

# **The Perils of QALYs: Addressing Discrimination Against People with Disabilities and Serious Chronic Conditions**

**June 20, 2019**

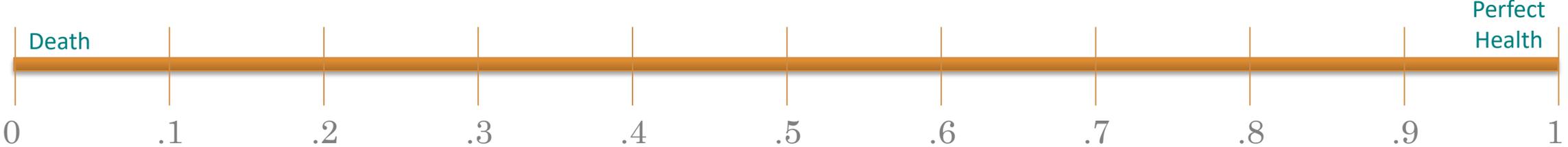


# What is a QALY Exactly?



# QALYs discriminate against people with disabilities by placing a lower value on their lives

*What's the value of your life?*



Person with Cancer



Person with Rheumatoid Arthritis



Person with Diabetes

# QALYs as a Means of Measuring Health Quality

- Measure of disease or disability burden and treatment efficacy in mitigating it;
- 1 QALY = 1 year in 'perfect health',
- 0 QALY = Death
- $0 < x < 1$  = Disabled or sick life

Severe Parkinson disease	Parkinson disease, severe	difficulty in walking and daily activities. The person falls easily and has a lot of difficulty talking, swallowing, sleeping, and remembering things.	0.575 (0.396–0.73)
Severe epilepsy	Epilepsy, seizures >= once a month	has sudden seizures one or more times each month, with violent muscle contractions and stiffness, loss of consciousness, and loss of urine or bowel control. Between seizures the person has memory loss and difficulty concentrating.	0.552 (0.375–0.71)
Less severe epilepsy	Epilepsy, seizures 1-11 per year	has sudden seizures two to five times a year, with violent muscle contractions and stiffness, loss of consciousness, and loss of urine or bowel control.	0.263 (0.173–0.367)
Seizure-free, treated epilepsy	Generic uncomplicated disease: worry and daily medication	has a chronic disease that requires medication every day and causes some worry but minimal interference with daily activities.	0.049 (0.031–0.072)
Mild multiple sclerosis	Multiple sclerosis, mild	has mild loss of feeling in one hand, is a little unsteady while walking, has slight loss of vision in one eye, and often needs to urinate urgently.	0.183 (0.124–0.253)
Severe multiple sclerosis	Multiple sclerosis, severe	has slurred speech and difficulty swallowing. The person has weak arms and hands, very limited and stiff leg movement, has loss of vision in both eyes and cannot control urinating.	0.719 (0.534–0.858)
Moderate multiple sclerosis	Multiple sclerosis, moderate	needs help walking, has difficulty with writing and arm coordination, has loss of vision in one eye and cannot control urinating.	0.463 (0.313–0.613)
Asymptomatic multiple sclerosis	Asymptomatic	--	--
Severe respiratory problems and speech problems due to motor neuron disease	Severe respiratory and speech problems	(combined DW)	0.438 (0.304–0.581)
Moderate respiratory problems and speech problems due to motor neuron disease	Moderate respiratory and speech problems	(combined DW)	0.265 (0.184–0.36)
Mild respiratory problems and speech problems due to motor neuron			0.069

Symptomatic dysthymia	Major depressive disorder, mild episode	The person sometimes sleeps badly, feels tired, or has trouble concentrating but still manages to function in daily life with extra effort.	0.145 (0.099–0.209)
Bipolar disorder manic state	Bipolar disorder, manic episode	is hyperactive, hears and believes things that are not real, and engages in impulsive and aggressive behavior that endanger the person and others.	0.492 (0.341–0.646)
Bipolar disorder residual state	Bipolar disorder, residual state	has mild mood swings, irritability and some difficulty with daily activities.	0.032 (0.018–0.051)
Bipolar disorder depressive state	Major depressive disorder, moderate episode	has constant sadness and has lost interest in usual activities. The person has some difficulty in daily life, sleeps badly, has trouble concentrating, and sometimes thinks about harming himself (or herself).	0.396 (0.267–0.531)
Anxiety disorders, currently without symptoms	Asymptomatic	--	--
Moderate anxiety disorders	Anxiety disorders, moderate	feels anxious and worried, which makes it difficult to concentrate, remember things, and sleep. The person tires easily and finds it difficult to perform daily activities.	0.133 (0.091–0.186)
Severe anxiety disorders	Anxiety disorders, severe	constantly feels very anxious and worried, which makes it difficult to concentrate, remember things and sleep. The person has lost pleasure in life and thinks about suicide.	0.523 (0.362–0.677)
Mild anxiety disorders	Anxiety disorders, mild	feels mildly anxious and worried, which makes it slightly difficult to concentrate, remember things, and sleep. The person tires easily but is able to perform daily activities.	0.03 (0.018–0.046)
Anorexia nervosa	Anorexia nervosa	feels an overwhelming need to starve and exercises excessively to lose weight. The person is very thin, weak and anxious.	0.224 (0.15–0.312)
Bulimia nervosa	Bulimia nervosa	has uncontrolled overeating followed by guilt, starving, and vomiting to lose weight.	0.223 (0.149–0.311)

