



Health, Well-Being and Precision Medicine

健康福祉與精準醫療

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Washington University in St. Louis

SCHOOL OF MEDICINE

HEALTH is ...

WELL-BEING is ...

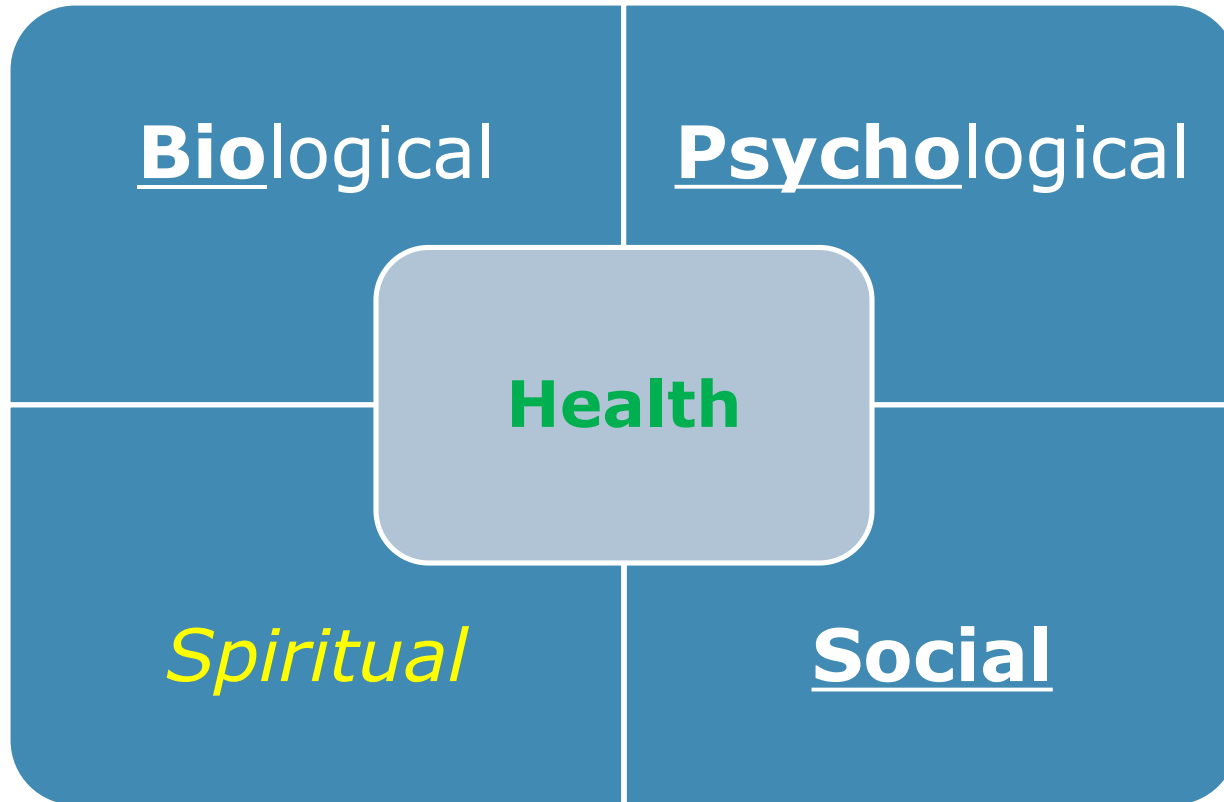
**PRECISION MEDICINE
is ...**

Smarter Health Care

Making *Person-Centered, Data-Driven* Health Care
Better, Faster and Cheaper

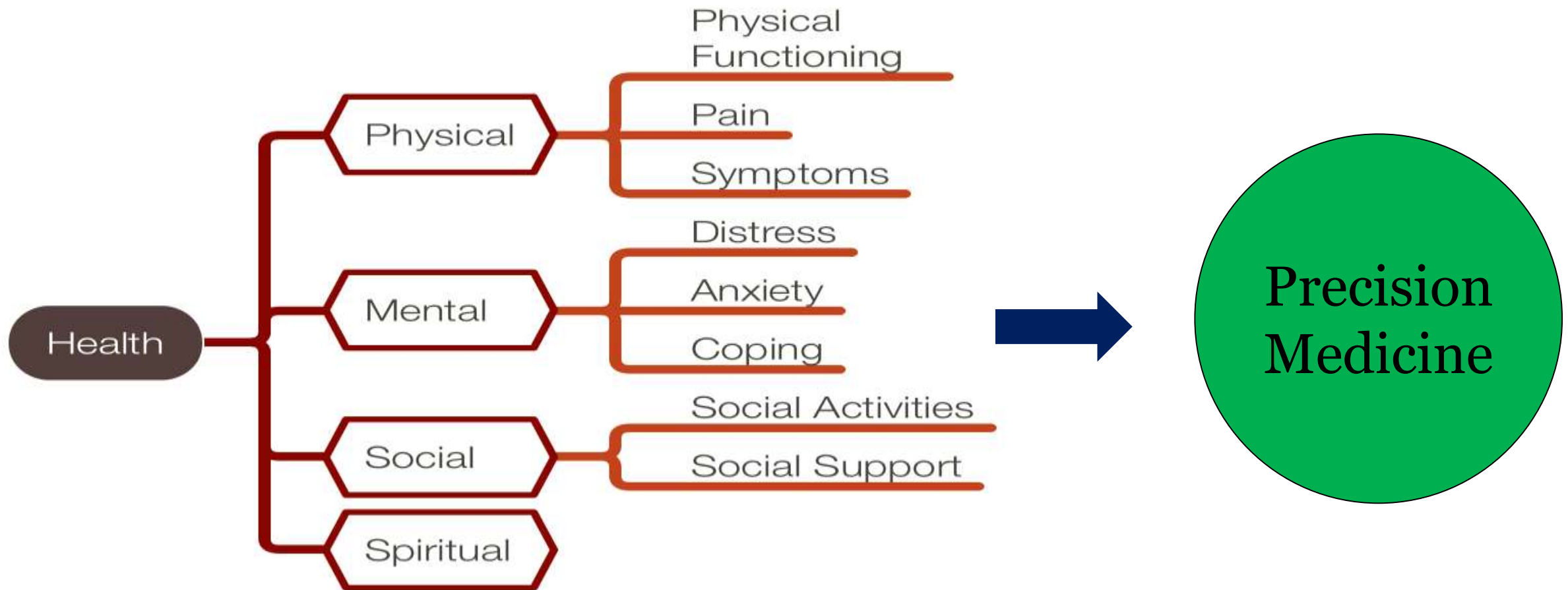


Biopsychosocial Model of Health



- To understand a person's medical condition, three factors need to be considered.
 - Bio (physiological pathology)
