The Perspective of People with Pain

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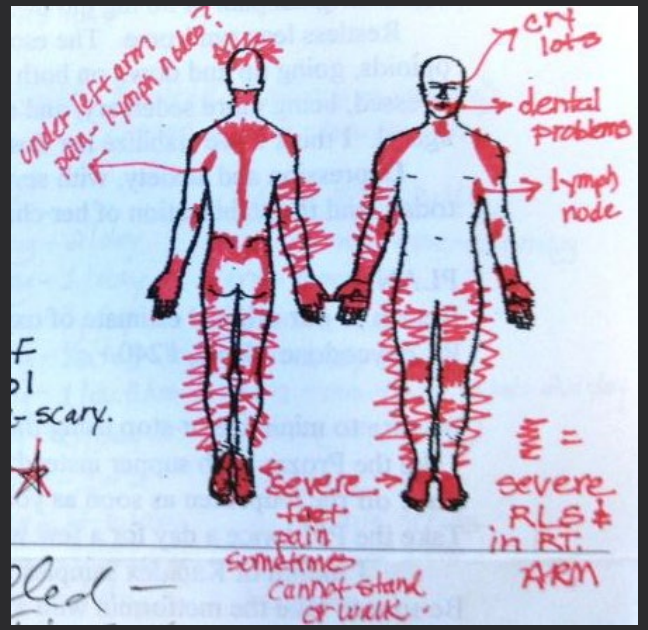
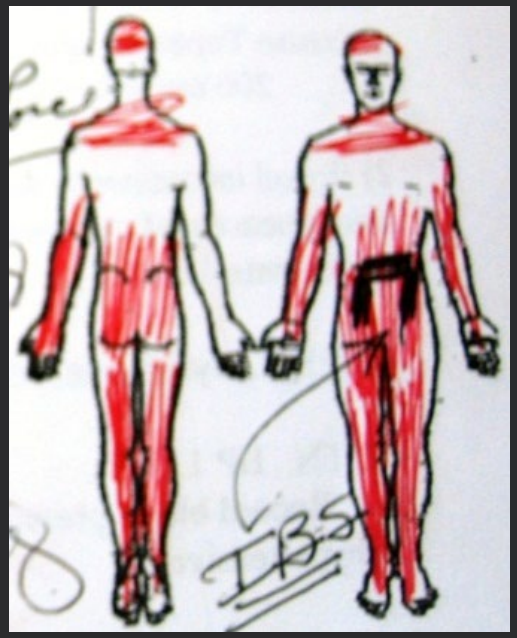
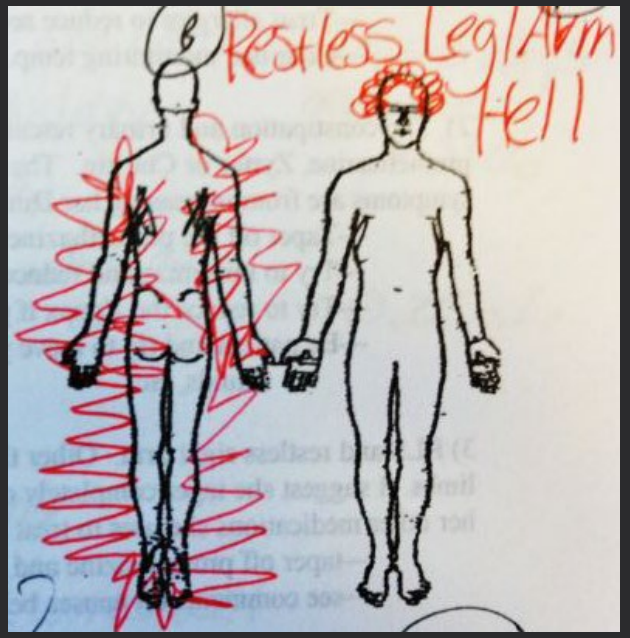
www.ChronicPainResearch.org