Severe cannabis dependence	Cannabis dependence	uses marijuana daily and has difficulty controlling the habit. The person sometimes has mood swings, anxiety and hallucinations, and has some difficulty in daily activities.	0.266 (0.178–0.364)
Other drug use disorders	Cocaine dependence, mild	uses cocaine at least once a week and has some difficulty controlling the habit. When not using, the person functions normally.	0.116 (0.074–0.165)
Severe major depressive disorder	Major depressive disorder, severe episode	has overwhelming, constant sadness and cannot function in daily life. The person sometimes loses touch with reality and wants to harm or kill himself (or herself).	0.658 (0.477–0.807)
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Dysthymia, currently without symptoms	Asymptomatic	--	--
Symptomatic dysthymia	Major depressive disorder, mild episode	feels persistent sadness and has lost interest in usual activities. The person sometimes sleeps badly, feels tired, or has trouble concentrating but still manages to function in daily life with extra effort.	0.145 (0.099–0.209)
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# Peter Singer on “Why We Must Ration Health Care”

- “Disability advocates might argue that such judgments, made by people without disabilities, merely reflect the ignorance and prejudice of people without disabilities when they think about people with disabilities.”
- “We should, they will very reasonably say, ask quadriplegics themselves to evaluate life with quadriplegia. If we do that, and we find that quadriplegics would not give up even one year of life as a quadriplegic in order to have their disability cured, then the QALY method does not justify giving preference to procedures that extend the lives of people without disabilities over procedures that extend the lives of people with disabilities.”

# Peter Singer on “Why We Must Ration Health Care”

- “This method of preserving our belief that everyone has an equal right to life is, however, a double-edged sword. If life with quadriplegia is as good as life without it, there is no health benefit to be gained by curing it.”
- Essentially, QALYs force a choice between access to specialized medical treatment and non-discrimination in health care.

# Challenges with QALY Model

- Under population survey models, the non-disabled population may systematically overestimate the burden of life with disability.
  - Research suggests a majority of American public says they would rather have HIV than be blind (Scott, 2016).
- Common QALY measure (EuroQol-5D) rates inflammatory arthritis as “worse than death” (Harrison, 2009).
  - Significant variation between TTO and VAS quality of life assessments reported under EuroQol-5D
- Under models where PWD self-report QoL, well supported people with disabilities who report relatively high levels of quality of life due to access to adequate support may find it very hard to demonstrate sufficient gains in QoL due to treatment efficacy.

# **QALYs and evLYGs**

## The evLYG

ICER's future reports will incorporate more prominently a calculation of the Equal Value of Life Years Gained (evLYG), which evenly measures **any** gains in length of life, regardless of the treatment's ability to improve patients' quality of life.

In other words, if a treatment adds a year of life to a vulnerable patient population – whether treating individuals with cancer, multiple sclerosis, diabetes, epilepsy, or a severe lifelong disability – that treatment will receive the same evLYG as a different treatment that adds a year of life for healthier members of the community.

## Supplementing the QALY, Not Replacing It

To maintain the ability of cost-effectiveness analyses to reflect the full benefits that treatments may have on quality of life, ICER will continue to calculate each treatment's QALY gained. The cost per QALY gained remains the best way for policymakers to understand how well the price of a treatment lines up with its benefits and risks for patients.

By understanding a treatment's cost per evLYG, as well as its traditional cost per QALY, policymakers can take a broader view of cost-effectiveness and be reassured that they are considering information that poses no risk of discrimination against any patient group. If ICER's analysis finds a major difference in these two measures, we will include specific language in our report describing the underlying characteristics of the treatment and the condition that lead to the difference.

The QALY remains the gold standard in cost-effectiveness analyses for many reasons, and a systematic departure from using the QALY would risk undervaluing treatments that improve the quality of life more than other alternatives for that condition. By drawing greater attention to the analysis of a treatment's evLYG, however, ICER hopes to provide peace of mind to concerned patients and policymakers, while furthering the ability of cost-effectiveness analysis to support explicit, transparent discussions in the U.S. on how best to align a drug's price with its benefits for patients.

life **exactly the same** across all diseases, regardless of the patient population's age, severity of illness, or level of disability.

## WITH evLYG, ONE ADDED YEAR = ONE ADDED YEAR



*ICER welcomes broad stakeholder input on the QALY and the evLYG as we update our value assessment framework in 2019.*

# Why the evLYG Doesn't Fix the Problem

- The evLYG **partially** mitigates the life-extension problem – if insurers use it.
- But it still offers payers a means of refusing access to an effective and beneficial drug
- The evLYG doesn't address the undervaluing of quality of life improvements or ignoring clinical knowledge.
- QALY-based systems are less effective than condition-specific means of assessment

# ICER Analysis for Spinraza

**Table ES11. Results for Spinraza versus BSC in Infantile-Onset (Type I) SMA: Health Care Sector Perspective**

	Drug Treatment Costs	Non-Treatment Health Care Costs	Total Costs	QALYs	LYs	Incremental Results	
						Cost/QALY Gained	Cost/LY Gained
<b>Spinraza</b>	\$2,231,000	\$1,653,000	\$3,884,000	3.24	7.64	\$1,112,000	\$590,000
<b>BSC</b>	\$0	\$789,000	\$789,000	0.46	2.40	--	--

BSC: best supportive care, LY: life-year, QALY: quality-adjusted life year

# ICER Analysis for Spinraza

**Table 6.2. Threshold Prices for Spinraza in Presymptomatic SMA**

	Per QALY*	Per LYG*
Threshold Price at \$50,000/QALY	\$8,000	\$10,500
Threshold Price at \$100,000/QALY	\$36,400	\$41,400
Threshold Price at \$150,000/QALY	\$64,800	\$72,300
Threshold Price at \$200,000/QALY	\$93,200	\$103,000
Threshold Price at \$300,000/QALY	\$150,000	\$165,000
Threshold Price at \$500,000/QALY	\$264,000	\$289,000

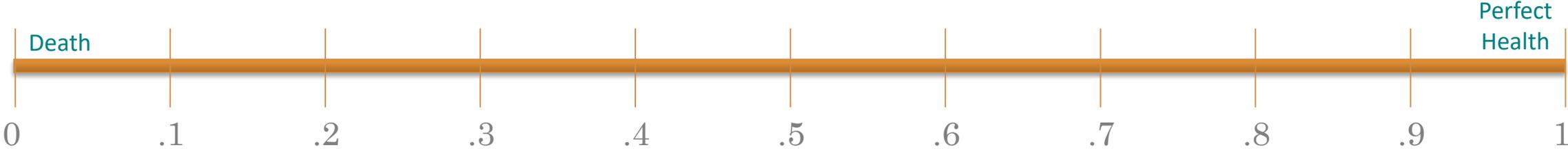
LYG: life-year gained, QALY: quality-adjusted life year

\*Annual price to reach thresholds includes any potential mark-up and represents treatment price in years 2+.



