

Dwelling characteristics

Education

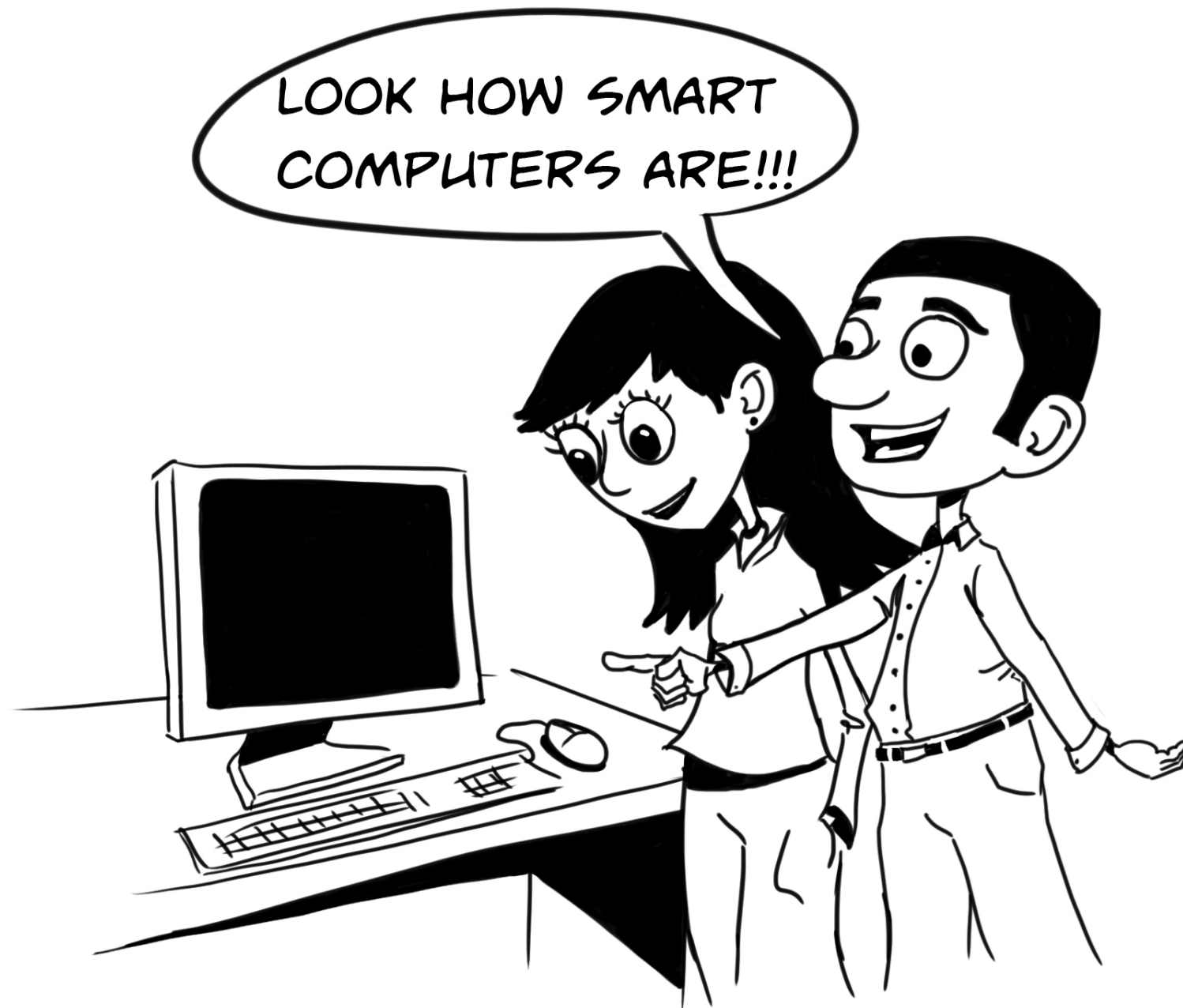
Employment

Income

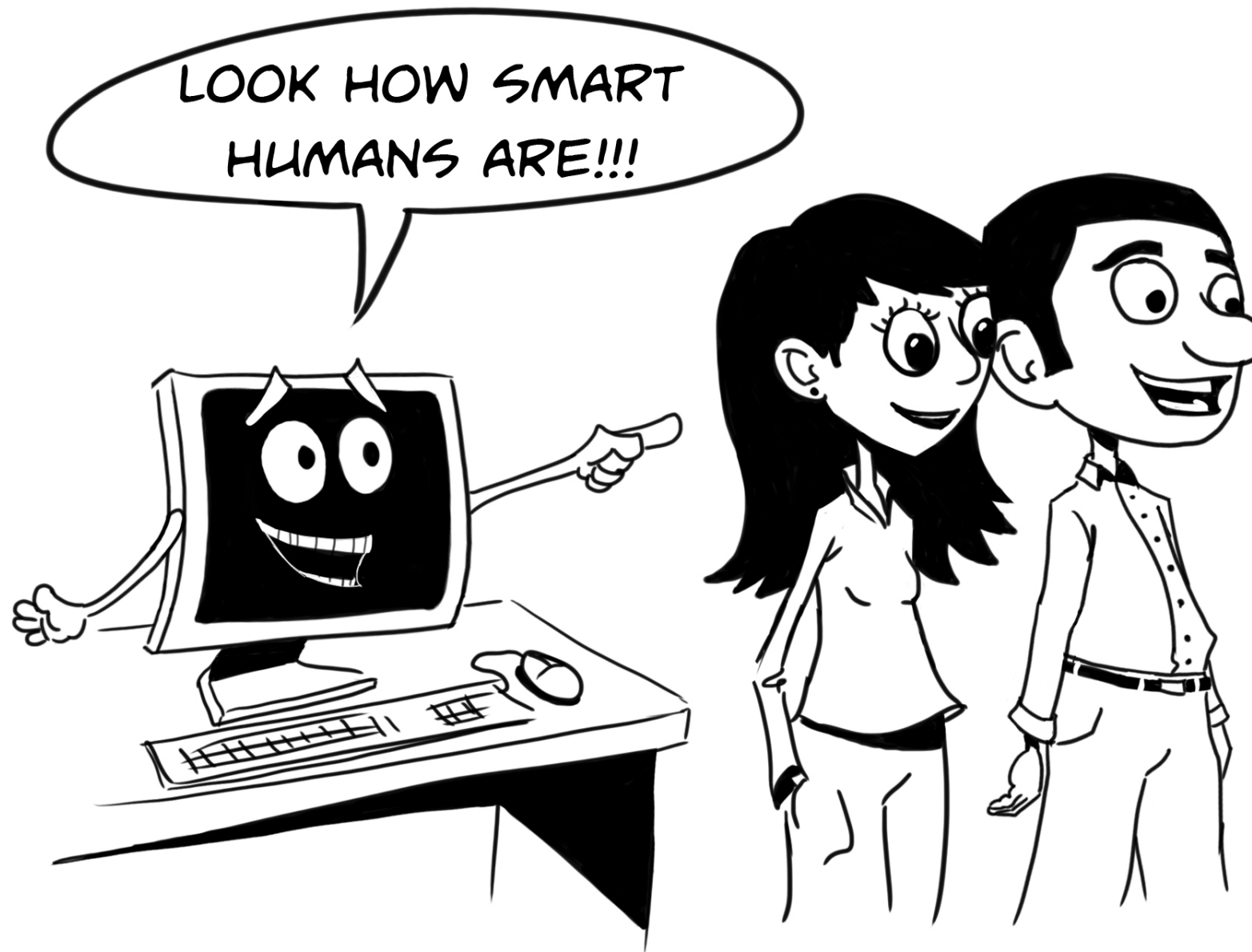
Social Characteristics

Socioeconomic Status

Anthropomorphism



Pragmamorphism (thanks to Emmanuel Derman)



3. We should move away from pragmatism

Function (Activity Limitation) - CHAQ

- CHAQ based on the adult Stanford HAQ
- For childhood arthritis ➡ most widely used patient-reported measure
- Valid, reliable, and responsive in childhood arthritis
- Parents can report for children

CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

In this section, we are interested in learning how your child's illness affects his/her ability to function in daily life. Please feel free to add any comments on the back of this page. In the following questions, please check the one response which best describes your child's usual activities (averaged over an entire day) **OVER THE PAST WEEK**. ONLY NOTE THOSE DIFFICULTIES OR LIMITATIONS WHICH ARE DUE TO ILLNESS. If most children at your child's age are not expected to do a certain activity, please mark it as "Not Applicable". For example, if your child has difficulty in doing a certain activity or is unable to do it because he/she is too young but NOT because he/she is RESTRICTED BY ILLNESS, please mark it as "Not Applicable".

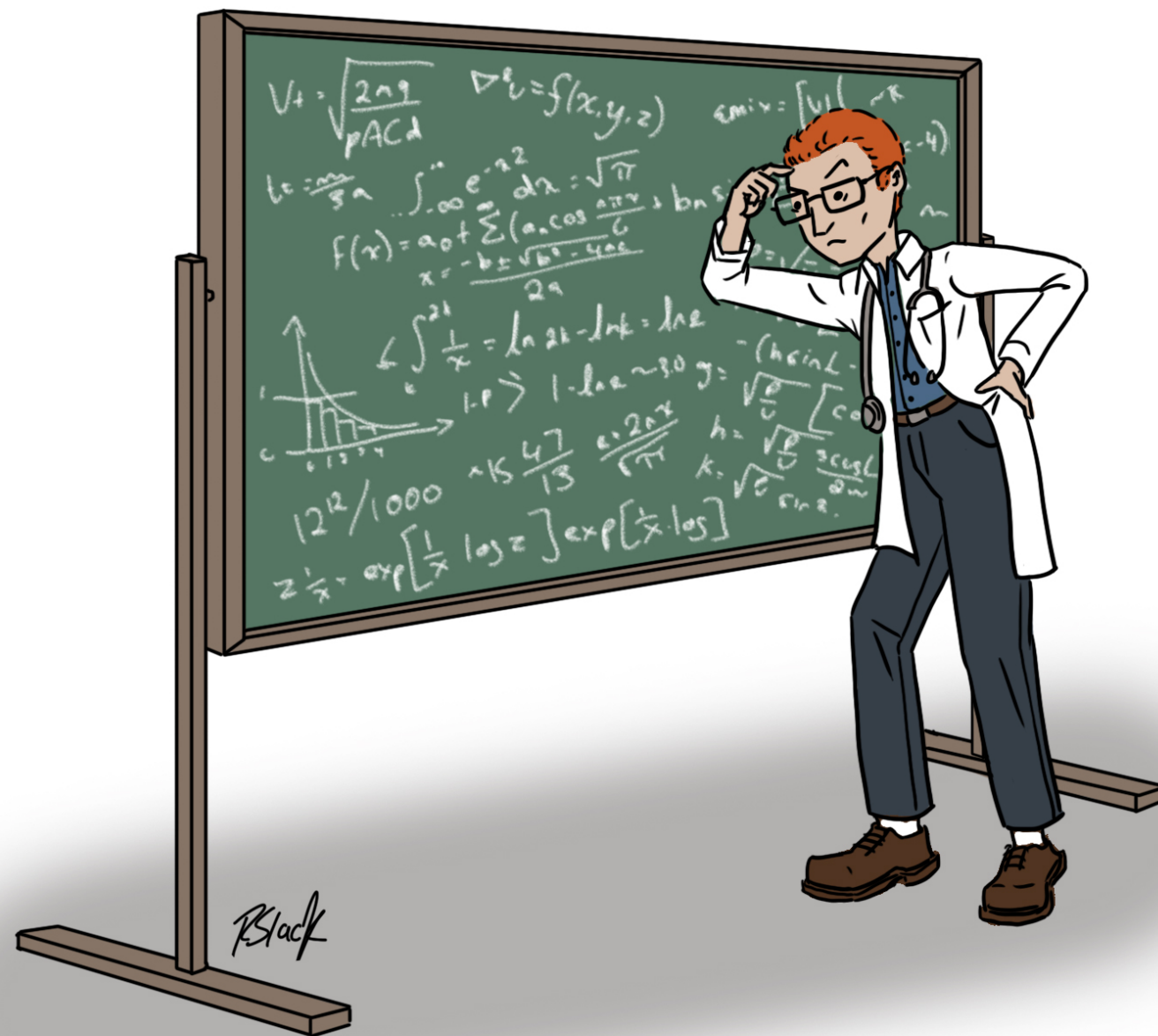
| | Without ANY Difficulty | With SOME Difficulty | With MUCH Difficulty | UNABLE To Do | Not Applicable |
|---|--|-------------------------|-------------------------|-----------------|-------------------|
| DRESSING & GROOMING | | | | | |