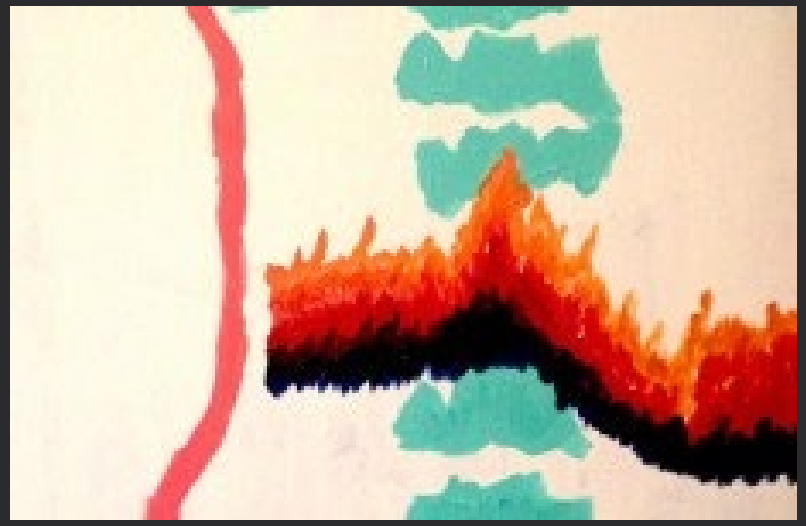
EPIDEMIC OF CHRONIC ILLNESS

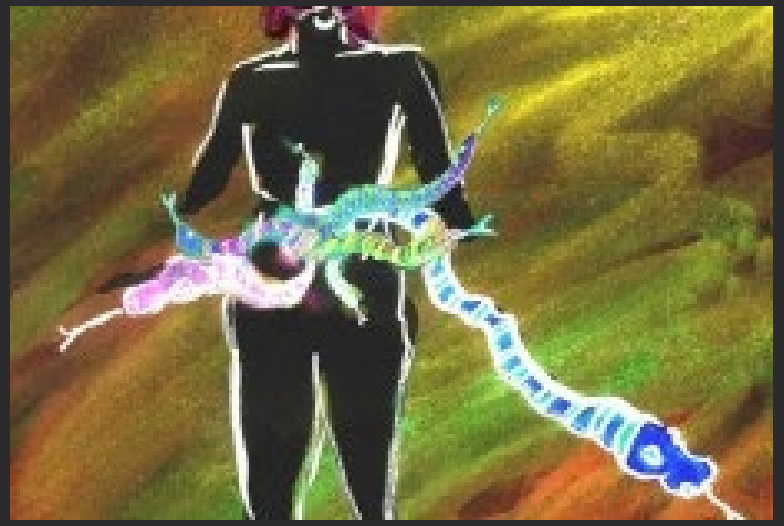






in·vis·i·ble





Source: PainExhibit.org

mis·un·der·stand·ing (noun):

