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# LESSONS LEARNED FROM MEASURING WHAT MATTERS

# Why Measure?

- Discriminate (screening measures)
- Evaluate
- Predict

*Kirshner B, Guyatt GH. A methodologic framework for assessing health indices. J Chronic Dis. 1985; 38:27-36.*

- Understand and to fix (*Lord Kelvin*)
- (Can't understand what you cannot measure, and you cannot fix what you cannot understand)

# What matters?

## Kerr White and the 5 D's

- Death
- Disease
- Discomfort
- Disability
- Dissatisfaction
- (Destitution)

*White KL. Discussion of An Historical View of Teaching of Medical Care Administration. American Journal of Public Health and the Nations Health 1969; 59(Suppl 1):61-66.*



# What matters?

# To whom?

## Outcomes


- Mortality
- Morbidity
- Disability
- Satisfaction
- Cost
- QOL

## Stakeholders

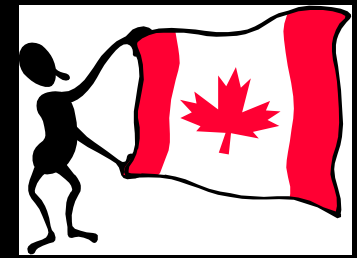
- Patient / person / client
- Clinician
- Family
- Society



# What's Canada got to do with this?

- Long history of measurement
  - Strong roots in measures for rehabilitation
  - Disease-specific measures primarily
  - Single public payer for health care may be impetus for evaluating outcomes
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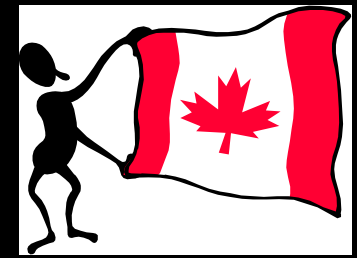
# Canadian eh!



- McGill Pain Scale (1971)
- Spitzer index (1981)
- Self rated health (1982)
- WOMAC (1982)
- 6MWT (1985)
- RNL (1987)
- Chronic Respiratory Disease Questionnaire-CRQ (1987)
- SMAF (1988)
- Berg Balance Scale (1989)
- IBDQ (1989)



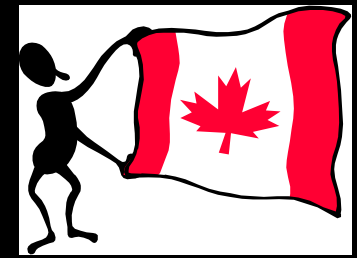
# Canadian eh!



- COPM (1991)
- GAS (1968/1992)
- TEMPA (1993)
- CMSA (1994)
- Fatigue Impact Scale (1994)
- Disability Assessment in Dementia (1994)
- Pain Catastrophizing Scale (1995)
- Activities Balance Confidence (ABC) (1995)
- HUI (1996)
- Toronto Extremity Salvage Score (TESS) (1996)
- DASH (1996)
- Quebec Back Pain Disability Scale (1996)
- MHAVIE (1996)
- McGill QOL (1997)
- STREAM (1999)
- LEFS (1999)




# Canadian eh!



- LIFE-H (2002)
- MQE (2002)
- PBSI (2003)
- MOCA (2005)
- Early Physical Function Post-Stroke (EPF-3d) (2009)
- Manitoba IBD Index (2009)
- Functional Recovery Stroke (F3m) (2009)
- GDS-Stroke (2010)
- Stroke Arm Ladder (2011)
- PBMSI (2013)
- B-CAM (2013)







# LESSONS LEARNED IN DEVELOPING 37 MEASURES

# New and Old Terminology

- **PRO**
  - *"any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else."*
- **Non-PRO - ClinRO**
  - Physical Performance
    - Directly measured (6MWT, Barthel Index)
    - Self-reported (Barthel Index)
    - Proxy-reported (Barthel Index)
  - Physical exam
    - Clinician assessed (APGAR)
- **Non-PRO - ObsRO**
  - Behaviour

# Measures can contain elements of PRO and Non-PRO

- Source of information on the construct is irrelevant to the measurement of the construct
- Measures of physical function and cognition can easily combine PRO and Non-PRO items and introduce flexibility in measurement
  - Early Physical Function Post-Stroke (EPF-3d)
  - Functional Recovery Stroke (F3m)
  - Stroke Arm Ladder
  - B-CAM