| Is your child able to: | | | | | |
| -Dress, including tying shoelaces and doing buttons? | _____ | _____ | _____ | _____ | _____ |
| -Shampoo his/her hair? | _____ | _____ | _____ | _____ | _____ |
| -Remove socks? | _____ | _____ | _____ | _____ | _____ |
| -Cut fingernails? | _____ | _____ | _____ | _____ | _____ |
| ARISING | | | | | |
| Is your child able to: | | | | | |
| -Stand up from a low chair or floor? | _____ | _____ | _____ | _____ | _____ |
| -Get in and out of bed or stand up in crib? | _____ | _____ | _____ | _____ | _____ |
| EATING | | | | | |
| Is your child able to: | | | | | |
| -Cut his/her own meat? | _____ | _____ | _____ | _____ | _____ |
| -Lift a cup or glass to mouth? | _____ | _____ | _____ | _____ | _____ |
| -Open a new cereal box? | _____ | _____ | _____ | _____ | _____ |
| WALKING | | | | | |
| Is your child able to: | | | | | |
| -Walk outdoors on flat ground? | _____ | _____ | _____ | _____ | _____ |
| -Climb up five steps? | _____ | _____ | _____ | _____ | _____ |
| * Please check any AIDS or DEVICES that your child usually uses for any of the above activities: | | | | | |
| ____ Cane | ____ Devices used for dressing (button hook, zipper pull, long-handled shoe horn, etc) | | | | |
| ____ Walker | ____ Built Up pencil or special utensils | | | | |
| ____ Crutches | ____ Special or Built Up chair | | | | |
| ____ Wheelchair | ____ Other (Specify: _____) | | | | |
| * Please check any categories for which your child usually needs help from another person BECAUSE OF ILLNESS: | | | | | |
| ____ Dressing and Grooming | | | | | ____ Eating |
| ____ Arising | | | | | ____ Walking |