failure to understand something correctly

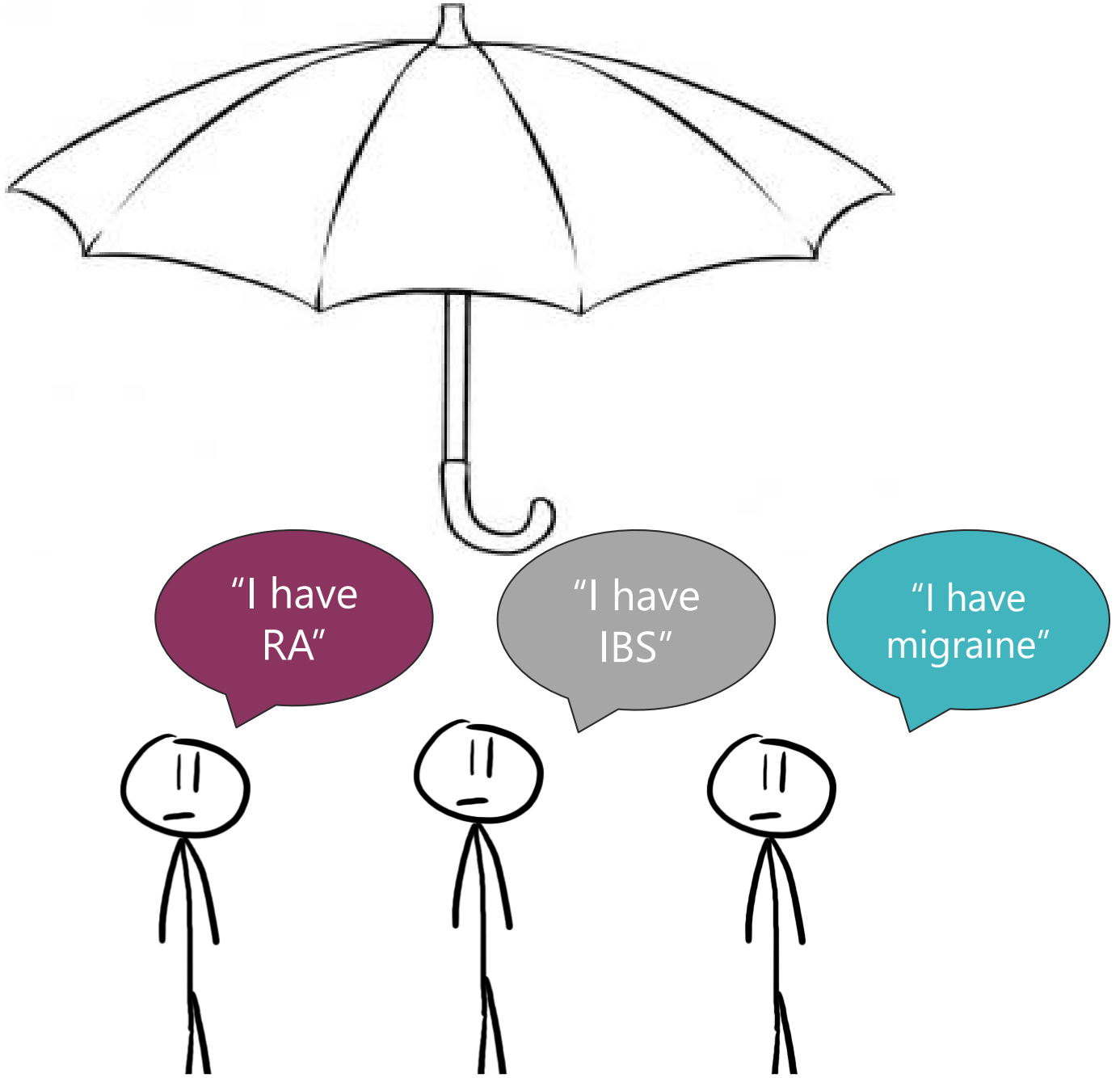
State of Confusion

WORDS
MATTER
DOUBLE
WORD

“PAIN” : Symptom? Disorder? Both?

... same term used to describe a symptom, secondary condition and a disease state?

vs.



Central component of pain - but also other system-specific symptoms

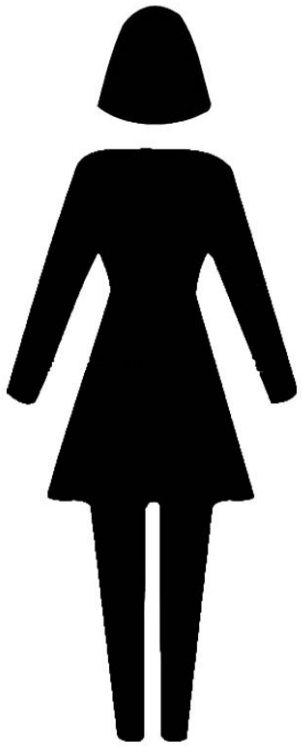
Comorbidities & Biopsychosocial Experience:
Not all "Chronic Pain" Looks the Same