 - Psycho (thoughts, emotions and behaviors such as psychological distress, fear/avoidance beliefs, current coping methods and attribution)
 - Social (socio-economical, socio-environmental, and cultural factors such as work issues, family circumstances and benefits/economics)

What is Health Measurement Capturing?

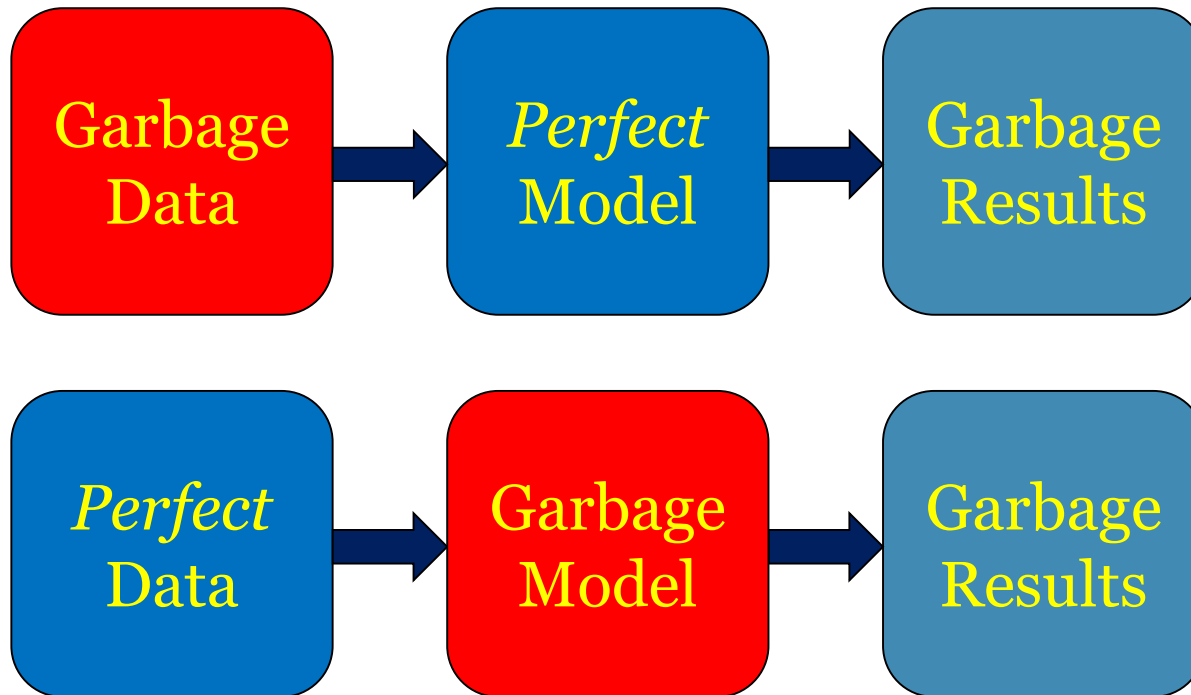


Precision/Personalized Medicine

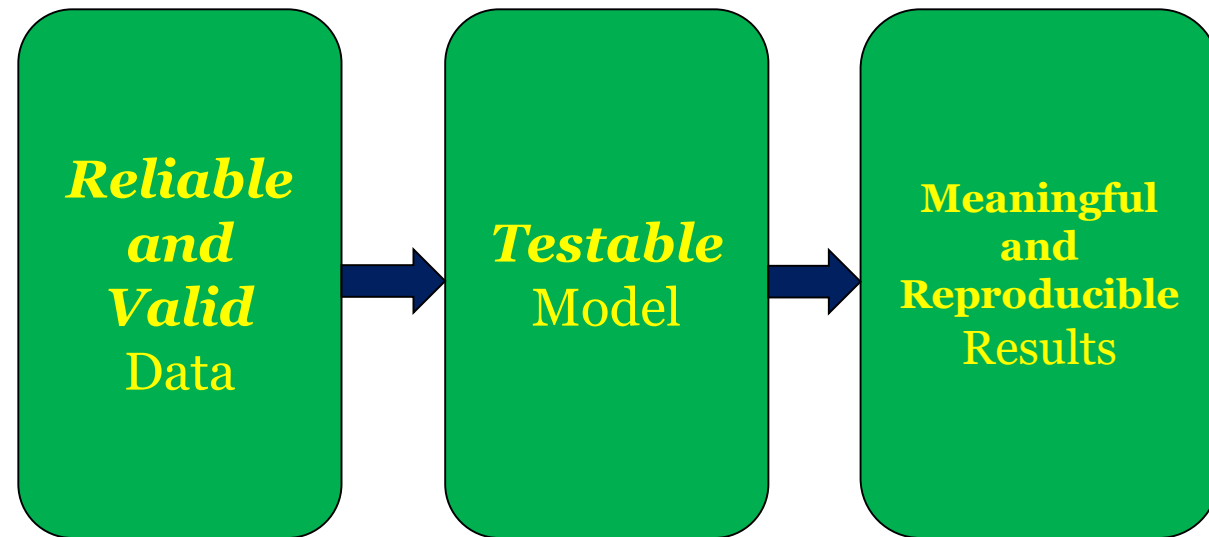
- One size does not fit all
- The right therapy for the right person at the right time
- The systematic use of information about each individual patient to select or optimize the patient's preventative and therapeutic care