The CHAQ is an "additive, ordinal" scale

What does this equal...?

Some + A lot + Some + None + Unable + Some = ?

We're physicians, not mathematicians



Weird scoring for ordinal scales

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| | Without ANY Difficulty | With SOME Difficulty | With MUCH Difficulty | UNABLE To Do | Not Applicable |
|--|---------------------------|-------------------------|-------------------------|-----------------|-------------------|
| DRESSING & GROOMING | | | | | |
| Is your child able to: | | | | | |
| -Dress, including tying shoelaces and doing buttons? | _____ | _____ | _____ | _____ | _____ |
| -Shampoo his/her hair? | _____ | _____ | _____ | _____ | _____ |
| -Remove socks? | _____ | _____ | _____ | _____ | _____ |
| -Cut fingernails? | _____ | _____ | _____ | _____ | _____ |
| ARISING | | | | | |
| Is your child able to: | | | | | |
| -Stand up from a low chair or floor? | _____ | _____ | _____ | _____ | _____ |
| -Get in and out of bed or stand up in crib? | _____ | _____ | _____ | _____ | _____ |
| EATING | | | | | |
| Is your child able to: | | | | | |
| -Cut his/her own meat? | _____ | _____ | _____ | _____ | _____ |
| -Lift a cup or glass to mouth? | _____ | _____ | _____ | _____ | _____ |
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| -Climb up five steps? | _____ | _____ | _____ | _____ | _____ |

* Please check any AIDS or DEVICES that your child usually uses for any of the above activities:

Cane Devices used for dressing (button hook, zipper pull, long-handled shoe horn, etc)
 Walker Built Up pencil or special utensils
 Crutches Special or Built Up chair
 Wheelchair Other (Specify: _____)

* Please check any categories for which your child usually needs help from another person BECAUSE OF ILLNESS:

Dressing and Grooming Eating
 Arising Walking

UNABLE to walk



SOME difficulty in cutting fingernails, opening a cereal box & writing

The CHAQ is really 30 separate ordinal (categorical) scales

$$4^{30} = 1.152 \times 10^{18}$$

unique possible answers

Each with a different value?

Rasch models / IRT

Multi-attribute utility theory

The Hemophilia Joint Health Score (selected items)

| HJHS Item | Item Level | Current HJHS Score |
|--|---|--------------------|
| Swelling | Severe - very swollen, no bony landmarks are visible | 3 |
| | Moderate - swollen, bony landmarks obscured to some degree | 2 |
| | Mild - swelling looks slightly "puffy", all bony landmarks are visible | 1 |
| | No swelling | 0 |
| Strength | Holds test position with minimal resistance | 2 |
| | Holds test position against gravity with moderate resistance | 1 |
| | Holds test position against gravity with maximum resistance | 0 |
| Joint Pain | Pain through active range | 2 |
| | No pain through active range; only pain on gentle overpressure or palpation | 1 |
| | No pain through active range of motion | 0 |
| Flexion Loss (Normal - Contralateral side) | Loss of > 20° | 3 |
| | Loss of 11° - 20° | 2 |
| | Loss of 5 - 10° | 1 |
| | Loss of < 5° | 0 |
| Extension Loss (Normal - Contralateral side) | Loss of > 20° | 3 |

The Hemophilia Joint Health Score (selected items)

| HJHS Item | Item Level | Current HJHS Score |
|--|---|--------------------|
| Swelling | Severe - very swollen, no bony landmarks are visible | 3 |
| | Moderate - swollen, bony landmarks obscured to some degree | 2 |
| | Mild - swelling looks slightly "puffy", all bony landmarks are visible | 1 |
| | No swelling | 0 |
| Strength | Holds test position with minimal resistance | 2 |
| | Holds test position against gravity with moderate resistance | 1 |
| | Holds test position against gravity with maximum resistance | 0 |
| Joint Pain | Pain through active range | 2 |
| | No pain through active range; only pain on gentle overpressure or palpation | 1 |
| | No pain through active range of motion | 0 |
| Flexion Loss (Normal - Contralateral side) | Loss of > 20° | 3 |
| | Loss of 11° - 20° | 2 |
| | Loss of 5 - 10° | 1 |
| | Loss of < 5° | 0 |
| Extension Loss (Normal - Contralateral side) | Loss of > 20° | 3 |