≠

Diabetic Neuropathy

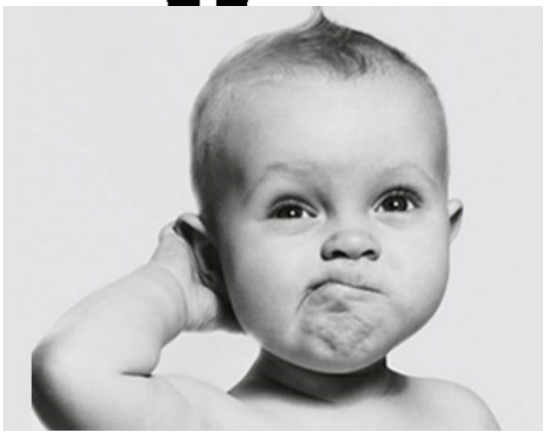
+ Diabetes
+Obesity
+Sleep Disorder

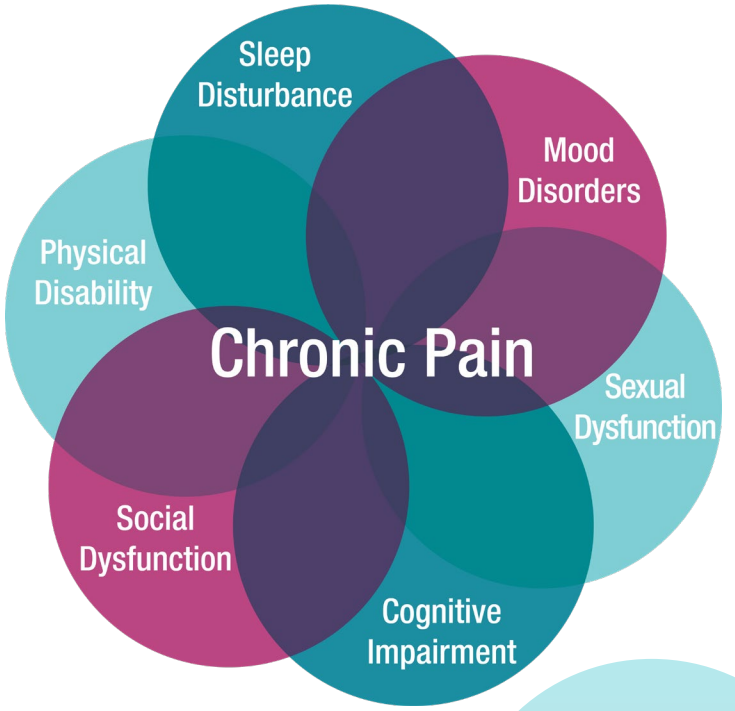
≠

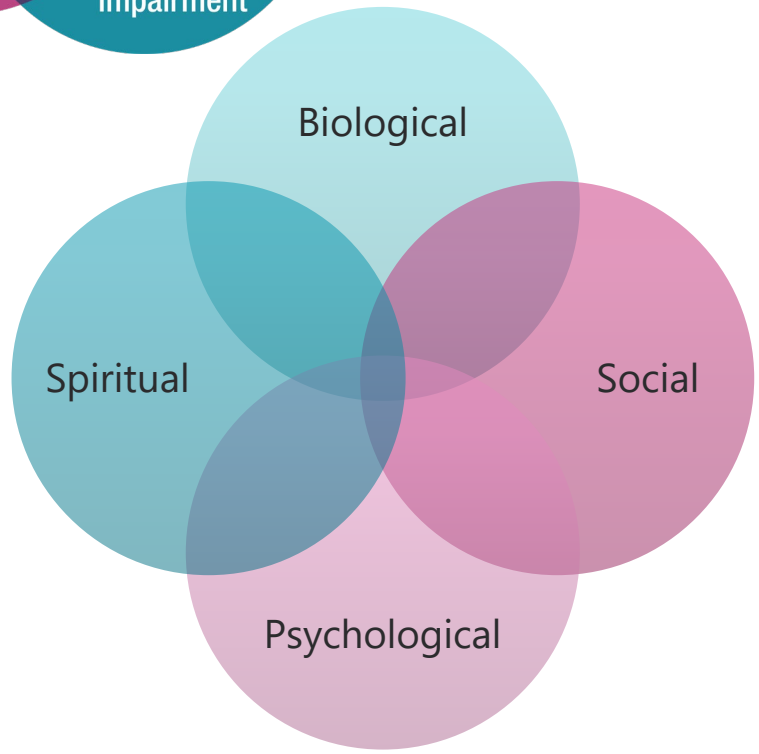


FM, IC, Migraine, TMD

+ Cognitive Impairment
+ Sleep Disorder
+ Chronic Fatigue
+ Mood Disorder
+ Sexual Dysfunction