Challenges in Health Measurement (for Predictive Modeling)

Garbage In, Garbage Out



Ideally



Evolving Methodologies (Measurement Sciences) and Technologies (Informatics) Offer Promises and Plausible Solutions



- Aid in the collection, processing and interpretation of health-related data in real-time
- Make timely information available when needed
- Provide better organized information
- Provide an efficient vehicle for the incorporation of health-related data into a busy clinic setting
- Facilitate patient-physician informed clinical decision making

What Can Health Measurement Do?

Measure What Matters



Why is Health Measurement Needed?



Quantify the medical condition

symptom frequency, severity



Characterize the person

level of impairment, mental health status



Compare to the norm (peers)

satisfaction, quality of care, expected outcomes



Guide optimal treatment/therapy options

surgical procedure, assistive technologies

Health Measurement to Management

Perspectives from Two Disciplines

Measurement Science

If you can't measure it,
you can't improve it.

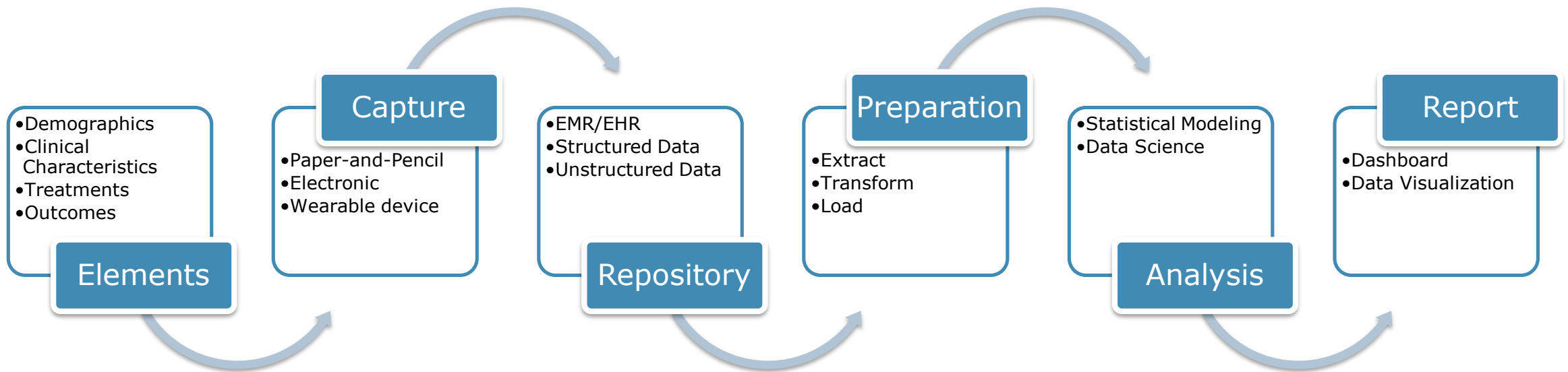
Data Science

If you can predict it,
you can prevent it.



A Patient's Health Data Journey

Turning Data Into Actionable Insights for Precision Medicine



Measurement-to-Management Steps



Why Does Health Measurement Matter?

- Identify specific areas for treatment or rehabilitation
- Facilitate physician-patient-family communications
- Inform shared clinical decision-making
- Predict short-term and long-term progress
- Develop individualized care plan
- Determine the value of treatment or therapy
- Evaluate the efficacy of drugs or medical devices
- Evaluate the effectiveness of interventions
- Improve quality of care/experience
- Reduce costs (medical and non-medical)
- Fulfill reimbursement requirements
-

The Needs to Integrate 'Subjective' Health Assessment in Clinical Settings for Precision Medicine

- Making health-related (e.g., patient-reported outcomes) data to be an integral part of patient care
 - easy to collect
 - clinically meaningful
 - psychometrically sound
 - easily interpretable
 - readily available
- Many disease-specific PRO measures are available, but few used in clinical practice

Needs and Challenges for Better Clinical Outcomes Assessment Tools

Needs

Assessment tools that are reliable, valid, and sensitive to detect meaningful change

