



# Living with Pain: A Patient's Perspective

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CHRISTIN VEASLEY

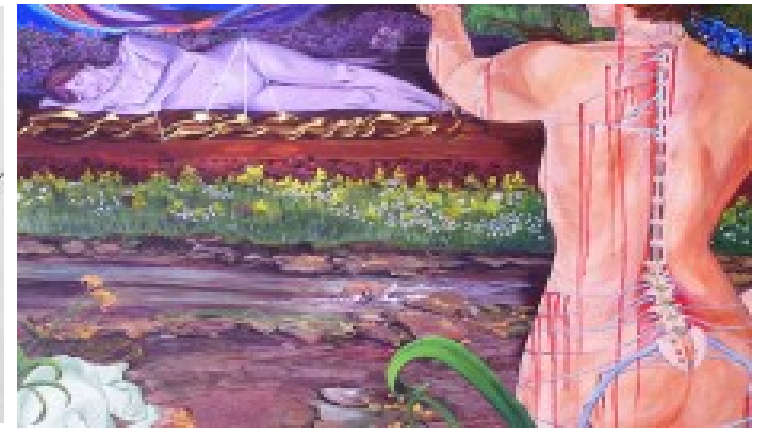
CO-FOUNDER & DIRECTOR, CHRONIC PAIN RESEARCH ALLIANCE

[WWW.CHRONICPAINRESEARCH.ORG](http://WWW.CHRONICPAINRESEARCH.ORG)

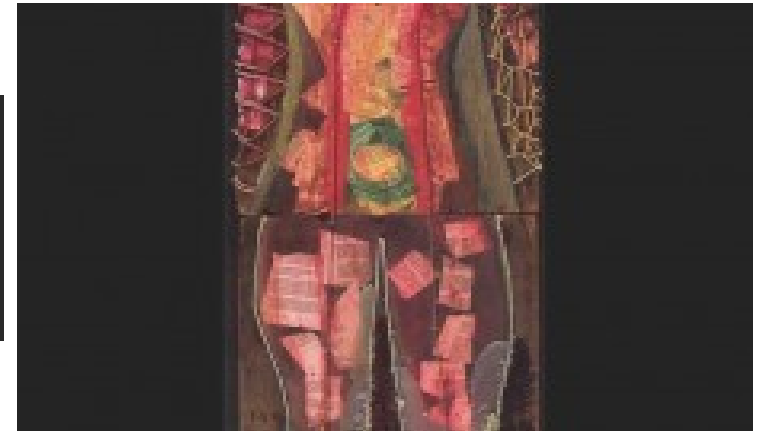


It's not  
always the  
tears that  
measure the  
pain.  
Sometimes it's  
the smile  
we fake.

CURIANO.COM



PAIN



# Where are we?

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AN HONEST ASSESSMENT

# Chronic pain is the most prevalent, costly & disabling U.S. health condition

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## PREVALENCE

100 million American adults (NAM, 2011)

126 million American adults had some pain in last three months (NHIS, Nahin, 2012)

## COST

\$560-635 billion annually (NAM, 2011)

## DISABILITY

In US: Painful arthritic, back/spine disorders #1 cause of disability (CDC, 2005, 2012)

Globally: Low back pain, migraine, neck pain & musculoskeletal disorders in the top 10 leading causes of 'years lived with disability' in 2016  
(Global Burden of Diseases, Injuries, and Risk Factors Study 2016)

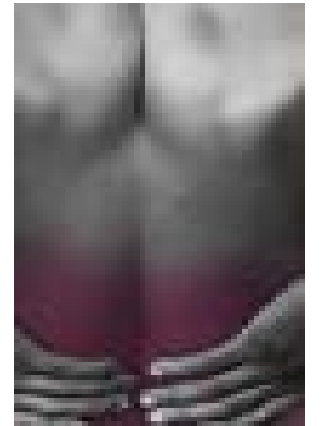
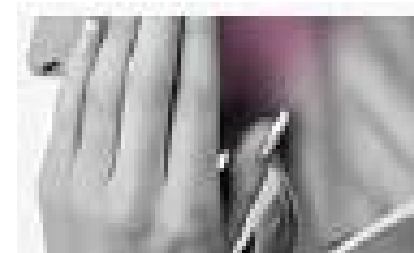
## FEDERAL PAIN RESEARCH INVESTMENT