# Response shift: Physical Function

	Construct	RS Potential
<b>Non-PRO</b>		
Performance	Units (m., m/sec, etc.) limitation, need for assistance/supervision)	NO
Self-reported	Limitation	NO
Observer reported	Limitation	NO
<b>PRO</b>	Difficulty	YES

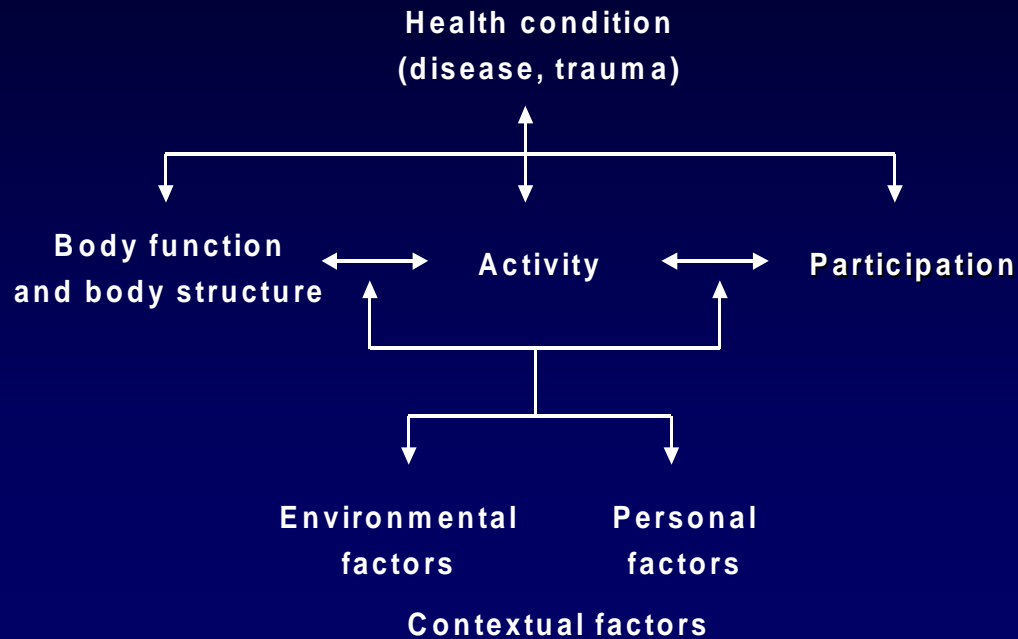


*Barclay-Goddard R, Lix LM, Tate R, Weinberg L, Mayo NE. Health-related quality of life after stroke: does response shift occur in self-perceived physical function? Arch Phys Med Rehabil. 2011 Nov;92(11):1762-9.*



# CANADA EARLY ADOPTER OF WHO INTERNATIONAL CLASSIFICATION OF FUNCTION (ICF)

## The biopsychosocial model of functioning and disability



# ICF

International  
Classification of  
Functioning,  
Disability  
and  
Health



World Health Organization  
Geneva

# Body function / Impairments

- Body functions are physiological functions of body systems, including psychological functions
- Impairments defined in terms of problems with
- PRO level impairments are synonymous with symptoms