Different forms of an assessment tool to measure different ability levels

Unbiased assessment tools across groups

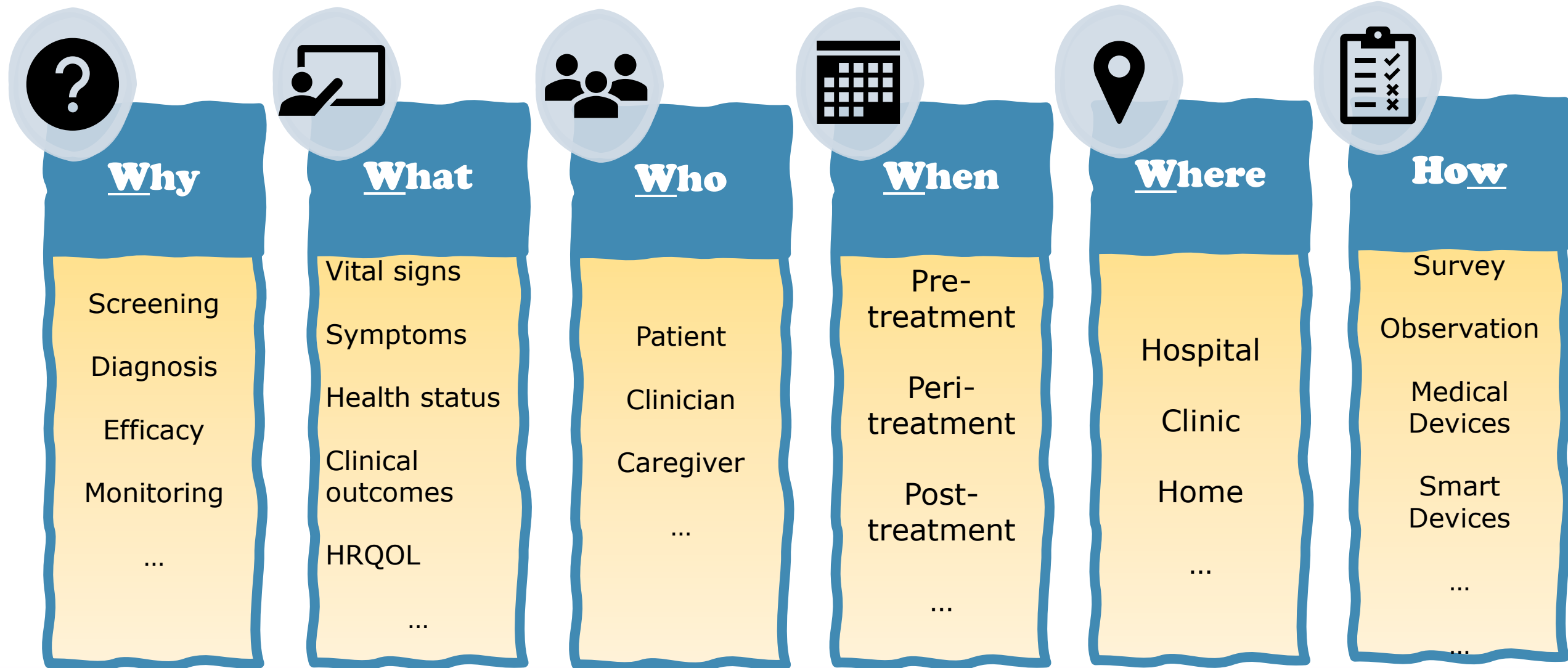
Challenges

A minimum set of items to reduce respondent (and staff) burden
(Less is More)

Different forms to be linked/equated on the same metric
(Score Cross-Walking)

Measurement invariance for meaningful group comparisons
(Equitable Measurement)

6 W's for Health Measurement



Sample Outcome Measures in Rehabilitation

| Discipline | Measurement Tool | Variables |
|-------------------------|--|---|
| Physical Therapy | <ul style="list-style-type: none"> • Berg Balance Scale • Dynamic Gait Index | <ul style="list-style-type: none"> -Balance -Dynamic gait |
| Occupational Therapy | <ul style="list-style-type: none"> • Activity Card Sort • Action Research Arm Test • Executive Function Performance Test | <ul style="list-style-type: none"> -Social, instrumental, and leisure activities -Upper extremity function -Executive function |
| Speech-Language Therapy | <ul style="list-style-type: none"> • Montreal Cognitive Assessment • Mann Assessment of Swallowing Ability | <ul style="list-style-type: none"> -Cognition -Swallowing |
| Other | <ul style="list-style-type: none"> • Fatigue Impact Scale • McGill Pain Questionnaire • Hospital Anxiety and Depression Scale | <ul style="list-style-type: none"> -Fatigue -Perceived pain -Anxiety and depression |

Sample OT Assessment Areas

- Hand Function
- Bimanual Tasks
- Fine Motor
- Grip Strength
- Pinch Strength
- Consciousness
- Executive Function
- Neglect
- Head Control
- Upright Tolerance
- Pressure Relief
- Fatigue
- Transfers Tub/Shower
- Participation
-



HealthMeasures

TRANSFORMING HOW HEALTH IS MEASURED



PROMIS®

Self-reported and parent-reported measures of global, physical, mental, and social health for adults and children in the general population and those living with a chronic condition



Neuro-QoL™

Self-reported and proxy-reported measures of physical, mental, and social health for adults and children living with a neurological condition

ASCQ-Me®

Adult Sickle Cell Quality of Life Measurement Information System

ASCQ-Me®

Self-reported measures of physical, mental, and social health for adults living with sickle cell disease



NIH Toolbox®

Performance tests of cognitive, motor, and sensory function and self-reported measures of emotional function for adults and children in the general population and those living with a chronic condition

What is Infometrics?

Informatics is the science of how to use data, information and knowledge to improve human health and the delivery of health care services.

Psychometrics is a field of study that incorporates the *techniques* and *theories* involved in psychological measurements.