# Disability weights create arbitrary standards for measuring quality of life improvements

*What's the value of your life?*



Severe MS



Moderate MS



Mild MS

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## Expanded Disability Status Scale (EDSS)

Score	Description
1.0	No disability, minimal signs in one FS
1.5	No disability, minimal signs in more than one FS
2.0	Minimal disability in one FS
2.5	Mild disability in one FS or minimal disability in two FS
3.0	Moderate disability in one FS, or mild disability in three or four FS. No impairment to walking
3.5	Moderate disability in one FS and more than minimal disability in several others. No impairment to walking
4.0	Significant disability but self-sufficient and up and about some 12 hours a day. Able to walk without aid or rest for 500m
4.5	Significant disability but up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance. Able to walk without aid or rest for 300m
5.0	Disability severe enough to impair full daily activities and ability to work a full day without special provisions. Able to walk without aid or rest for 200m
5.5	Disability severe enough to preclude full daily activities. Able to walk without aid or rest for 100m
6.0	Requires a walking aid – cane, crutch, etc. – to walk about 100m with or without resting
6.5	Requires two walking aids – pair of canes, crutches, etc. – to walk about 20m without resting
7.0	Unable to walk beyond approximately 5m even with aid. Essentially restricted to wheelchair; though wheels self in standard wheelchair and transfers alone. Up and about in wheelchair some 12 hours a day

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6.5	Requires two walking aids – pair of canes, crutches, etc. – to walk about 20m without resting
7.0	Unable to walk beyond approximately 5m even with aid. Essentially restricted to wheelchair; though wheels self in standard wheelchair and transfers alone. Up and about in wheelchair some 12 hours a day
7.5	Unable to take more than a few steps. Restricted to wheelchair and may need aid in transferring. Can wheel self but cannot carry on in standard wheelchair for a full day and may require a motorised wheelchair
8.0	Essentially restricted to bed or chair or pushed in wheelchair. May be out of bed itself much of the day. Retains many self-care functions. Generally has effective use of arms
8.5	Essentially restricted to bed much of day. Has some effective use of arms retains some self-care functions
9.0	Confined to bed. Can still communicate and eat
9.5	Confined to bed and totally dependent. Unable to communicate effectively or eat/swallow
10.0	Death due to MS

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Dysthymia, currently without symptoms	Asymptomatic	--	--
Symptomatic dysthymia	Major depressive disorder, mild episode	feels persistent sadness and has lost interest in usual activities. The person sometimes sleeps badly, feels tired, or has trouble concentrating but still manages to function in daily life with extra effort.	0.145 (0.099–0.209)
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# HAMILTON DEPRESSION RATING SCALE (HAM-D)

(To be administered by a health care professional)

Patient Name \_\_\_\_\_

Today's Date \_\_\_\_\_

The HAM-D is designed to rate the severity of depression in patients. Although it contains 21 areas, calculate the patient's score on the first 17 answers.

1. **DEPRESSED MOOD**  
(Gloomy attitude, pessimism about the future, feeling of sadness, tendency to weep)  
0 = Absent  
1 = Sadness, etc.  
2 = Occasional weeping  
3 = Frequent weeping  
4 = Extreme symptoms

2. **FEELINGS OF GUILT**  
0 = Absent  
1 = Self-reproach, feels he/she has let people down  
2 = Ideas of guilt  
3 = Present illness is a punishment; delusions of guilt  
4 = Hallucinations of guilt

3. **SUICIDE**  
0 = Absent  
1 = Feels life is not worth living  
2 = Wishes he/she were dead  
3 = Suicidal ideas or gestures  
4 = Attempts at suicide

4. **INSOMNIA - Initial**  
(Difficulty in falling asleep)  
0 = Absent

6. **INSOMNIA - Delayed**  
(Waking in early hours of the morning and unable to fall asleep again)  
0 = Absent  
1 = Occasional  
2 = Frequent

7. **WORK AND INTERESTS**  
0 = No difficulty  
1 = Feelings of incapacity, listlessness, indecision and vacillation  
2 = Loss of interest in hobbies, decreased social activities  
3 = Productivity decreased  
4 = Unable to work. Stopped working because of present illness only. (Absence from work after treatment or recovery may rate a lower score).

8. **RETARDATION**  
(Slowness of thought, speech, and activity; apathy; stupor.)  
0 = Absent  
1 = Slight retardation at interview  
2 = Obvious retardation at interview  
3 = Interview difficult  
4 = Complete stupor