Developing a new scoring scheme for the Hemophilia Joint Health Score 2.1

Tiago Ribeiro MD candidate¹ | Audrey Abad BSc² | Brian M. Feldman MD, MSc, FRCPC^{3,4}

Question # 5

Which of these two scenarios represent a healthier joint?
(all else being equal)

Swelling
No swelling

Extension Loss (Normal - Contralateral side)
Loss of 5 - 10°

this one

this combination is impossible

Swelling
Moderate - swollen, bony landmarks obscured to some degree

Extension Loss (Normal - Contralateral side)
Loss of < 5°

this one

this combination is impossible

OR

they are equal

« undo last choice

skip this question for now »

1% complete

TABLE 3 Normalized HJHS item weights and item level scores (means)

| HJHS item | Item weight (sum to 1) | Item levels | Item-level score (0-100) |
|--|------------------------|--|--------------------------|
| Swelling | 0.121 | Severe—very swollen, no bony landmarks are visible | 0 |
| | | Moderate—swollen, bony landmarks obscured to some degree | 36.8 |
| | | Mild—swelling looks slightly “puffy”; all bony landmarks are visible | 65 |
| | | No swelling | 100 |
| Duration of swelling | 0.057 | ≥6 months | 0 |
| | | No swelling or <6 months | 100 |
| Muscle atrophy | 0.08 | Severe—flattening of muscle belly is noted | 0 |
| | | Mild—mild flattening of muscle belly is noted | 60.5 |
| | | None | 100 |
| Crepitus of motion | 0.109 | Severe—audible and/or palpable grinding and crunching during joint motion | 0 |
| | | Mild—slightly audible and/or palpable grinding and crunching during joint motion | 59.9 |
| | | None | 100 |
| Strength | 0.13 | Trace or no muscle contraction | 0 |
| | | Able to partially complete range of motion against gravity | 36.2 |
| | | Holds test position with minimal resistance | 60.5 |
| | | Holds test position against gravity with moderate resistance | 79.3 |
| | | Holds test position against gravity with maximum resistance | 100 |
| Joint pain | 0.11 | Pain through active range | 0 |
| | | No pain through active range; pain only on gentle overpressure or palpation | 68.7 |
| | | No pain through active range of motion | 100 |
| Global gait (walking, stairs, running, hopping on 1 leg) | 0.138 | No skills are within normal limits | 0 |
| | | 3 skills are not within normal limits | 26.6 |
| | | 2 skills are not within normal limits | 50.6 |
| | | 1 skill is not within normal limits | 73.3 |
| | | All skills are within normal limits | 100 |
| Flexion loss (normal-contralateral side) | 0.115 | Loss of >20° | 0 |
| | | Loss of 11°-20° | 35.2 |
| | | Loss of 5°-10° | 71.4 |
| | | Loss of <5° | 100 |
| Extension loss (normal-contralateral side) | 0.139 | Loss of >20° | 0 |
| | | Loss of 11°-20° | 38.3 |
| | | Loss of 5°-10° | 72 |
| | | Loss of <5° | 100 |
| Total | 1.00 | | |

Note: Item weights indicate how important each item is relative to other items when identifying a healthy joint (N = 41). Attributes for each item level are ranked highest (eg, healthiest) to lowest.

| HJHS Item | Item weight (sum to 1) | Item Level | Single Level (0-100) | Current HJHS Score |
|------------------|-------------------------------|---|-----------------------------|---------------------------|
| | | Severe - flattening of muscle belly is noted | 0 | 2 |
| Muscle Atrophy | 0.08 | Mild - mild flattening of muscle belly is noted | 60.5 | 1 |
| | | None | 100 | 0 |