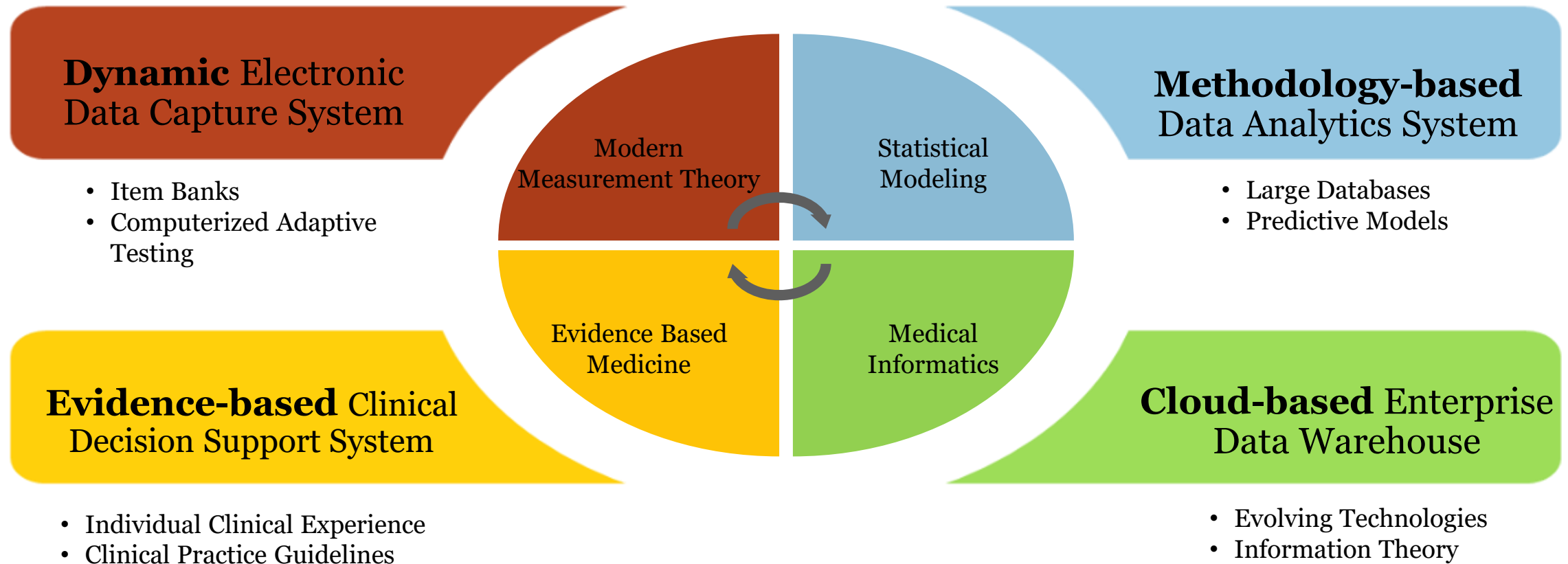
Infometrics = An integration of Informatics and Psychometrics

What is Clinical Infometrics?

- A synthesis of measurement science, data science, information technology, and evidence-based medicine to guide ***informed decision making*** in real time and to improve ***symptom and disease management*** over time.

Clinical Infometrics™-based System

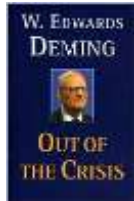
A BIG Data System to Support Clinical Research, Education and Practice



“Measurement Science” Component

- “If You Can’t Measure It, You Can’t Manage It.”

- *W. Edwards Deming*



W. Edwards Deming (1986). *Out of the crisis*.
Cambridge, MA: MIT Press.

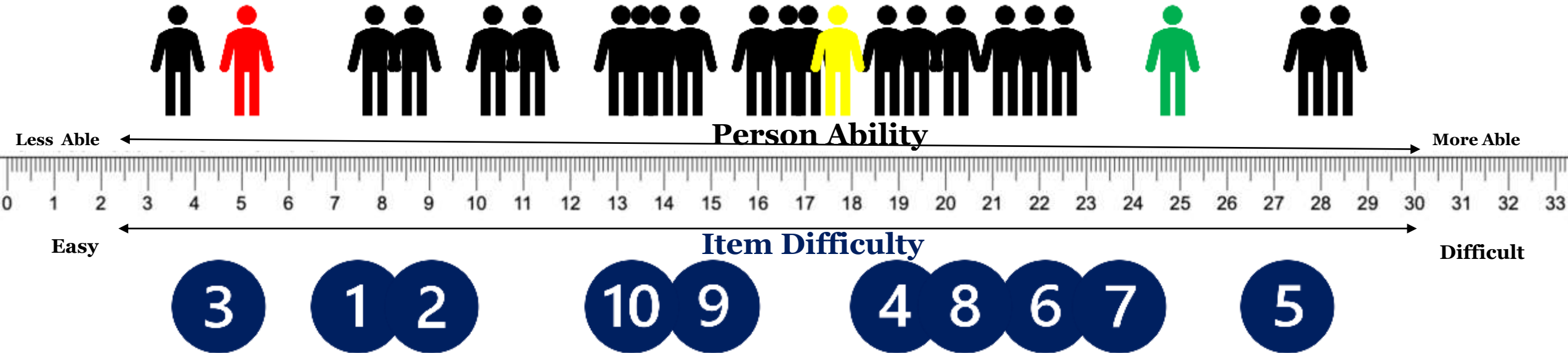
- “If You Can’t Measure It, You Can’t Improve It.”