# Hamilton Depression Rating Scale

TOTAL ITEMS 1 TO 17: \_\_\_\_\_

0 - 7 = Normal

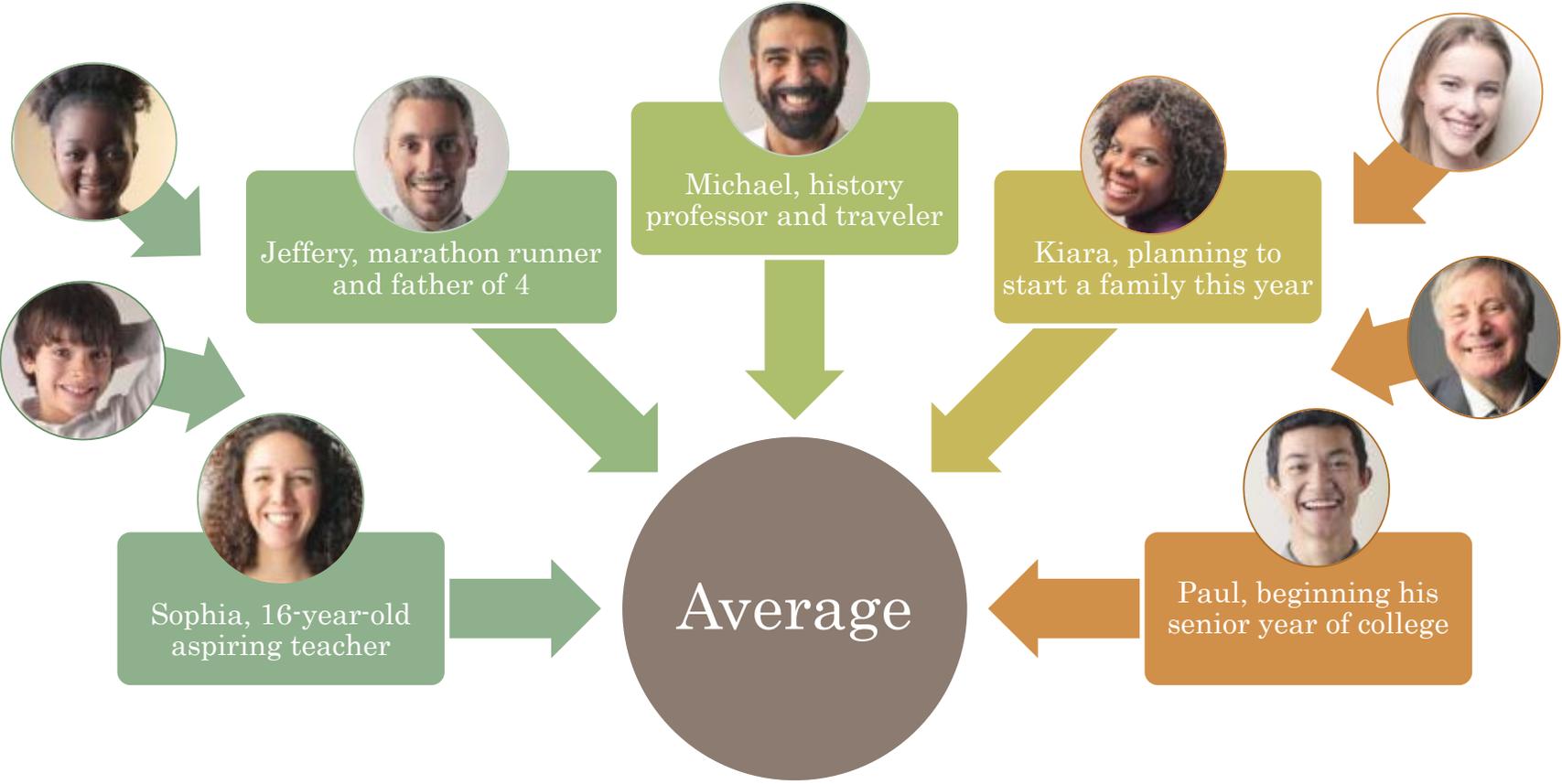
8 - 13 = Mild Depression

14-18 = Moderate Depression

19 - 22 = Severe Depression

$\geq 23$  = Very Severe Depression

# QALYs ignore differences in patient needs and preferences because they are based on averages



# **Different People Respond Differently to the Same Drugs**

**For many conditions, such disparities  
are reflected in clinical knowledge –  
but not yet in research literature**

# Limitations of QALY-Based Cost Effectiveness Analysis



QALYs are acknowledged by experts to discriminate against people with disabilities by placing a lower value on their lives



QALYs devalue the full range of benefits and costs that matter to patients through simplified “disability weight” systems



QALYs ignore important variability in patients’ individual needs and preferences because they are developed using population averages

# Value Our Health

- PIPC and many of its partners have spent significant effort identifying how patients and people with disabilities view value
- Response is Value Our Health!
  - Consensus-driven principles for value assessment supported by organizations

# Principles for Value Assessment

- Acknowledge diversity and differences among patients and people with disabilities
- Should not be misused by payers and policymakers to limit patient access
- Developed using transparent processes and methods
- Meaningfully engage with patient and provider organizations
- Rely on a range of sound, patient-centered sources of evidence
- Address costs and benefits that matter to the patient
- Produce evidence on the value of treatments based on patient-centered outcomes

# Key Flaws in ICER's Approach

- Reliance on Discriminatory Methods
  - QALYs and similar one-size-fits-all summary metrics
- Failure to Meaningfully Engage Expert Stakeholders
  - Left out of the deliberation and voting process
- Failure to Consider Outcomes that Matter to Patients and People with Disabilities
  - Payers' perspectives over patients' needs
- Premature Assessments
  - Early assumptions, oversimplified models, and incomplete data
- Lack of Transparency to Patients and People with Disabilities
  - Black box of assumptions and limitations

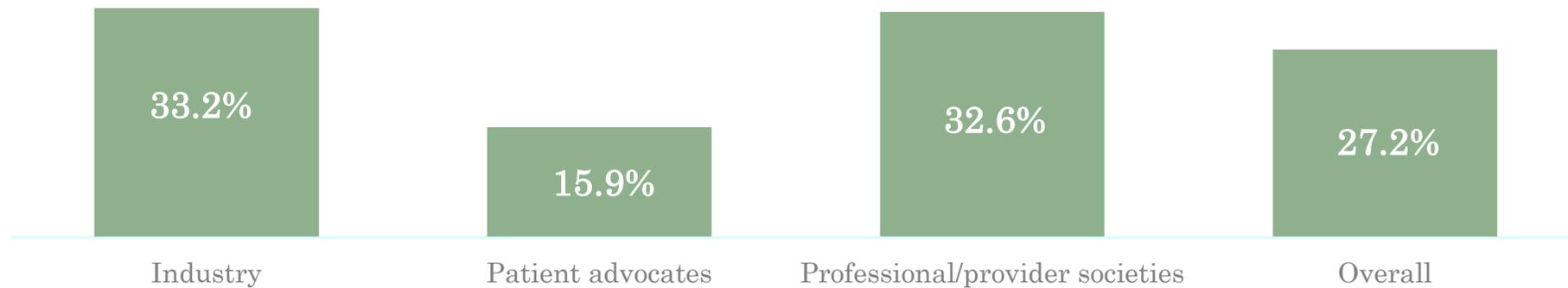
*38 patient and disability groups sent comment letter to ICER on June 10*

# Lack of *Meaningful* Patient Engagement in Development of ICER Studies

Despite ICER acknowledging a majority of comments, only 27 percent were incorporated into final reports.