The weighted scale has much better properties

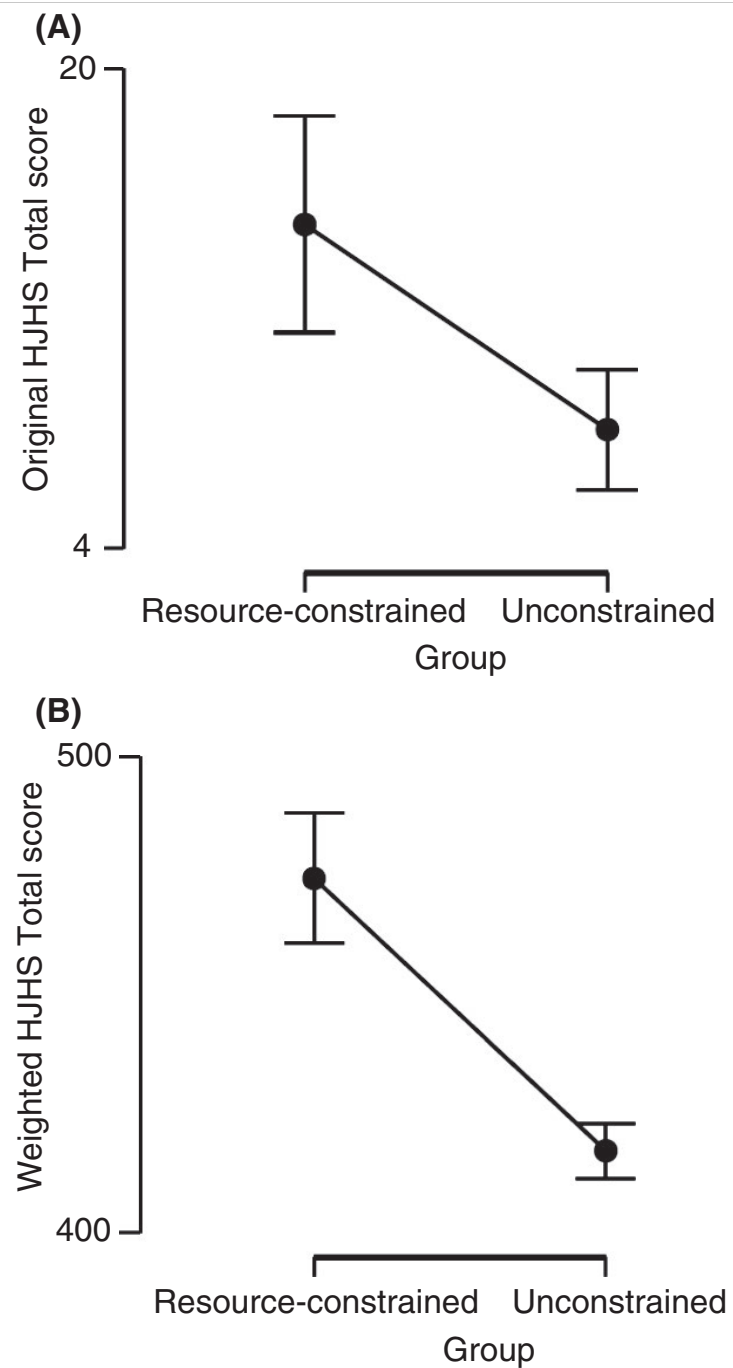
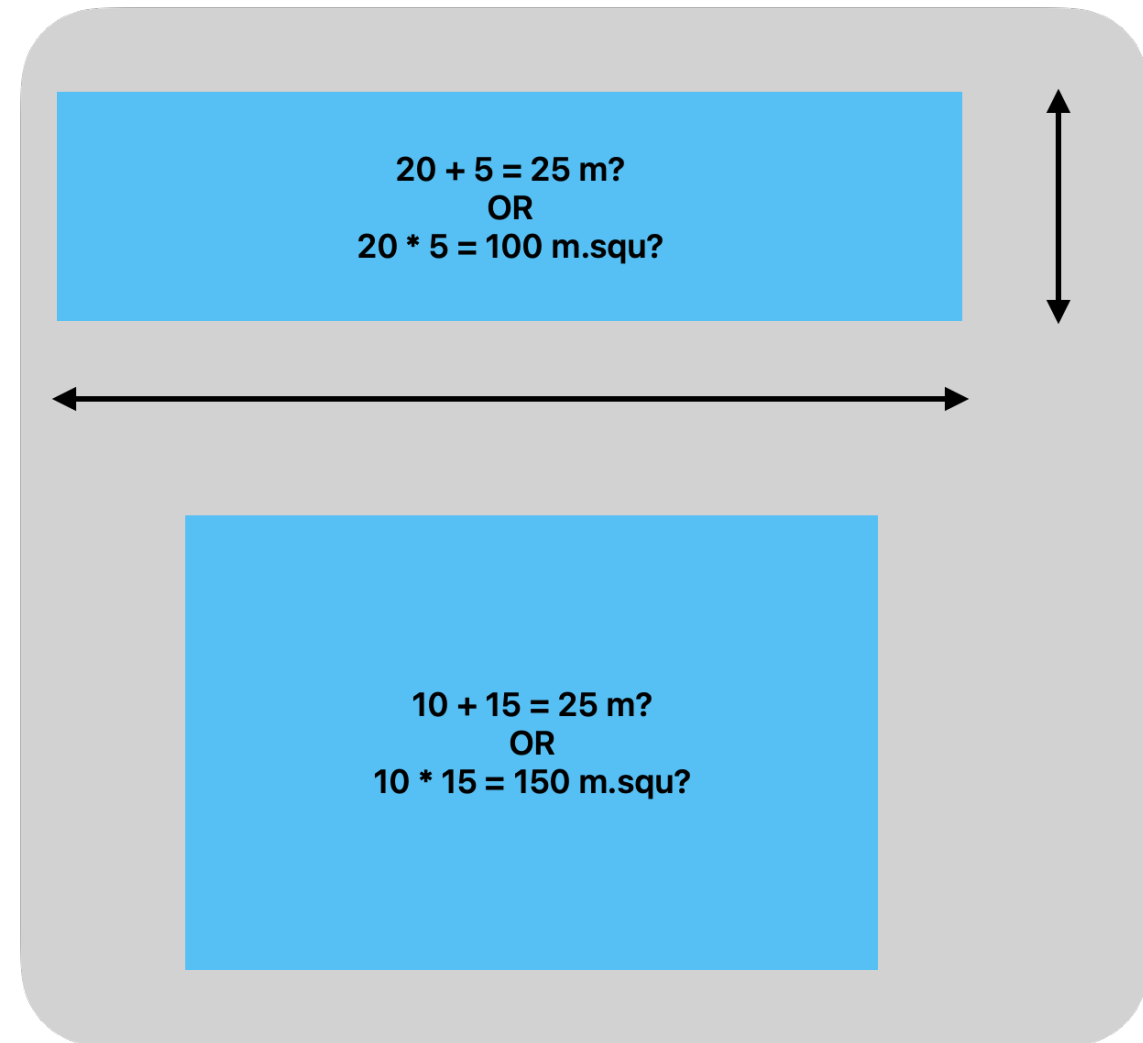
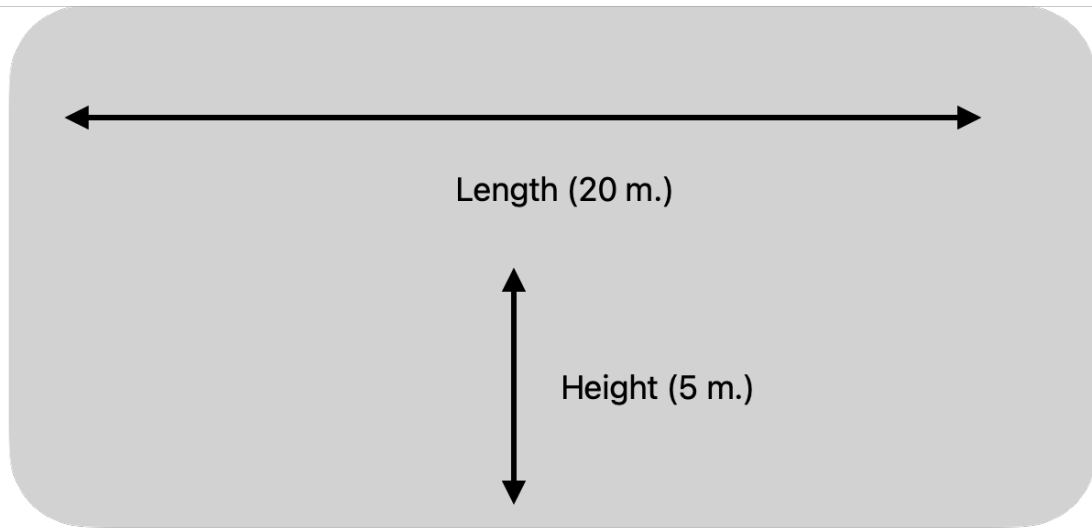