- *Peter Drucker*

- Classical Test Theory
- Modern Measurement Theory:
Item Response Theory
 - Scale development / refinement
 - Scale linking / equating
 - Differential item functioning
 - Item banking
 - Computerized adaptive testing (CAT)

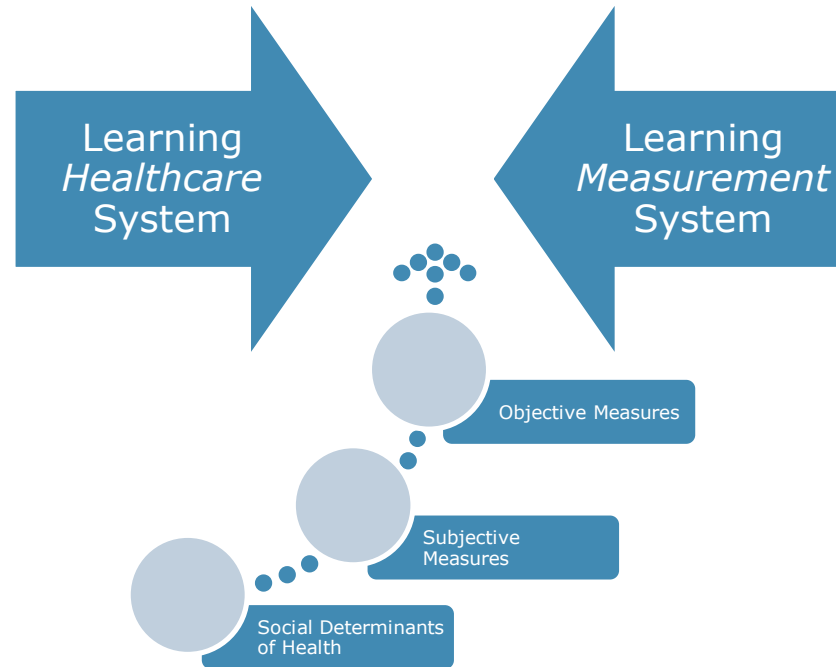
Item Response Theory (IRT) to the Rescue

- A family of mathematical models that describe the relationship between a person's latent trait (e.g., ability) being measured and the item characteristics (e.g., difficulty) of an assessment tool.



“Data Science” Component

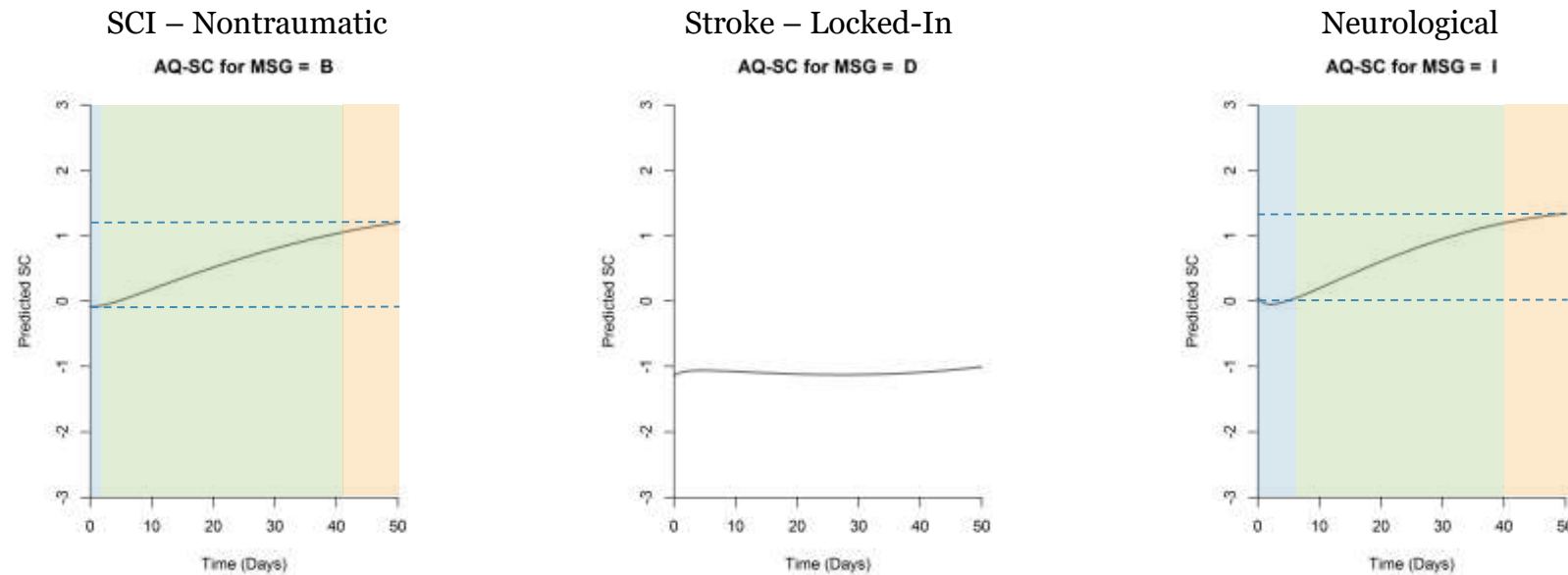
- If you can predict it, you can prevent it.