Comments from patient advocates were half as likely to be incorporated compared to other stakeholder groups.

Percentage of Stakeholder Comments Incorporated Into ICER Final Evidence Reports



All comments: Industry, N=208; patient advocates, N=157; professional/provider societies, N=95

# Patient advocates most frequently commented on adequacy of existing evidence, patient perspective, and transparency.

## Adequacy of Existing Evidence

“Lack of long-term data should not justify undervaluing new migraine therapies. We are concerned that a premature assessment based on inadequate evidence could result in delayed treatment access for migraine patients who have already waited years for a viable therapy.”

-Headache and Migraine Policy Forum<sup>1</sup>

## Patient Perspective

“Patients must have a meaningful role in the discussion of value given that they are directly impacted by a report that seeks to define the effectiveness and value of their treatment options. Therefore, accounting for how patients define the value of their treatment options should be critical to ICER’s analysis.”

-Aimed Alliance<sup>2</sup>

## Transparency

“[We] respect the proprietary nature of the effort; however, the lack of transparency calls into question its validity... Furthermore, there needs to be transparency about the expert clinicians who are advising on the real-world use of the therapies, the model inputs, and how the model will be used.”

-LUNGeivity Foundation<sup>3</sup>

1. ICER. Migraine: Public Comment. <https://icer-review.org/material/cgrp-response-to-comments/>
2. ICER. Osteoporosis: public comments. <https://icer-review.org/material/osteo-draft-report-comment/>
3. ICER. Non-small cell lung cancer: public comments. <https://icer-review.org/material/nsclc-public-comments>.

# QALYs Have Historically Been Rejected by Policymakers

- The ACA explicitly prohibits PCORI from using the cost-per-QALY to determine effectiveness, and further restricts use in Medicare to determine coverage, reimbursement, or incentive programs.
- In 1992, HHS rejected Oregon's prioritized list of covered services for Medicaid citing the potential for violating the ADA due to use of QALYs and cost effectiveness.

# Oregon Health Plan

“Oregon's plan in substantial part values the life of a person with a disability less than the life of a person without a disability. This premise is discriminatory and inconsistent with the Americans with Disabilities Act.

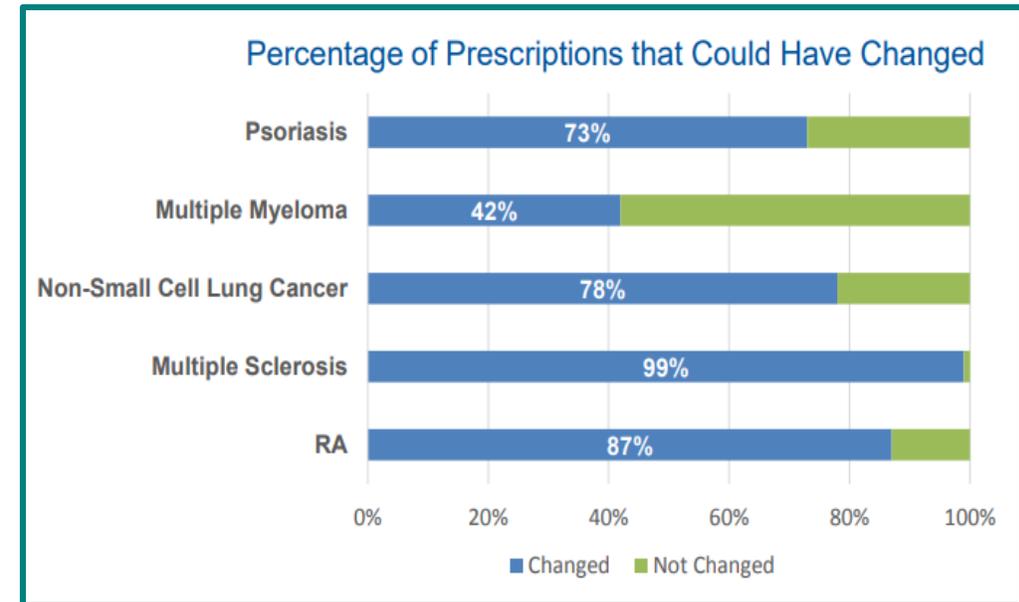
Given the outpouring of comments received by this department and the White House on this issue, I am confident in saying Oregon would have been sued if we had approved the waiver, preventing Oregon from implementing the plan for years. Accordingly, we requested revision of the proposal to remove factors impermissible under the Americans with Disabilities Act.”

– Louis Sullivan, HHS Secretary, Letter in the New York Times, Aug 13, 1992

# Why do QALYs Matter? Medicaid Access to Care!

A significant number of patients in five disease areas would lose access to treatments they are currently on, which their doctors deemed best for them, if Medicaid began utilizing an ICER-based formulary.

- Between 42% and 99% of patients across five disease areas would be required to switch treatments if Medicaid used ICER's judgement to determine patient access.
- Essentially all Medicaid patients with MS would be forced to switch treatments, since ICER has deemed only one medication "high value" for MS, and it accounts for only .04% of prescriptions.
- 87% of Rheumatoid Arthritis prescriptions would change if Medicaid used an ICER-based formulary.

