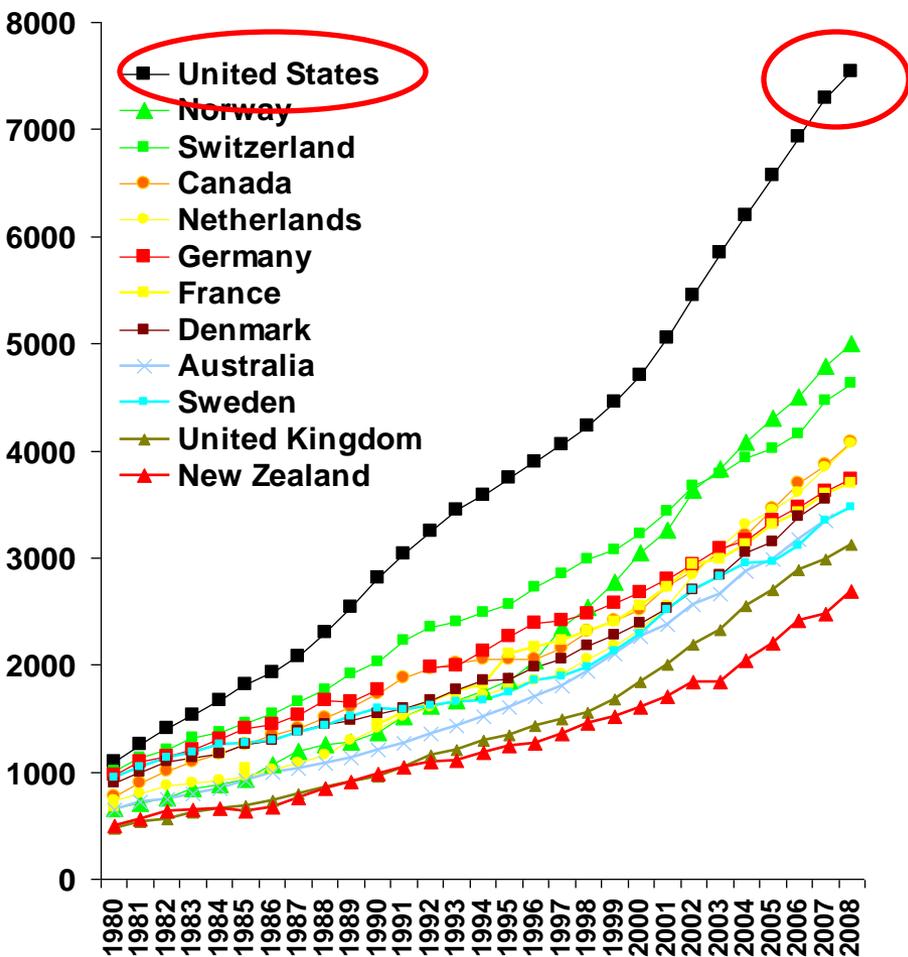


# Our Costs Are More

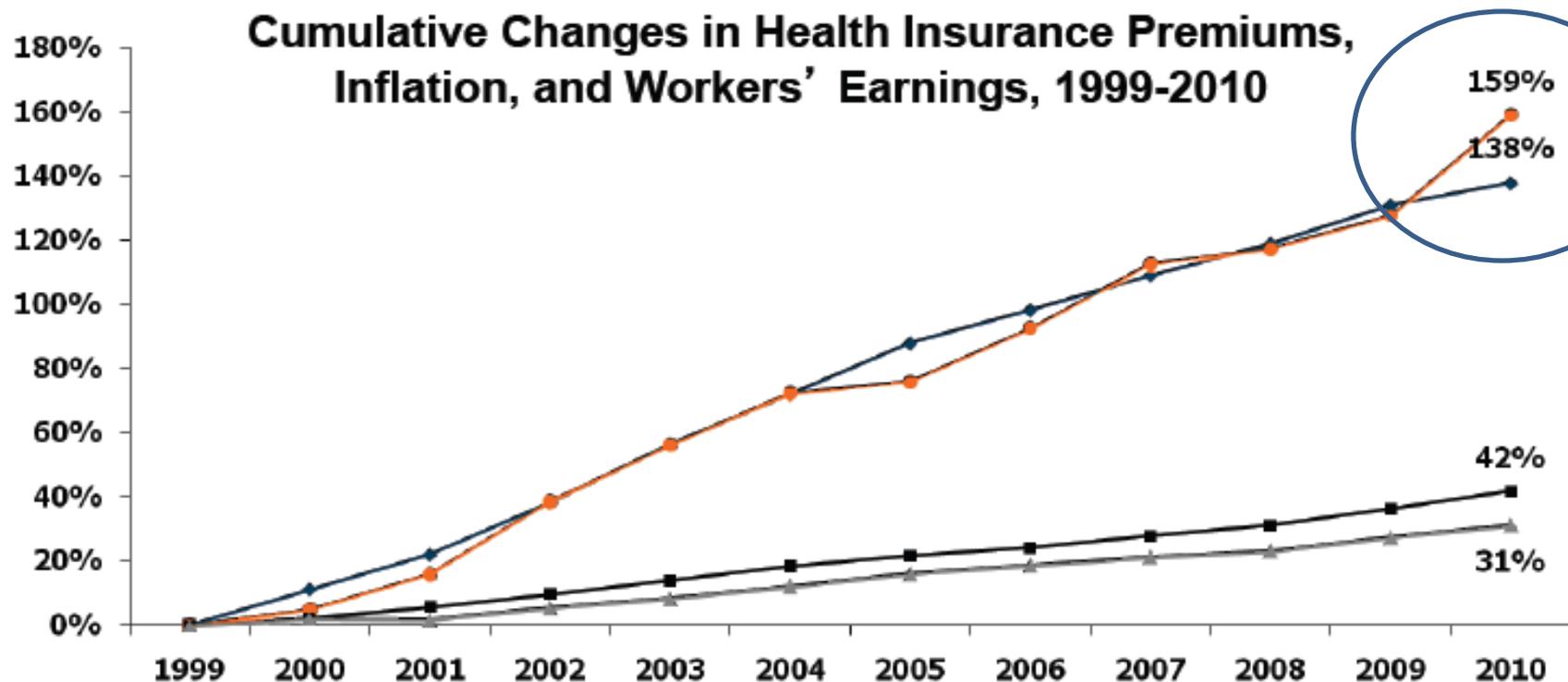
International Comparison of Spending on Health, 1980–2008

Average spending on health per capita (\$US PPP)

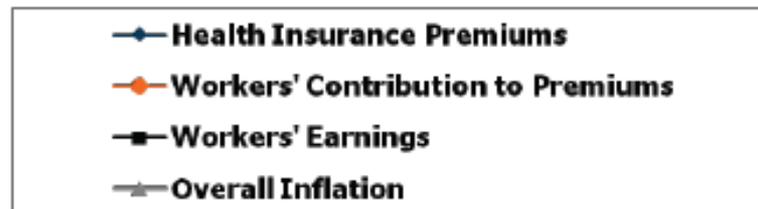
Total expenditures on health as percent of GDP