- Selection of predictive variables (risk factors)
- Model Building
 - Multivariate linear regression
 - Logistic regression
 - Classification and regression trees
 - Generalized additive models
 - Structural equation models
 - Neural networks
 - Machine learning
 -
- Model assessment, validation, and refinement

Predictive Models

- Self Care:

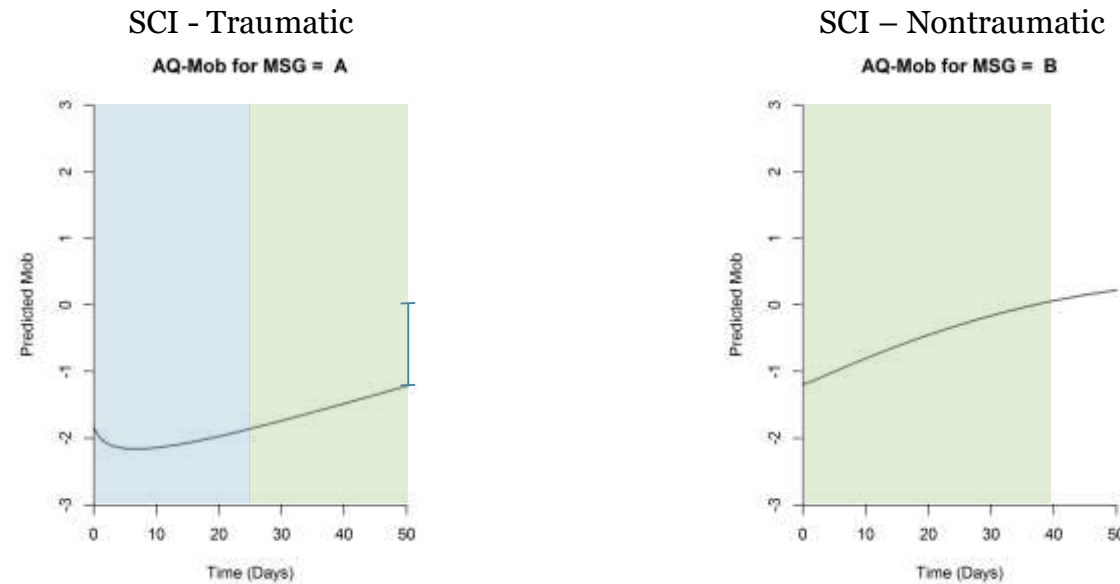


Different MSGs have differently shaped curves and are admitted at different levels

The expected 50-day change in Self Care for these groups is fairly dramatic.

Predictive Models

- Mobility:



On the other hand, we'd expect to see Mobility gains right away for MSG B

Data Analysis

Descriptive



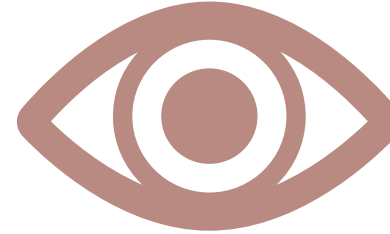
What happened?

Diagnostic



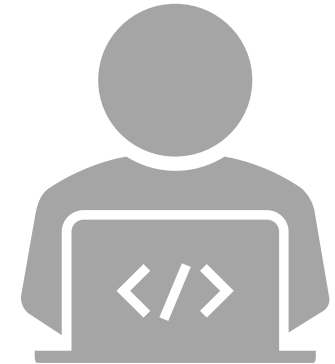
Why did it happen?

Predictive



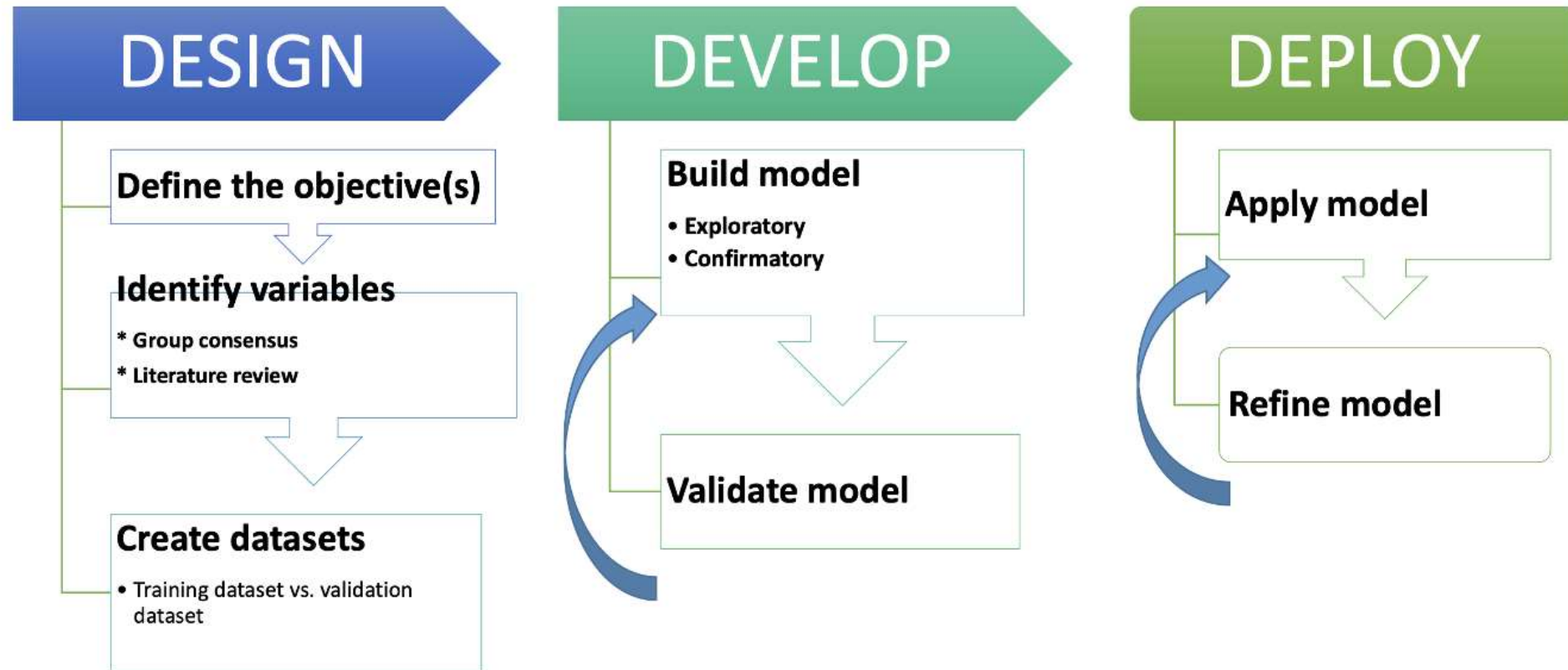
What is likely to happen in the future?