FIGURE 2 This figure illustrates the difference between (A) original HJHS total scores and (B) weighted HJHS total scores

relative efficiency = 5.4

4. We must scale measures better

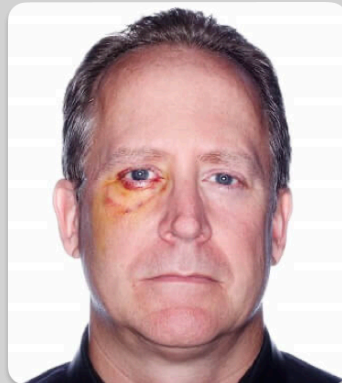
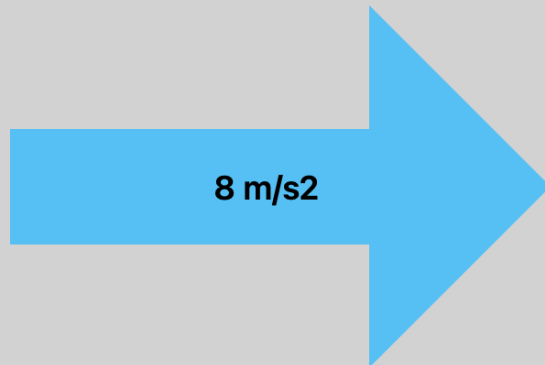
Many of our health concepts are "multi-dimensional"



Newton's second law of motion



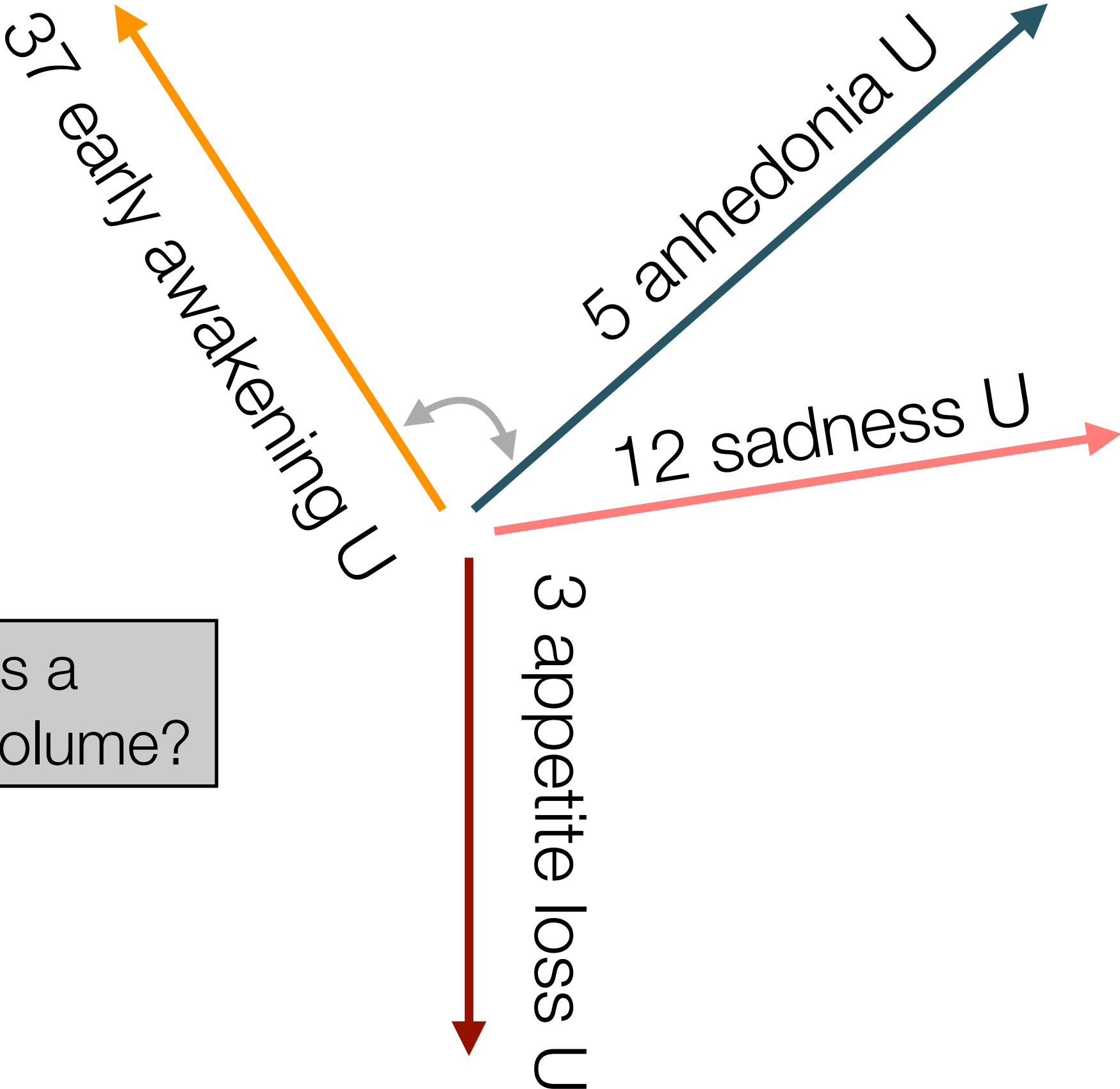
2 kg



Force = 10? ❌

Force = 16 Newtons ✅

Depression as a hypergeometric volume?