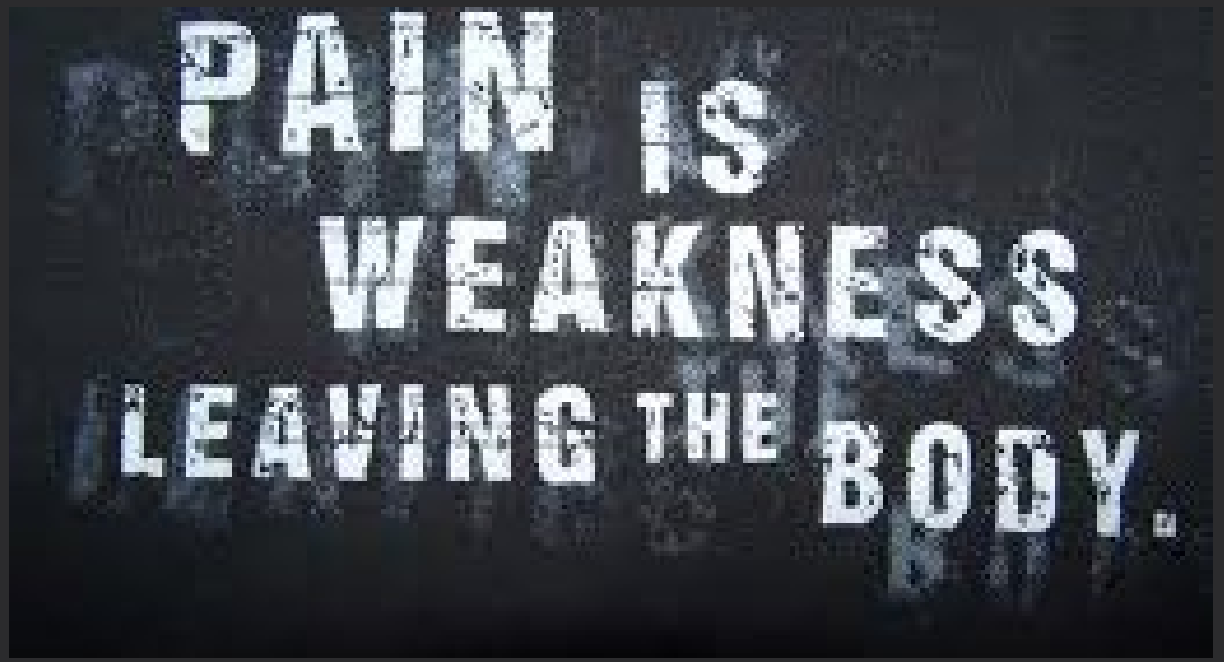


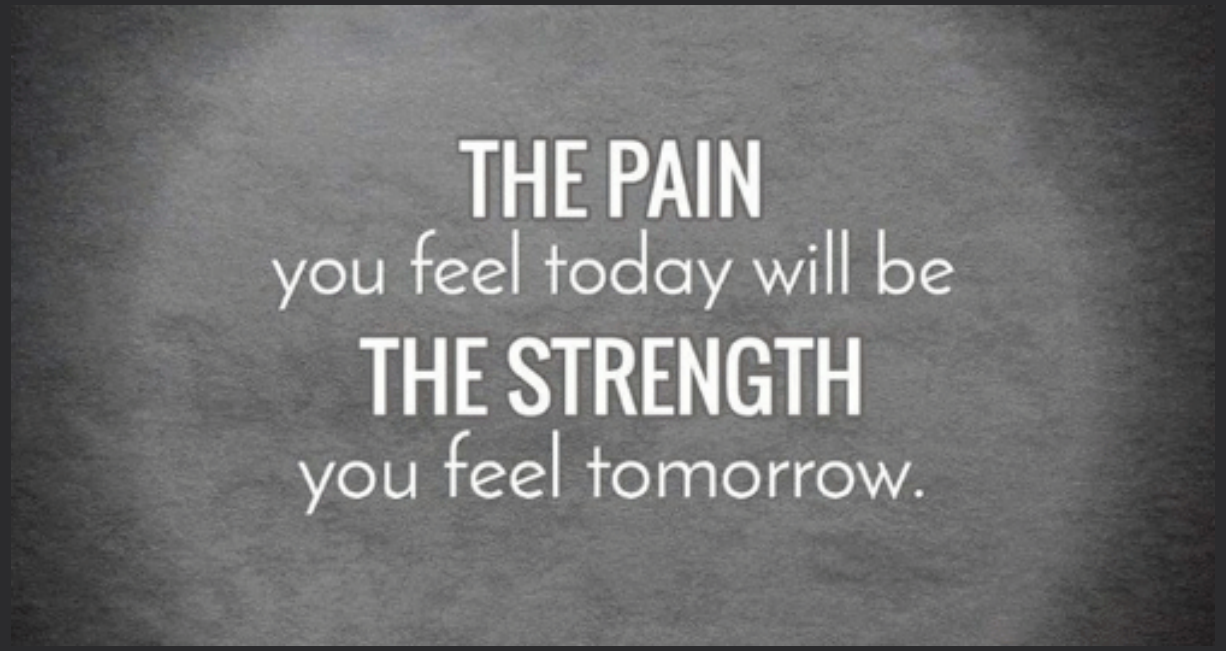




stig·ma·ti·za·tion
action of regarding someone as worthy of disgrace or great disapproval
bi·as
cause to feel or show inclination or prejudice for or against someone

NO PAIN
NO GAIN


PAIN IS
WEAKNESS
LEAVING THE BODY.