<1% of annual cost



## Missing from the Conversation

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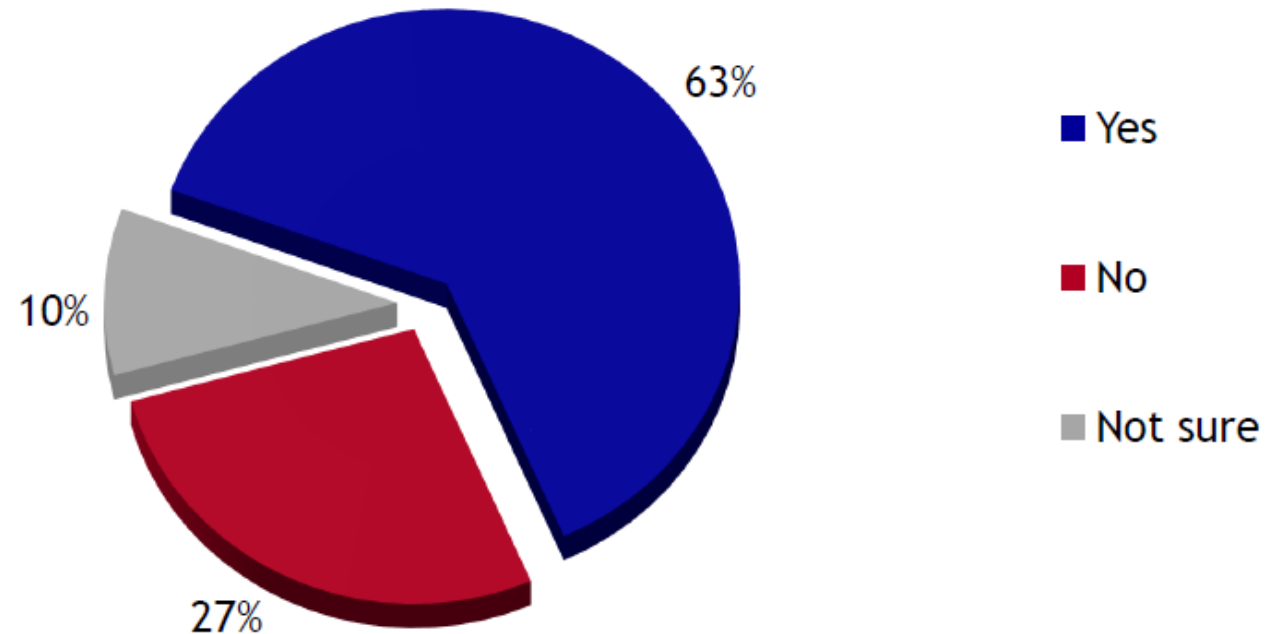


**Voices of People with Pain**

Where does  
the public  
stand?

## Most Americans Know Someone Who Sought Pain Medicine

Do you know anyone who experienced pain so severe that they sought prescription medicines to treat it?



Zogby  
Analytics

Source: A Research!America poll of U.S. adults conducted  
in partnership with Zogby Analytics in March 2013.