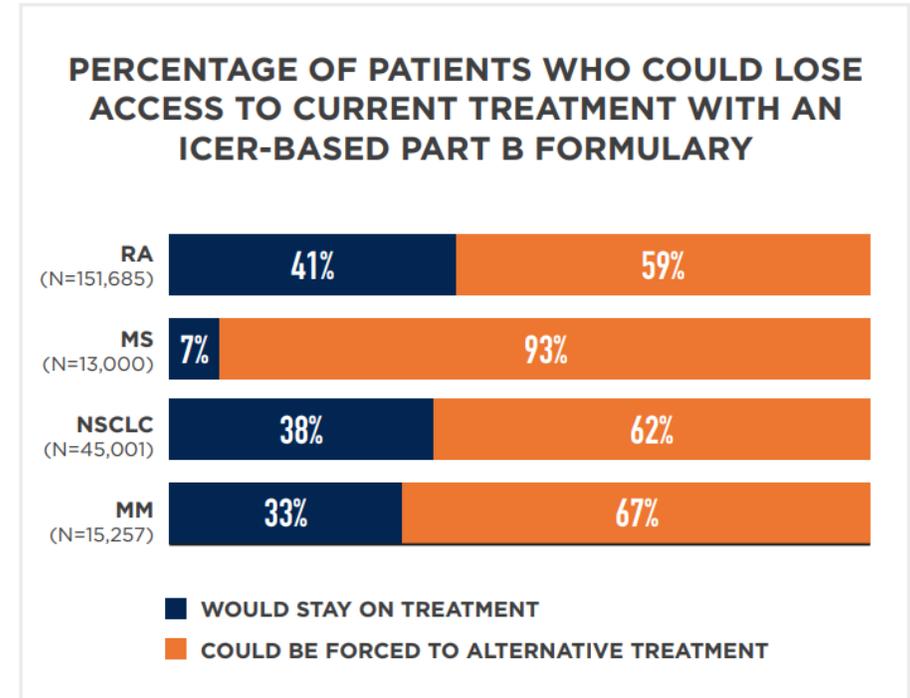


# Why do QALYs Matter?

## Medicare Part B Access to Care!

More than half of Medicare Part B beneficiaries in the selected disease areas would lose access to needed care if ICER's judgments were used as a government value standard.

- Between 55% and 62% of patients across four disease areas would be required to switch treatments if Medicare used ICER's judgement to determine patient access in Medicare Part B.
- The switch would most impact MS patients most significantly – nearly 93% of patients would lose access to the treatment their physician prescribed.



# Implications for Veterans and Military

- In 2017, ICER announced a partnership with the VA “to integrate ICER reports into the VA formulary management process of evaluating the comparative clinical effectiveness and value of drugs.”
  - Over 40 organizations signed a letter expressing concern to the VA
- In a recent review, PIPC found that ICER evaluated 54 drugs at low-intermediate value and 42 of them are not covered on the national VA formulary
- DOD is now implementing Section 702 of the FY 2018 NDAA which seeks to “pay for value” by allowing drugs to be excluded from the formulary that “provides very little or no clinical effectiveness to covered beneficiaries and the Department under the program.”
  - It is not clear who defines “clinical effectiveness” and “value” for DOD

# Experience in Other Countries

## Worse Outcomes

For breast, colon, lung and prostate cancers, 5-year survival rates are higher in U.S. than those in Canada, France, Germany, Italy, Japan and the U.K.

## Fewer Options

Almost 80% of cancer medicines reviewed by U.K. health officials between 2007 and 2014 had some form of access restriction.

## Slower Access

U.S. patients have access to cancer medicines on average 2 years earlier than patients in other developed countries

News > Health > NHS

### Miracle drug that could prolong this four-year-old's life 'too costly' for NHS

The one medication that could slow down Francesca's degenerative condition has been rejected as 'not cost effective' by drugs regulator

### Cystic fibrosis sufferers denied life-prolonging drug by NHS

The maker of a costly treatment now licensed for sufferers as young as six is trying to strike a deal with the health service

See [www.pipcpatients.org/access](http://www.pipcpatients.org/access) to learn more about other countries.



# Developments in States

- New York: Passed legislation allowing for use of “value” assessments to determine supplemental rebates, also allowing for drugs with multiple in a class to be excluded from formularies. This year’s budget gave more explicit authority to use a third party like ICER to determine that “target” price.
  - Letter signed by over 40 groups opposing provision in budget
- Massachusetts: Proposed policies modeled on New York reference “value”
  - Disability groups actively opposing and calling for a ban on use of QALYs
- California: The Legislative Analyst Office has provided recommendations to consider the New York model.
- Other states are also considering similar policies referencing third party value assessments to determine reimbursement and coverage