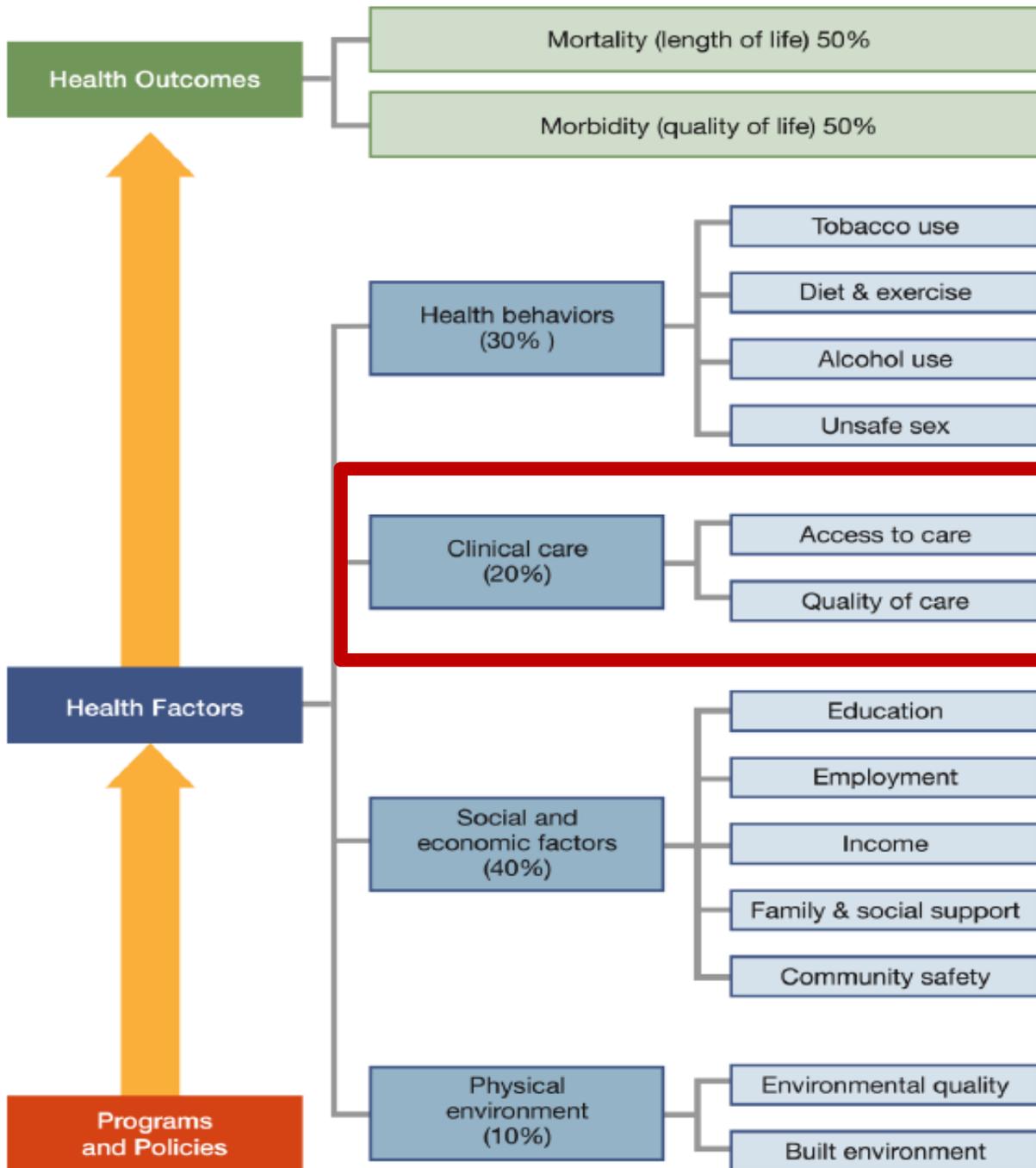


# Insurance Cost Growth Quadruple the Rate of Wages and Inflation



Source: Kaiser/HRET Survey of Employer-Sponsored Health Benefits, 1999-2010. Bureau of Labor Statistics, Consumer Price Index, U.S. City Average of Annual Inflation (April to April), 1999-2010; Bureau of Labor Statistics, Seasonally Adjusted Data from the Current Employment Statistics Survey, 1999-2010 (April to April).





# What Are We Trying to Achieve?

## And what Contributes?

Univ. Wisconsin - RWJF  
County Health Rankings