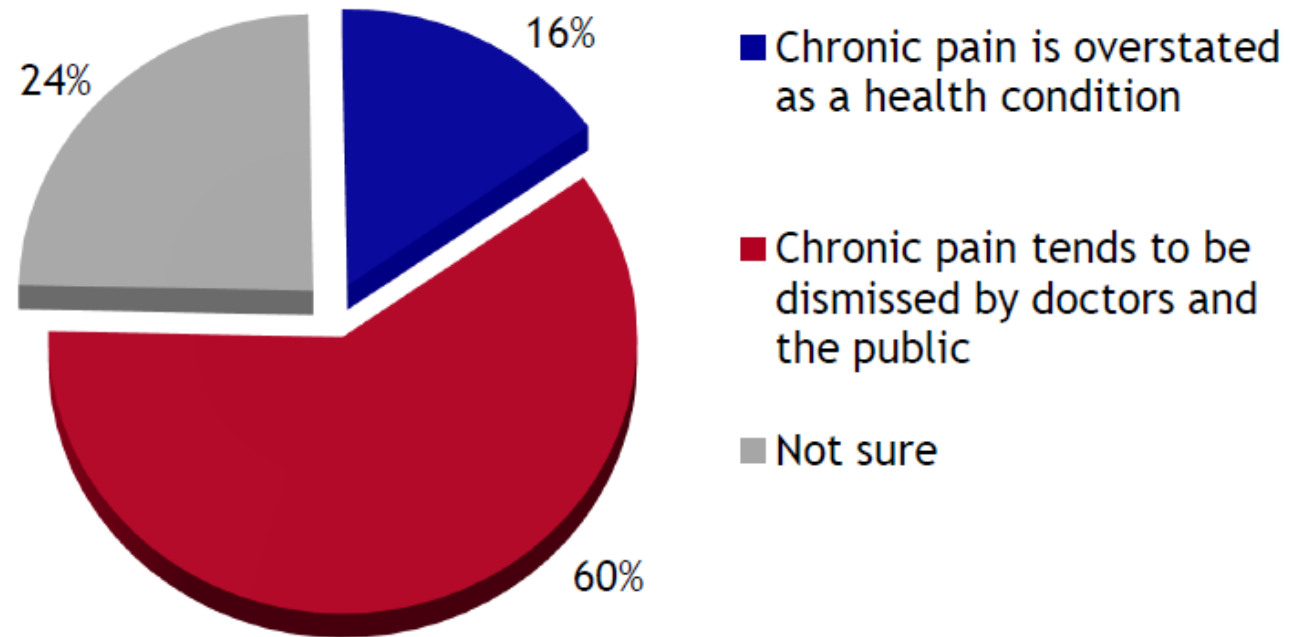
RESEARCH  
AMERICA  
AN ALLIANCE FOR DISCOVERIES IN HEALTH



Where does  
the public  
stand?

## Majority: Chronic Pain Tends to be Dismissed by Doctors, Public

Which statement is closer to your view?



Zogby  
Analytics

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in March 2013.

RESEARCH  
AMERICA  
AN ALLIANCE FOR DISCOVERIES IN HEALTH



Where does  
the public  
stand?

*MAJOR Disconnect*

## Chronic Pain Ranks Below Many Other Conditions as Major Health Problem

Which of the following would you describe as a major health problem in the U.S.? (multiple responses allowed)

Cancer	59%
Heart disease	52%
Diabetes	52%
Drug addiction	47%
Depression	42%
Alcoholism	37%
Alzheimer's disease	34%
<b>Chronic pain</b>	<b>18%</b>
Parkinson's disease	15%
Not sure	15%

# Reasons for Public Disconnect – Many & Complex

## #1: Using same word to describe different pain states

*“Pain” is used to describe both a symptom and a chronic disorder*



“Pain”  
brief  
acute warning mechanism

≠

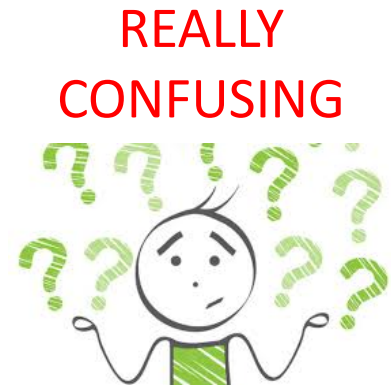


“Pain”  
transient  
secondary to cancer, etc.

≠



“Pain”  
Chronic  
neurologic disorder in itself



# Reasons for Public Disconnect – Many & Complex

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## #2: Specific pain condition vs. “chronic pain” or “chronic pain disorder”