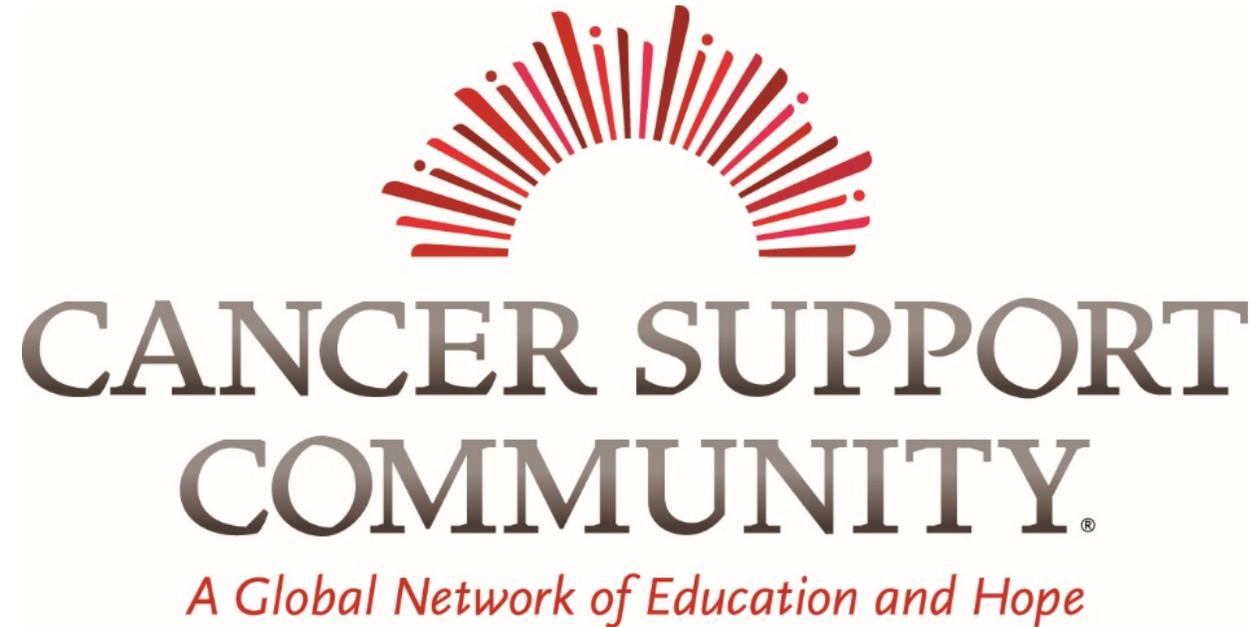
*Buzzwords: “value”, “cost effectiveness”, “third parties”, “based on ‘evidence-based research’”*

# A Better Way Forward: Partner with Patients

- Use patient-centered and transparent methods when utilizing evidence in making coverage decisions that impact patients' access to medicines
  - National Health Council's Patient Centered Value Model Rubric
- Do not depend on a single measure of value to determine coverage and care decisions and instead rely on a range of evidence developed using patient-centered methods
  - Center for Patient-Driven Value Assessment (PAVE)
  - Innovation and Value Initiative (IVI)
  - Multi-Criteria Decision Analysis (MCDA)
- Commit to full transparency around decision making that impacts patient access
  - Advance value-based benefit design that encourages clinically-appropriate treatment and adequately considers patient needs as recommended by clinicians.

# Value Our Health

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**Value Our Health  
Capitol Hill Briefing  
June 20, 2019**

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# Perspectives of Patients with Cancer on the Quality-Adjusted Life Year as a Measure of Value in Healthcare

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- Exploration of patient awareness, understanding, and perspectives on the quality-adjusted life year
- Cross Sectional
- Mixed Methods
- Measures:
  - Sociodemographic and health characteristics
  - Health literacy measures
    - Brief Questions to Identify Patients with Inadequate Health Literacy
    - Cancer Health Literacy Test 6 (CHLT-6)
  - Perspectives on QALY
  - Open-ended qualitative items

Sex		Annual Household Income	
Male	17.3%	Less than \$20,000	15.8%
Female	82.7%	\$20,000 to \$59,999	35.2%
		\$60,000 to \$99,999	26.3%
		\$100,000 or more	22.7%
Race		Worked in Health Care	
White	87.7%	Yes	38.2%
Nonwhite	12.3%	No	61.8%
Hispanic Ethnicity		Most Common Cancers	
Hispanic	4.1%	Breast	44.2%
Non-Hispanic	95.9%	Leukemia	7.1%
		Lung	6.2%
		Melanoma	5.2%
Age		Highest Education Level	
18-24 years	6.4%	HS/GED or less	16.2%
45-59 years	37.4%	Some college	28.9%
60-74 years	50.0%	Bachelor's Degree	28.2%
75 years or older	6.3%	Graduate Degree	26.7%

# Data Analysis

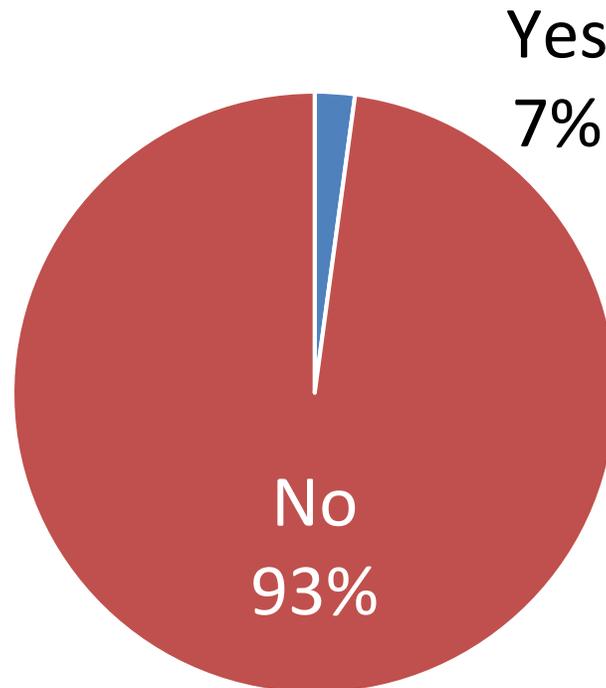
- Descriptive statistics
- Chi-square test of differences
- Independent samples t-test
- Logistic regression

# Health Literacy

- Almost 40% of participants had worked in some health care setting.
- Most scored high on *Brief Questions* (mean score of 9.9 out of possible 13, SD = 2.1)
- Most scored high on CHLT-6 (90% correct on all questions)

**Results indicated a participant population with the potential to understand complex health and cancer care topics such as the QALY**