5. We must treat multi-dimensionality more carefully

International Myositis Assessment and Clinical Studies Group core set

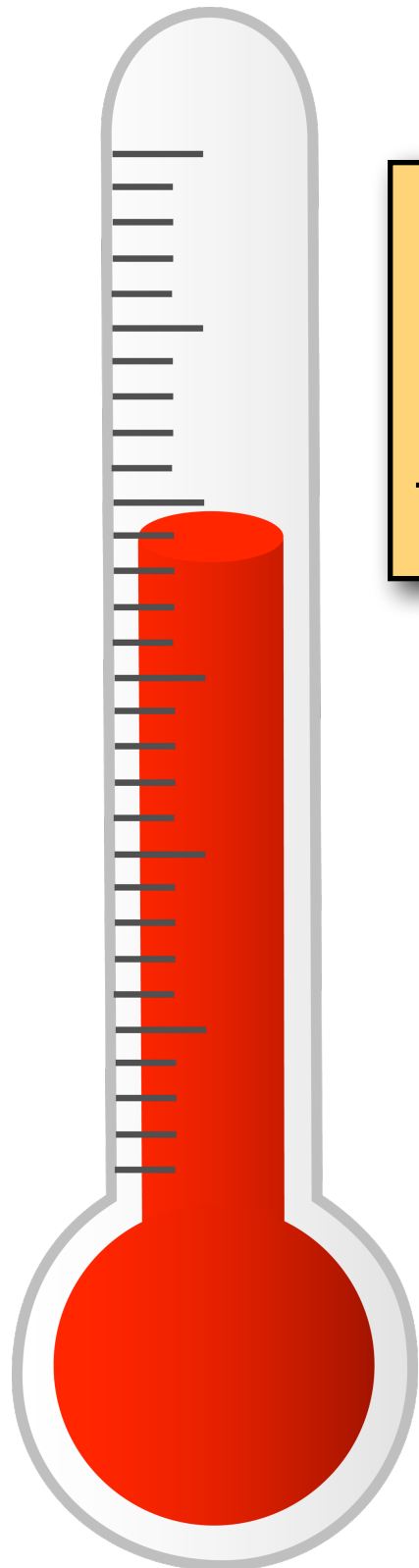
- Physician Global Assessment of Disease Activity (VAS/Likert)
- Patient / Parent Global Assessment of Activity (VAS/Likert)
- Manual Muscle Strength Testing
- Functional Assessment Tool (e.g. CHAQ)
- Muscle Enzymes
- Extra-muscular Assessment (Myositis Disease Activity Assessment Tool)

IMACS definition of improvement

- 3 of any 6 core set measures
 - improved by 20% or more
- No more than 2 worse by 25% or more
- Cannot get worse with MMT

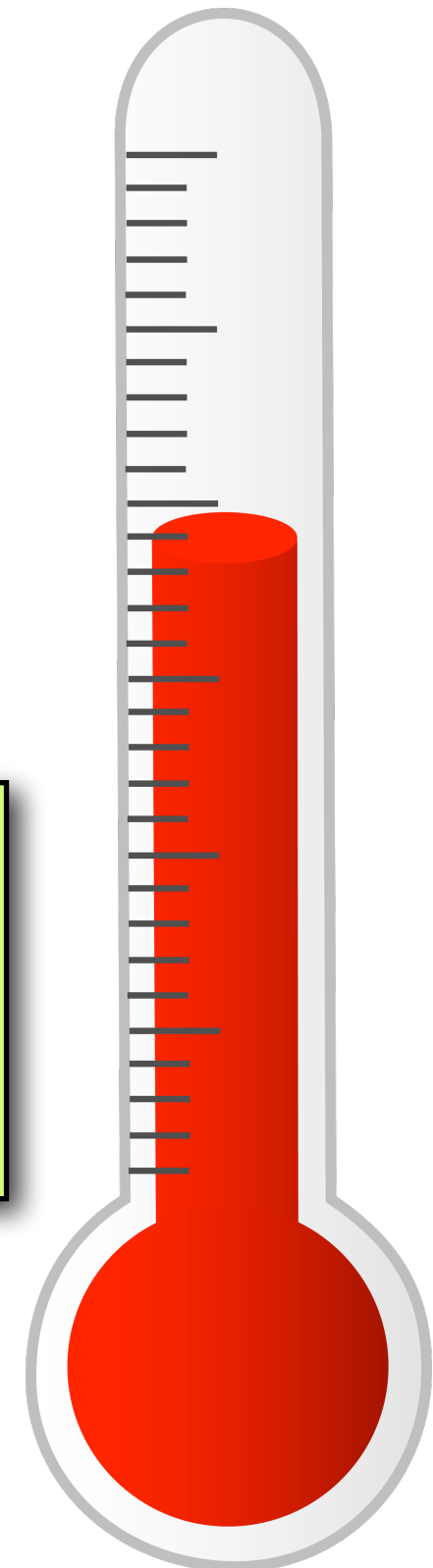
| Sensitivity | Specificity | PPV | NPV |
|-------------|-------------|------|------|
| 0.83 | 0.98 | 0.87 | 0.82 |

Percent (relative) change (for non-ratio measures)



10C — 20C
100% increase

50°F — 68°F
36% increase



SPECIAL ARTICLE

2016 American College of Rheumatology/European League Against Rheumatism Criteria for Minimal, Moderate, and Major Clinical Response in Juvenile Dermatomyositis