# Activity / Activity Limitation

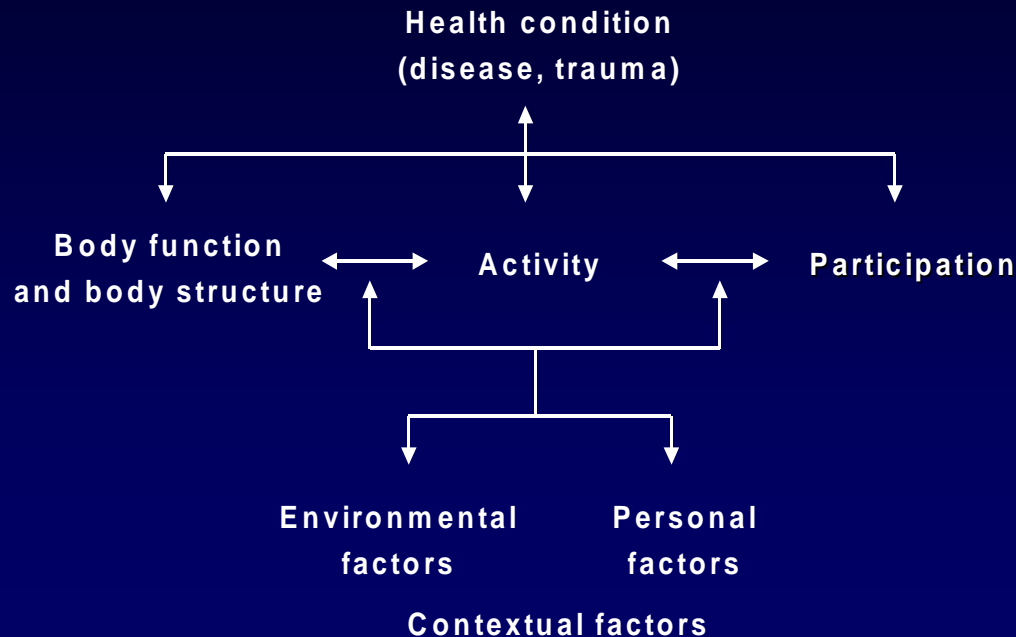
- Activities that are normal for any person
- Limitation is defined in terms of:
  - Capacity (what they can do): ClinRO / ObsRO
    - Includes concept of assistance or supervision
    - PRO: overestimates capacity
  - Performance (what they do do): ClinRO/ObsRO
    - Includes concept of assistance or supervision
    - PRO: overestimates performance
  - Difficulty: PRO
    - Susceptible to response shift
- MEASURE CAN DO, DOES DO, & DIFFICULTY



# Participation / Participation restrictions

- Takes societal point of view on roles
  - interpersonal relationships, major life areas (education, work, and economic life), and community, social and civic life
- Specifics defined by the person
  - Eg. Work is societal perspective but person defines their particular job
- Performance
  - Frequency, duration
  - Satisfaction with
  - Productivity (work)

## The biopsychosocial model of functioning and disability



ICF

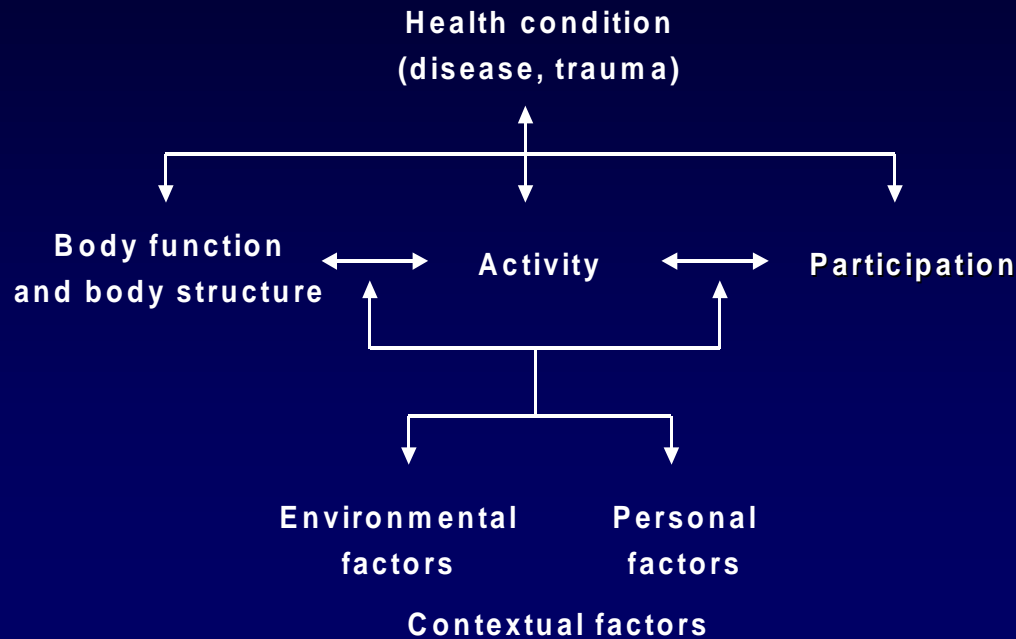
International  
Classification of  
Functioning,  
Disability  
and  
Health



World Health Organization  
Geneva

ICF provides an international common language and universal conceptual framework for describing functioning, disability and health

## The biopsychosocial model of functioning and disability



# ICF

International  
Classification of  
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World Health Organization  
Geneva