THE PAIN
you feel today will be
THE STRENGTH
you feel tomorrow.

MIND
OVER
Matter

It’s now become somewhat acceptable to have pain …

but not to be **WEAK** enough …

to allow yourself to be impacted by it …

HELLO
I AM
what you
label me

Insufficient workforce

No team-based medical home

Myriad of heterogenous pain disorders/subtypes

Symptom-based classification

Lack of scientific understanding

Lack of objective measures, markers, diagnostics

cha·os

a state of utter confusion
a total lack of organization or order

cri·sis

an unstable or crucial time in which
a decisive change is impending

cri·sis

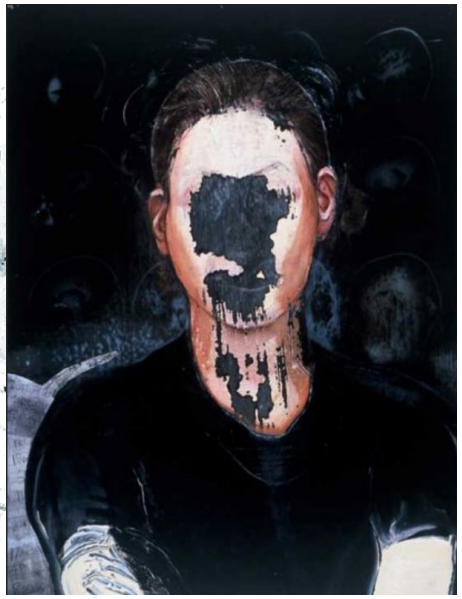
a dramatic emotional or circumstantial upheaval in a person's life

100 million

$600 billion

#1 Cause Disability

Deaths



Susan:
"To live in pain is to live in isolation."

www.PainExhibit.org

Explosion of Therapies

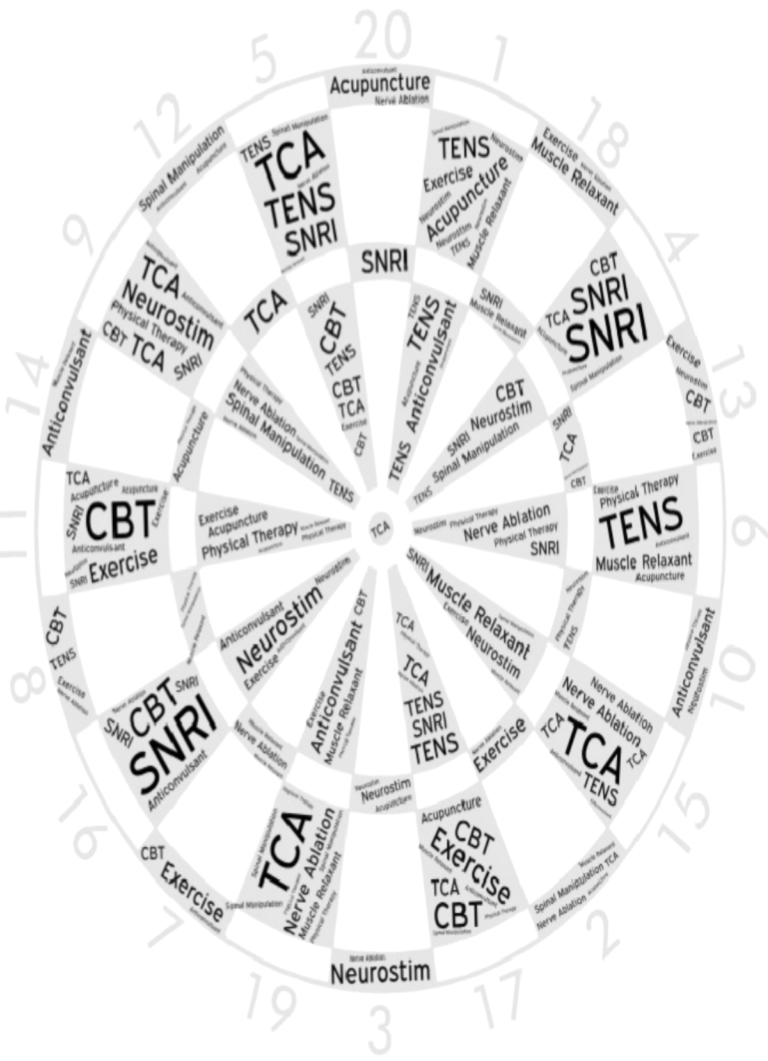
But … what works for whom? At what risk? At what cost?