*--Umbrella term that encompasses huge number of conditions*

*- What factors influence self-identification?*



*“chronic pain”  
“chronic pain disorder”*



*arthritis*



*IBS*

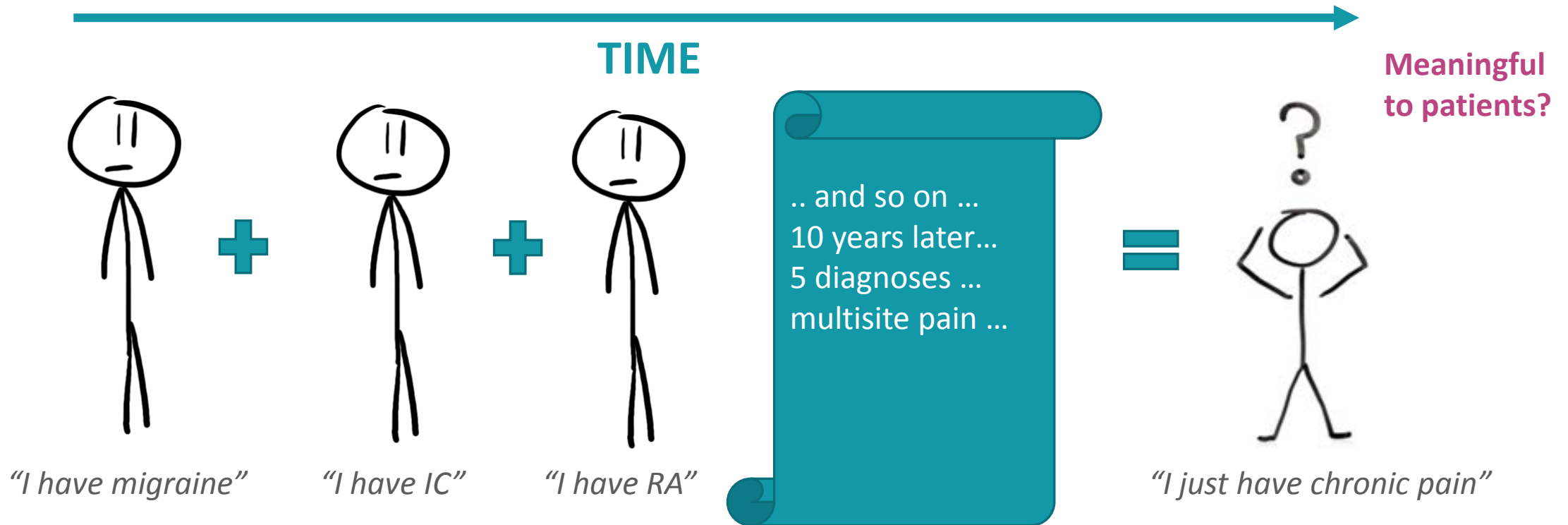


*migraine*

# Reasons for Public Disconnect – Many & Complex

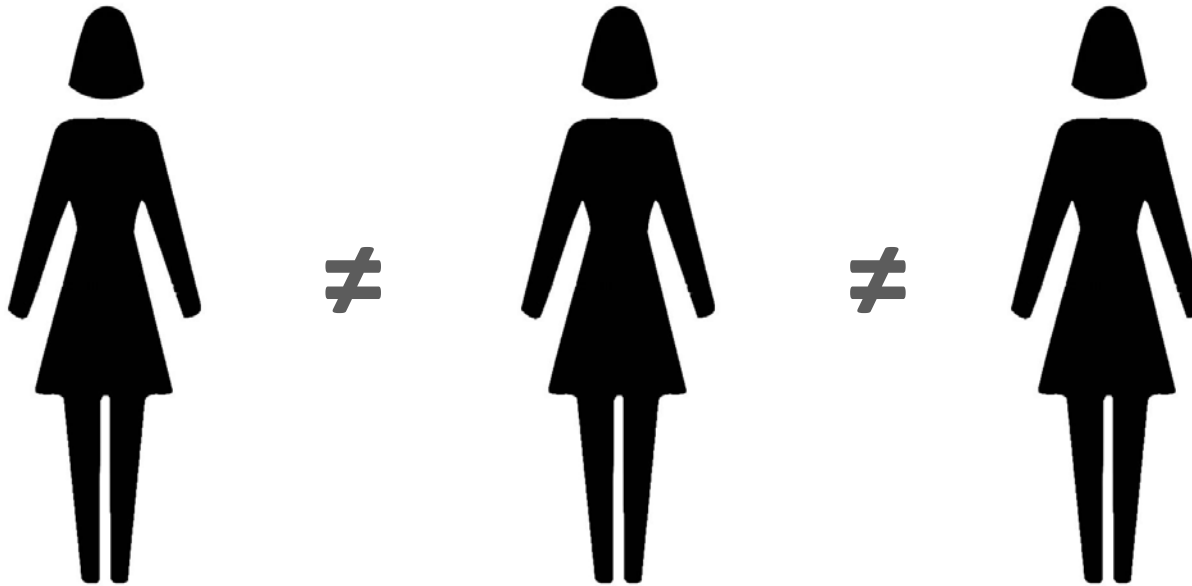
## #2: Specific pain condition v. “chronic pain”