Indicates WHAT Not HOW to measure



# Lessons Learned

- ICF components need different:
    - Conceptual approaches (models)
    - Therefore different types of measures
  - Impairments – Symptoms
    - Frequency, Duration, Intensity, Impact
    - First 3 may be formative
    - Impact may be reflective/may be formative
  - Do not easily go together in one measure
- 



# Lessons Learned

## Activity

- Likely reflective – true latent – model
- Fix the construct, the items will change
- Hierarchical by definition
- People move up and down the “ladder”
- Suitable for Rasch/IRT approaches to creating total scores

## Participation

- Likely formative – composite measure
- Items form the construct
- A count of the number of family and societal roles the person takes on is a good representation of participation
- Not suitable for Rasch/IRT

Not everything can be added up



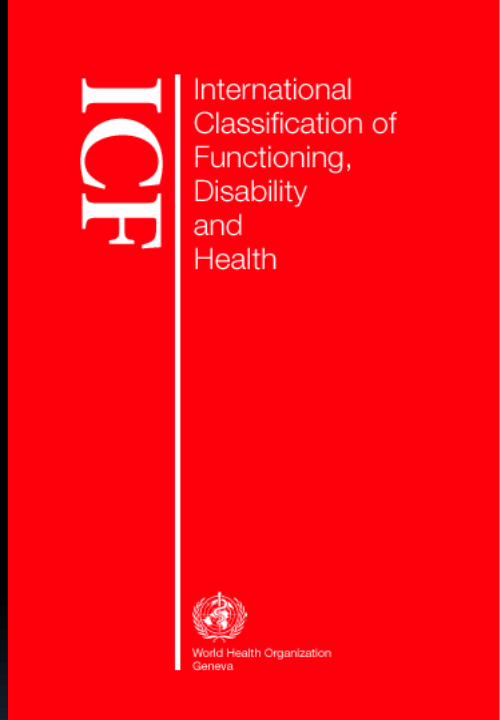
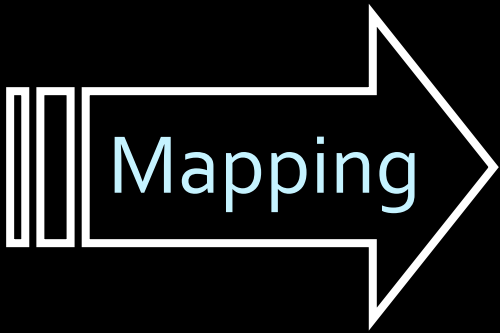
# ICF ~ Content Validity

WESTERN ONTARIO AND  
MCMASTER UNIVERSITIES  
Osteoarthritic Index  
(W)

Nottingham Health Profile

SF-36

*Health  
Status  
Measures*







# What matters - To whom

Patient	Clinician	Family
<b>Morbidity</b>		
Presence and severity of diseases		
<b>Impairments</b>		
Symptoms (what, frequency, duration, intensity, impact)	Physiological function cells, tissues, organs or markers there of; macro and micro structure of cells, tissues, organs	Behaviour (what, frequency, duration, bother, impact on family/caregivers)

# What matters - To whom

Patient	Clinician	Family
<b>Activity Limitations (mobility, self-care)</b>		
Satisfaction with Difficulty with Importance of Priority	Capacity to	Capacity to Performance in

# What matters - To whom


Patient	Clinician	Family
<b>Participation restrictions</b>		
What Frequency and duration Satisfaction with Difficulty with Importance of Priority	What Frequency and duration Performance	What Frequency and duration
<b>Health</b>		
Perceived health	Health status	No data (both?)

# What matters - To whom

Patient	Clinician	Family
<b>Quality of Life</b>		
Components Shortfalls Importance Priorities	Global	Symptoms Activity Participation
		<b>Society</b>
Personalized measures	Single Index	QALY
	Standardized Index	



# Summary

- Measurement needs considerable thought
  - If we do not get the measurement correct, the rest will be flawed
    - Understanding and fixing
  - One size may not fit all
    - Personalized measures
  - One measure may not capture all that is relevant
    - Need statistical methods for multiple outcomes
  - Not all things can be added up
  - Different constructs have different conceptual models
    - Formative (symptoms, participation, health status)
    - Reflective (true latents)
- 

One size may not fit all