"Unfortunately, the field of chronic pain treatment is strikingly deficient in high-quality scientific evidence."

Former FDA Commissioner Dr. Robert Califf
NEJM 2016;374:1480-5

Current Treatment of Chronic Pain: "Blindfolded Darts"

May be Good for Team-Building … but not so much for Personalized Medicine



"Without data, we are just docs with opinions."

What does pain research mean to patients?

Finally
Life
Help
Cure
Impatience
Improvement
Crucial
Wishful
Better
Finally
Elated
Cure
Promising
Grateful
Future
Important
Fantastic
Optimistic
Painfree
Believe
Crucial
Elated
Compassion
Future
Wonderful
Grateful
Good
Relief
Happy
Wishful
Needed
Awesome
Help
Encouraged
Relief
Awesome
Needed
Good
Help
Optimistic
Promising
Thankful
Happy
Wonderful
Possibility
Help
Cure
Fantastic
Finally
Confident
Excited
Life
Relief
Freedom
Important
Improvement
Life
Excited
Imperative
Elated
Encouraged

"Some people cannot be cured, but everyone can HEAL."
~Unknown

Patient Hopes for Pain Research

1. Objective measures, markers, predictors

2. Dynamic outcome measures that account for chronic pain complexity

- How to define "improvement?"
- Does VAS measure what we think? Does it really matter?
- Develop well-rounded measures that incorporate function, QOL, sleep, mood, etc.

3. Animal/human models that account for chronic pain complexity

- Multi-system illness - neurological, endocrine & immune systems
- Bidirectional impact of fatigue, mood, sleep, etc. on pain
- Bidirectional impact of other chronic diseases on pain

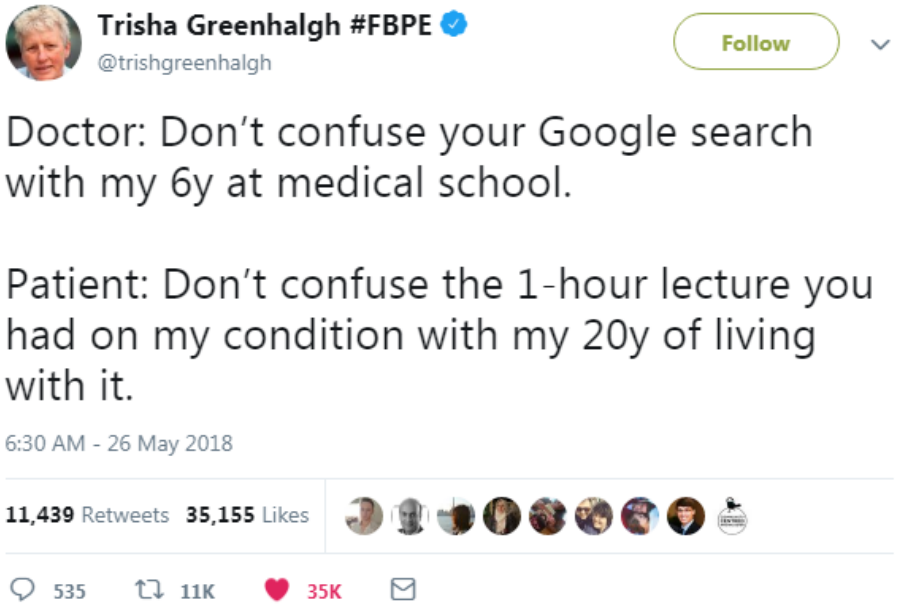
4. Trials that account for complexity & individuality of pain experience

- What is going to work for me – PMI?
- Impact of pain & non-pain comorbid conditions
- Effect of treatment combinations (Rx & NonRx)
- Function, QOL & individualized goal setting