# Patient Awareness of QALY

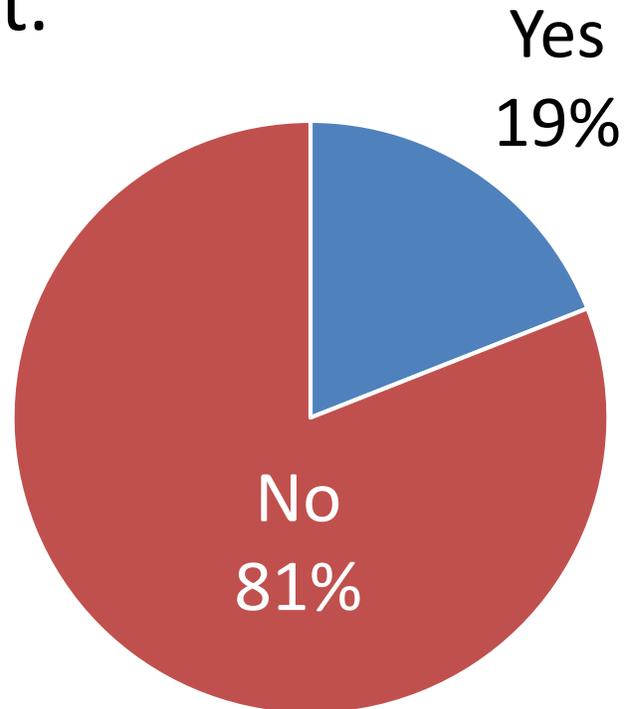


Participants that had heard of the QALY were:

- **Significantly more likely to have worked in health care**  
 $\chi^2 [1] = 8.34, P = .004$
- **Greater levels of overall health literacy**  
 $t (668) = 5.77, P < .001$

# Patient Understanding of QALY

After reading a brief explanation of the QALY, participants were asked if they understood the concept.

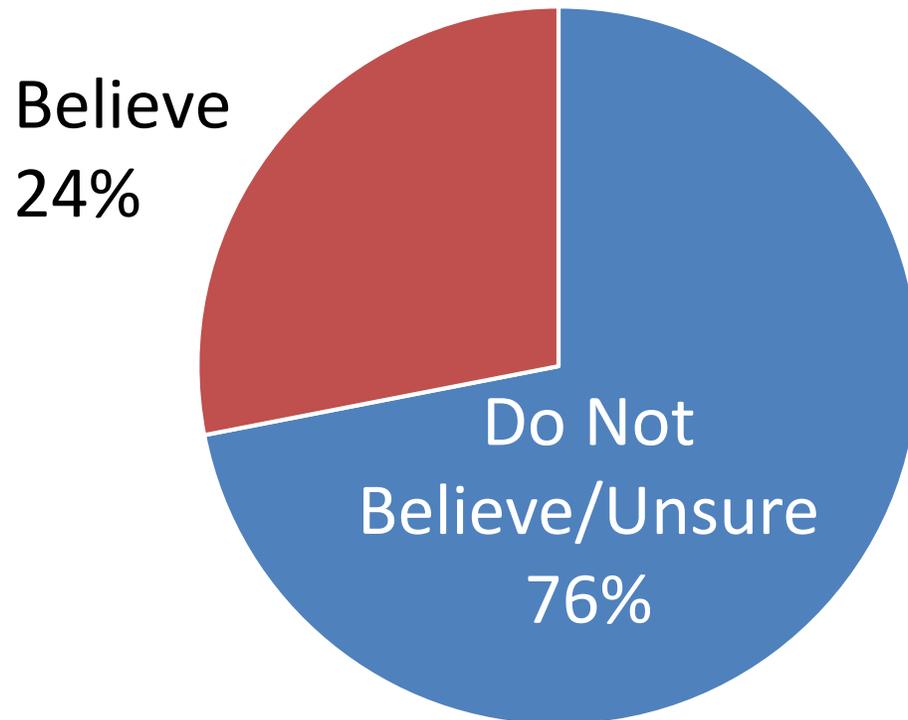


Participants who were more likely to report understanding of the QALY:

- **Bachelor's degree or higher**  
 $\chi^2 [1] = 14.58, P < .001$
- **Annual household incomes over \$100,000**  
 $\chi^2 [1] = 10.59, P = .001$
- **Greater levels of health literacy**  
 $t [580] = 4.64, P < .001$

# Patient Perspectives on the QALY

After reading an explanation of the QALY, participants were asked if they did or did not believe that the QALY was a good way to measure value in health care.



Participants who **did not believe/were unsure** if the QALY was a good measure of value were:

- **Women (78%)** vs. Men (65%)
- **Incomes less than \$100,000**

$$x^2 [1] = 5.17, P = 0.23$$

Participants who **did believe** the QALY was a good measure of value:

- **Higher health literacy levels**

$$t [582] = 2.49, P = .013$$

# Patient Thoughts on the QALY

- Three Major Themes
  - Opinions on QALY
  - Measuring Value
  - Value in Health Care and Decision Making

# Opinions on the QALY

- 59 of participants expressed specific opinions on the QALY
- 85% of those opinions were negative
- 15% positive comments included those who thought it could be a useful tool in health care decision making or cost control.

“I am afraid that if the QALY is used to determine treatment, some patients will not be given treatments that may help them.”

# Measuring Value

- Over half of the participants discussed the measurement of value in health
- 3 subthemes:
  - Concerns over quantitative scoring
  - The multifaceted nature of value
  - Imperfect measurement

“A measure like QALY cannot be applied in the same way to people of varying circumstances.”

“Ethically inappropriate”

“Immoral”

# Value in Health Care and Decision Making

- 126 participants mentioned the relationship between value in health care and decision making.
- 3 subthemes:
  - Patient autonomy
  - Concern about external decision makers
  - Cost

“I feel the decision for how long you live and how you are willing to live should be decided by the patient...Many patients would not want to live longer if they felt that had no quality of life and other would like to live as long as possible regardless of the quality of life they have...”

# Conclusion

- Awareness and understanding of the QALY is limited among cancer patients and survivors.
- Although some patients and survivors believe that the QALY could potentially be helpful in personal health care decision making, there is concern regarding how the QALY could be used by payers, policymakers, and other decision makers in determining access to care.



# CANCER SUPPORT COMMUNITY®

*A Global Network of Education and Hope*

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