*--Does this distinction exist as a function of time and # of pain diagnoses?*



# Reasons for Public Disconnect – Many & Complex

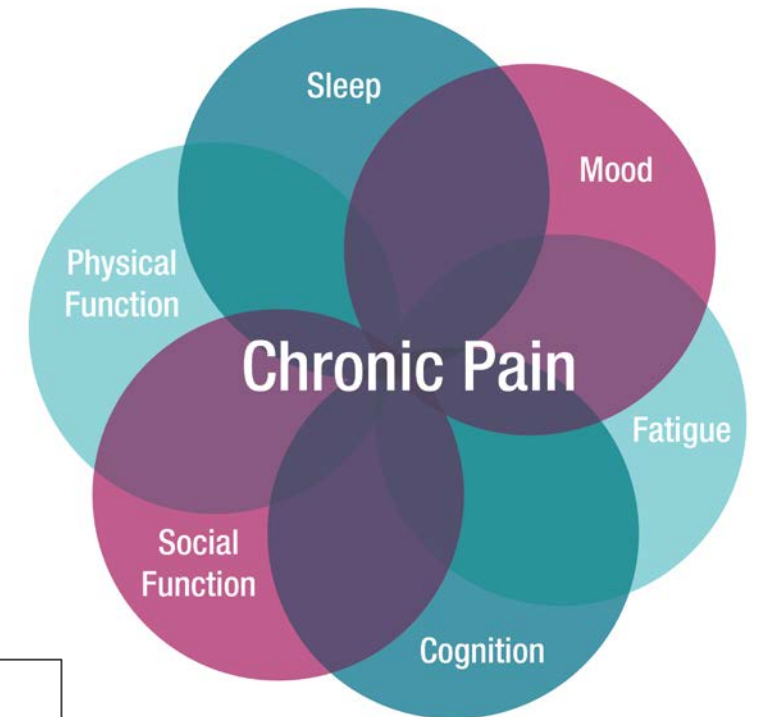
## #3: Complexity of the biopsychosocial pain experience



Age 50, fibromyalgia,  
fatigue, impaired  
physical function

Age 50, fibromyalgia,  
good psychosocial &  
physical function

Age 50, fibromyalgia,  
sleep disorder, depression  
& dyscognition

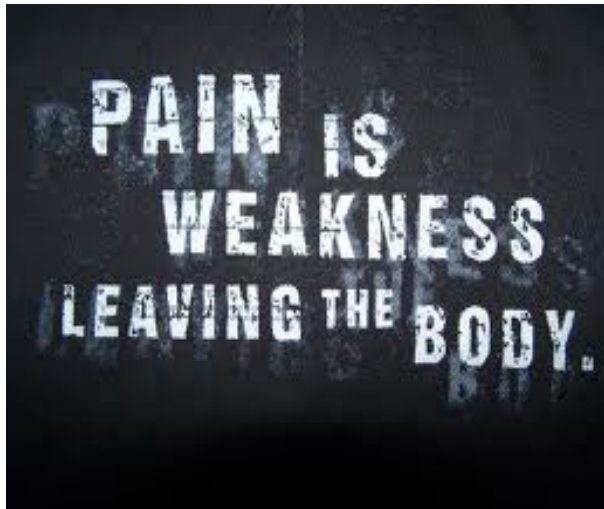


# Reasons for Public Disconnect – Many & Complex

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## #4: Stigma / Personal Biases

Now acceptable to have chronic pain ... **“WEAK”**  
but not to be impacted by it ...



# Reasons for Public Disconnect – Many & Complex

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## #5: Criminalization of pain

--Unintended consequence of policies, debate & media stemming from opioid epidemic

--Patients don't disclose pain condition because of common misconceptions:

1. You take opioids
2. You're an addict
3. Your main concern is access to opioids
4. You are a drug seeker
5. You are stockpiling medications
6. Or – all of the above (and/or others)

**CHRONIC PAIN**

**≠**

**OPIOID USER**

**≠**

**OPIOID ABUSER  
OPIOID MISUSER**

**≠**

**NOT DESERVING OF THE  
BEST, MOST HUMANE &  
EMPATHIC MEDICAL CARE**



# Reasons for Public Disconnect – Many & Complex

## #5: Criminalization of pain

“Pain medication is inadequate. But with it I am more consistently functional and can minimize being housebound, bedridden, or hospitalized. I can be a responsible homeowner, spouse, parent; I can work as a teacher, a writer, an editor.”