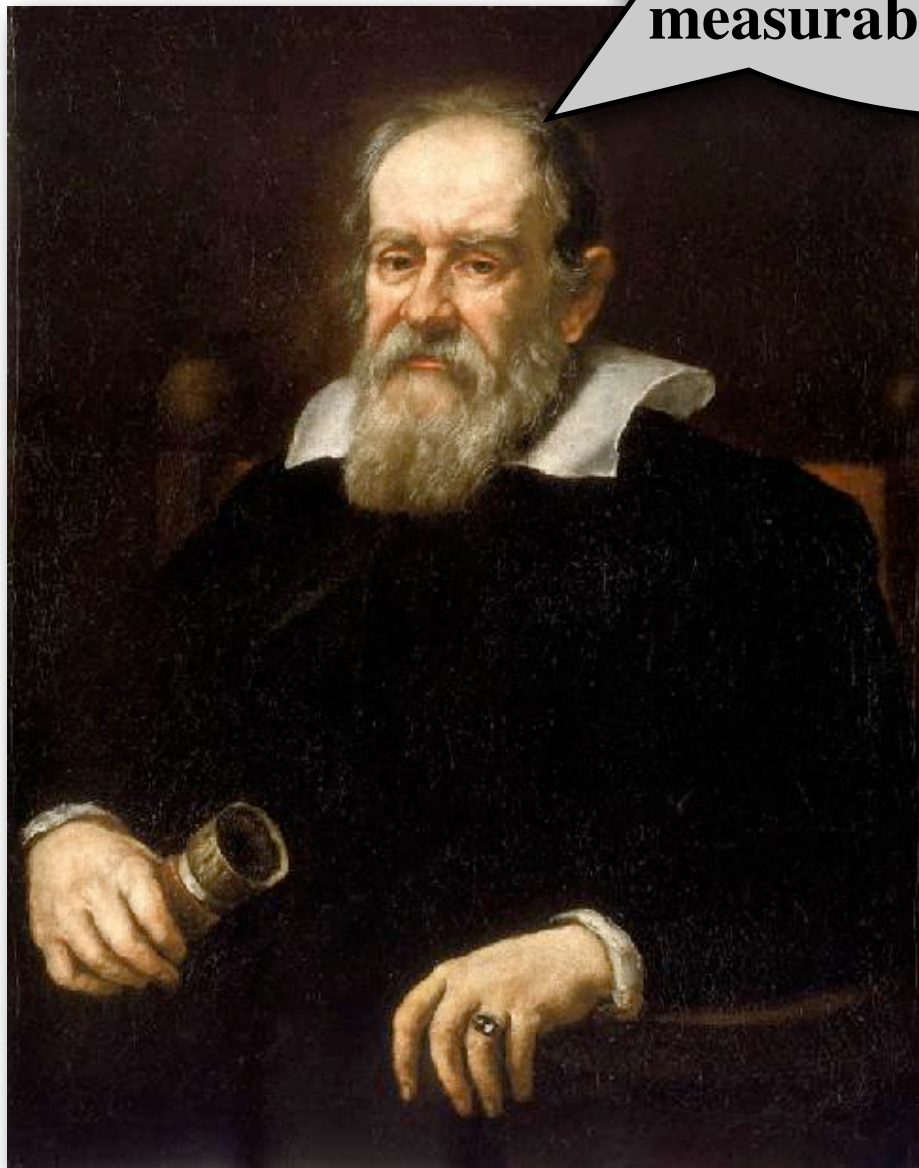
An International Myositis Assessment and Clinical Studies Group/Paediatric
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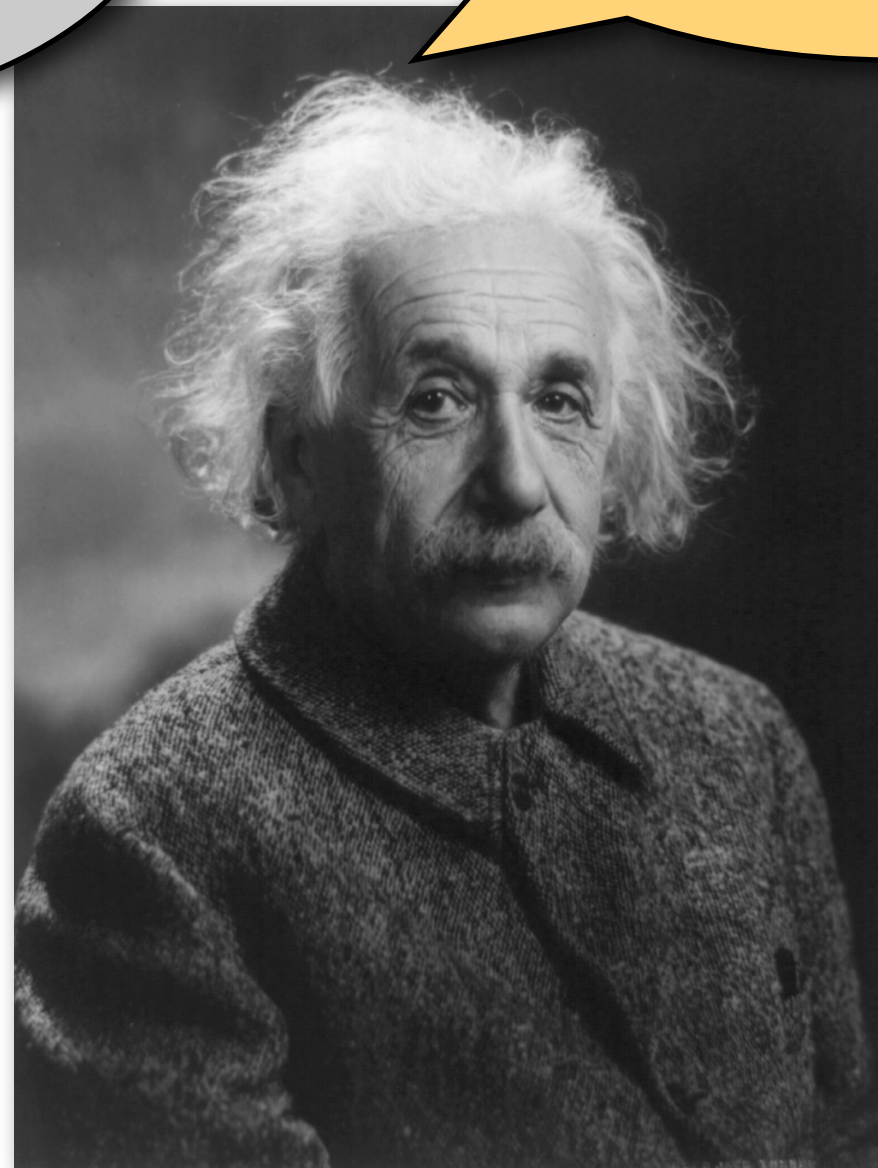
6. We need to learn how to value change better

You can't manage what you don't measure

Count what is countable, measure what is measurable. What is not measurable, make measurable.



Not everything that can be counted counts, and not everything that counts can be counted.



1. You can't manage what you don't measure
2. Measurement tools must give us the truth
3. We should move away from pragmatism
4. We must scale our measures better
5. We must treat multi-dimensionality more carefully
6. We need to learn how to value change better