5. Reverse Translation & Broad Inclusion

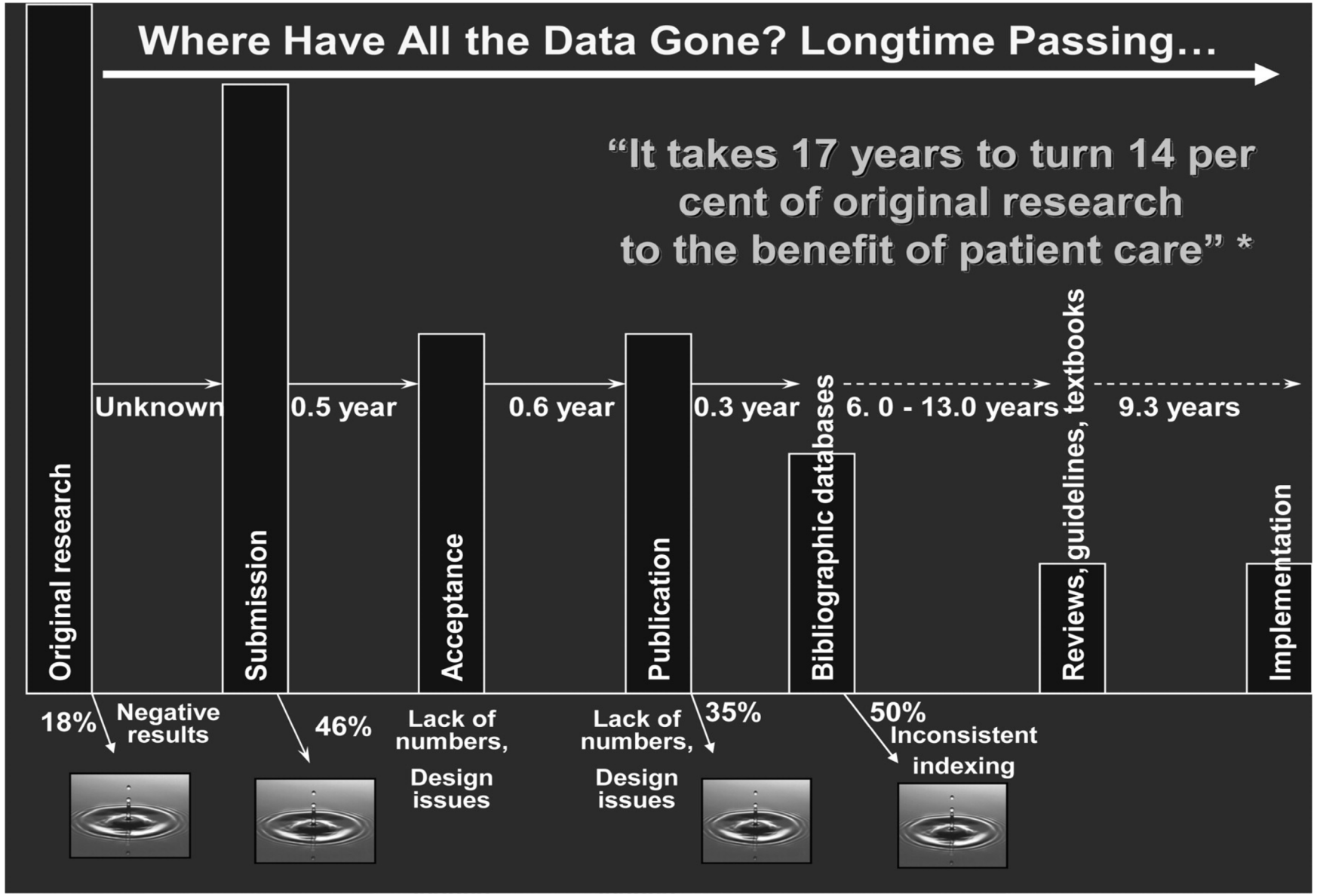
- Listen to and learn from patients
- Include patients (and other stakeholders) early and often

Mutual Value & Respect



Slide Courtesy of: Dr. Christine Chambers @drcchambers

Knowledge Translation



Balas EA, Boren SA. Yearbook of Medical Informatics 2000: Patient-centered Systems. 2000: 65–70.
Green L. Fam Pract. 2008;25(suppl_1):i20-i24.

Include All Stakeholders & Implementation Science Plans Early and Often

Bridge the Translational Divide

Ensure Successful Implementation

Reduce the Knowledge Translation Gap

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Research Alliance

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