“I’ve never been arrested, found to be out-of-compliance, had a substance-related accident or hospitalization, but increasingly I am a suspect, treated less as a patient and more as a criminal.”

“The feelings of humiliation and degradation don’t fade; they simmer.”

“... abuse of prescription pain medication is a serious problem; people are dying. But a vastly larger group of us are living — in unremitting pain, in the face of which we do the best we can to remain productive and independent, to benefit, rather than burden, our families and society at large. Most of us have accepted ever-more-onerous restrictions, no matter how humiliating — urination on command, guilty-until-proven-innocent — regardless of how they clash with American values and medical ethics.”



By Donald N.S. Unger | FEBRUARY 03, 2015

# Public Disconnect

One of many tweets circulated after an ad aired for pain-related opioid-induced constipation:



## Computer that determines how much pain a patient is in just by looking at their face could help doctors spot fakers

- Researchers believe the system will be useful in separating 'real pain from fake'
- People express pain differently, which makes it hard for doctors to gauge
- The system is personalized by taking into account age, sex and complexion
- Researchers hope the system will one day be available as an app on phones
- Past research suggests computer systems are 30% more effective than humans

By [ALEXANDRA THOMPSON](#) HEALTH REPORTER FOR MAILONLINE

PUBLISHED: 10:39 EDT, 4 September 2017 | UPDATED: 10:43 EDT, 4 September 2017



A computer is being developed that rates how much pain someone is in by detecting small changes to their facial expressions.

# Public Disconnect – End Result

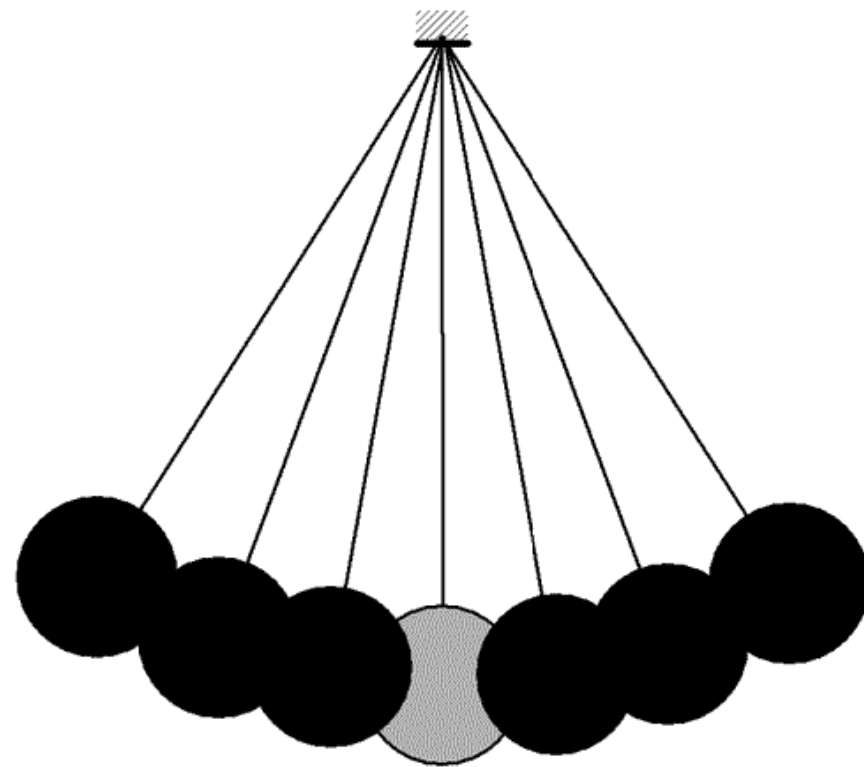
Is it really that hard to understand why people with pain remain silent?



**Pain is  
when you're  
slowly dying on  
the inside and  
you're way too  
weak to speak  
about it so you  
keep silent and  
suffer, alone.**

NOFACEWRITES

# Pendulum Swing in the Medical Scientific World



No one gets opioids
Basic science focus - drives all else
Biologic measures w/ little-to-no self-report
Placebo-controlled RCTs
No patient/stakeholder involvement in research

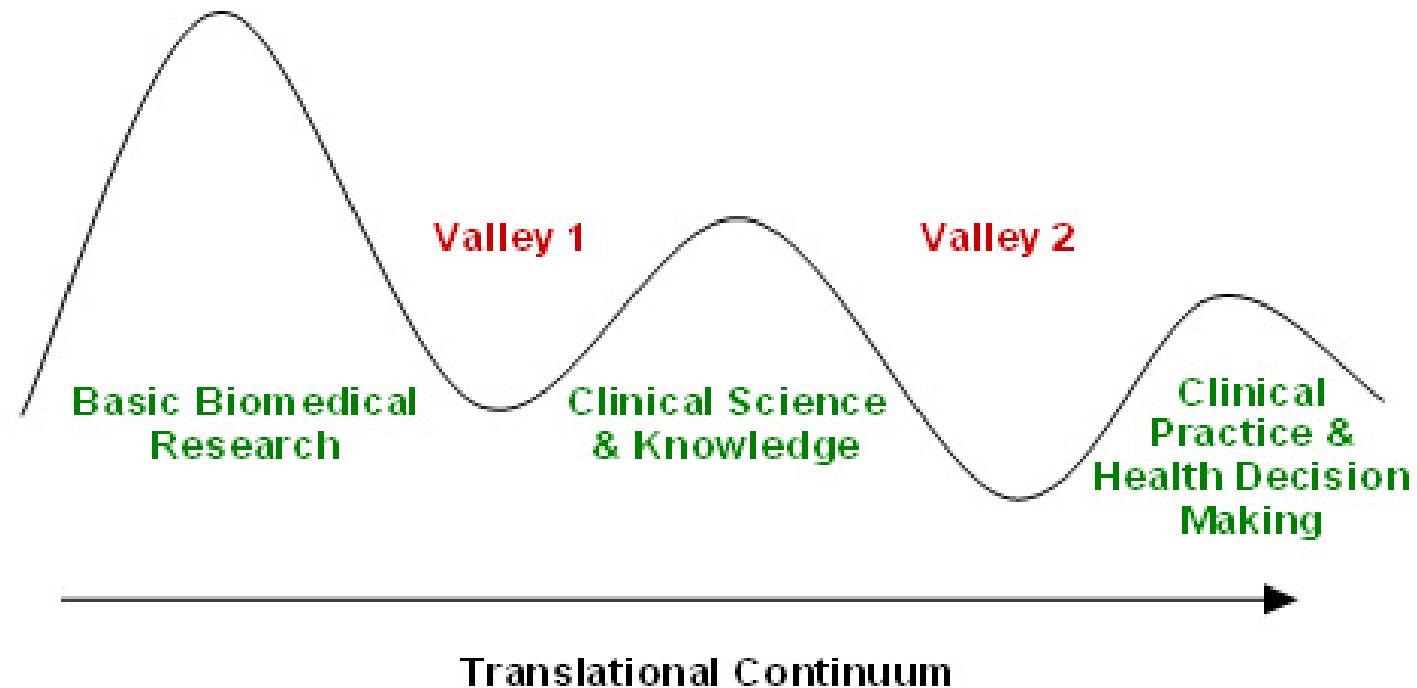
What's best  
for patients

Everyone gets opioids
Prioritization of translational/clinical
Prioritization of Patient Reported Outcomes
Pragmatic/real world trials
Patient-driven research & multi-stakeholder networks

# Translation?

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Are scientific discoveries surviving the valley(s) of death and translating to improved treatment options?



*In the interim ....*

*what's happening with patients?*

# Chaos (noun): *complete disorder & confusion*

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- Shortage of pain specialists
- Primary Care treating chronic pain without education, expertise & time
- No medical home with multimodal coordinated treatment
- The field of chronic pain treatment being “strikingly deficient” in quality evidence to assess benefits and risks (FDA, 2016)
- Well-meaning clinicians left without evidence to guide clinical decision-making
- Experimenting with myriads of treatments, many with unknown benefits & risks
- Profound impact on health and all aspects of quality of life and functioning



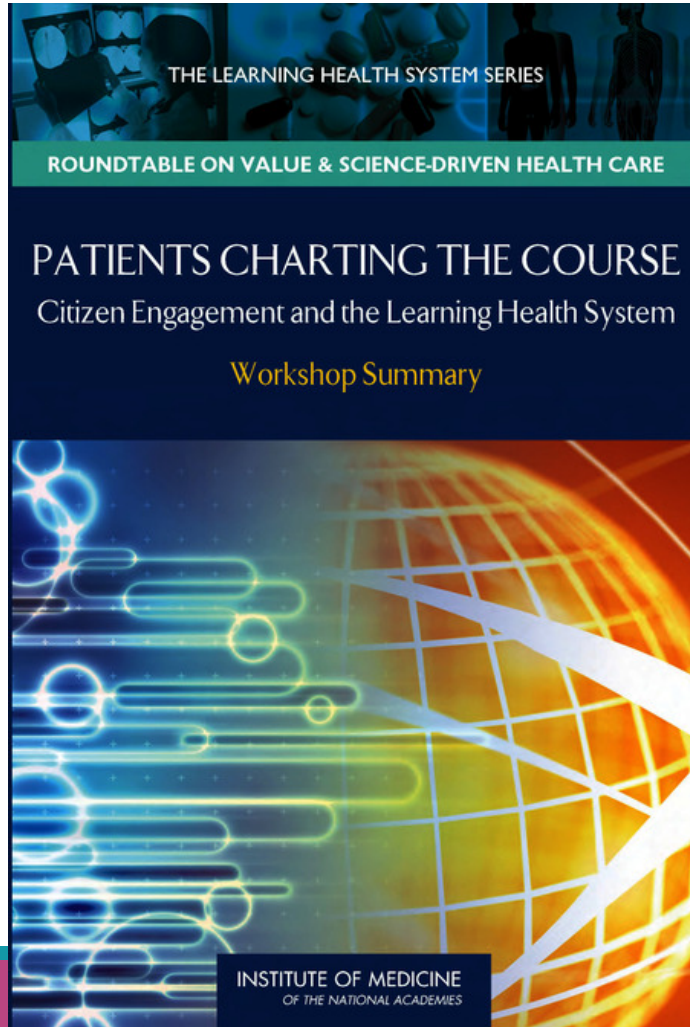
IT'S OUR RESPONSIBILITY

# Patient Hopes for Research

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1. Objective measures of pain
2. Dynamic measures that account for complexity of the chronic pain experience
  - How do you define “improvement?”
  - Does VAS really measure what you think it’s measuring? Does a number matter?
  - How can you incorporate sleep, mood, fatigue, function, etc., into a better, more well-rounded measure?
3. Animal and human models that account for the complexity of the chronic pain experience
  - Multi-system illness involving neurological, endocrine & immune systems
  - Bidirectional impact of non-pain domains on pain (i.e., fatigue, mood, sleep, etc.)
4. Trials that account for complexity & individuality of pain experience
  - What is going to work for me – PMI?
  - Combinations of treatments | Impact of other pain/non-pain conditions
  - Function, QOL & individualized goal setting
5. Reverse Translation & Broad Inclusion
  - Listen to and learn from patients
  - Include patients (and other stakeholders) early and often in the research process

# Patients Essential Partners in Research



“...patients bring unique and important perspectives to health care, as well as the ability to spark improvement; both of which are essential to closing important gaps in health system performance and ensuring that care is effective.”

“Unfortunately, patients, families, and caregivers too often are not engaged as meaningful decision makers in their own care or as partners in health research.”

“This shortcoming has been associated with improvements in the effectiveness, safety, and patient experience of care.”

# Broad Stakeholder Inclusion



# What do patients need?



Hope is being  
able to see  
that there is  
light despite  
all of the  
darkness.

*Desmond Tutu*

\_\_\_\_\_

\_\_\_\_\_



*“My chronic pain continues to worsen, despite my best efforts and those of my health care providers. Research is one of a few things that still gives me hope. I’m so grateful to pain researchers who devote their todays to making my tomorrow better.”*

IT'S OUR RESPONSIBILITY