Prescriptive



What is the best course of action?

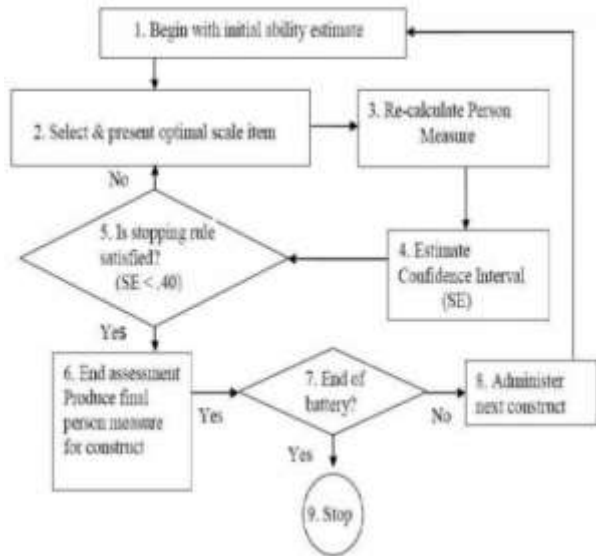
3D Modeling Process



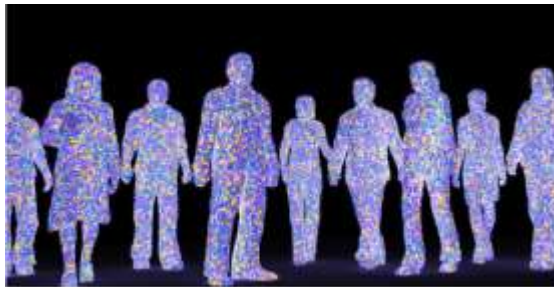
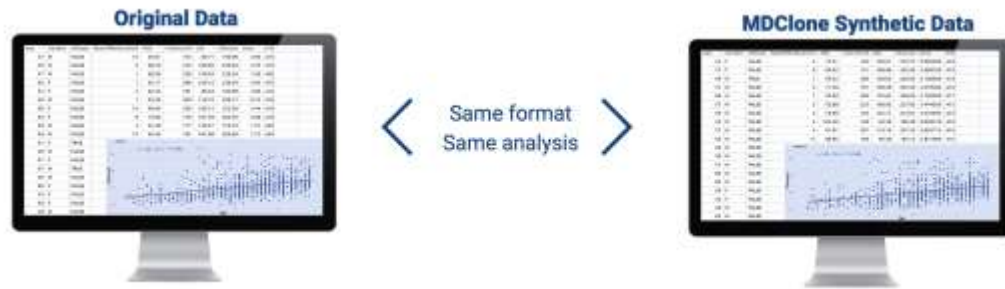
“Information Technology” Component

- Deal with the resources, devices, and methods required to optimize the acquisition, storage, retrieval, and use of information in health and biomedicine
- Health Information Technology (HIT)
 - Inpatient
 - Online nursing notes, vital signs
 - Bar-coded data collection
 - MD order entry, notes
 - Wireless/handheld access
 - Outpatient
 - Online order entry and notes for past few years
 - Chemotherapy protocol/tracking software
 - Longitudinal surgical outcomes tracking
 - Home/Community
- Electronic Medical Records (EMR) / Electronic Health Records (EHR)
- ***Enterprise Data Warehouse (EDW)***

Smarter Methodologies and Technologies Offer Plausible Solutions



MDClone and Synthetic Patient Data at WUSM



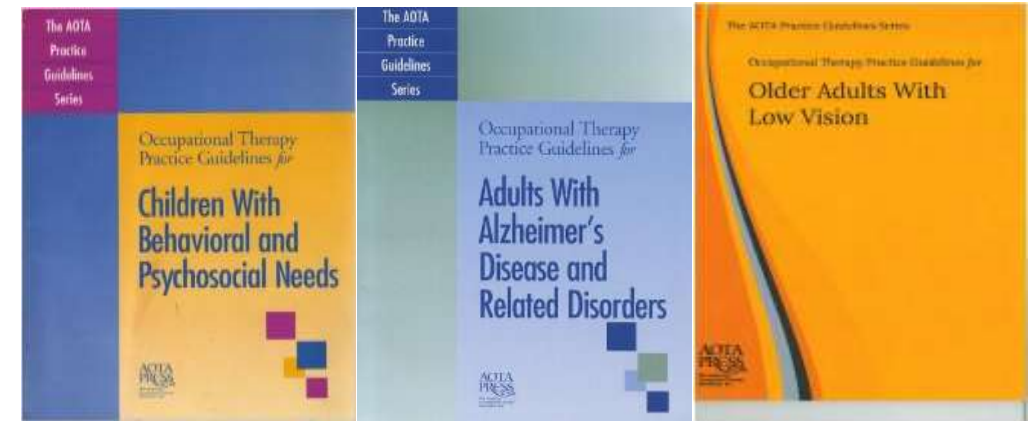
Synthetic data mimics real health-care data without patient-privacy concerns

Such data now available to university researchers, could help speed research.

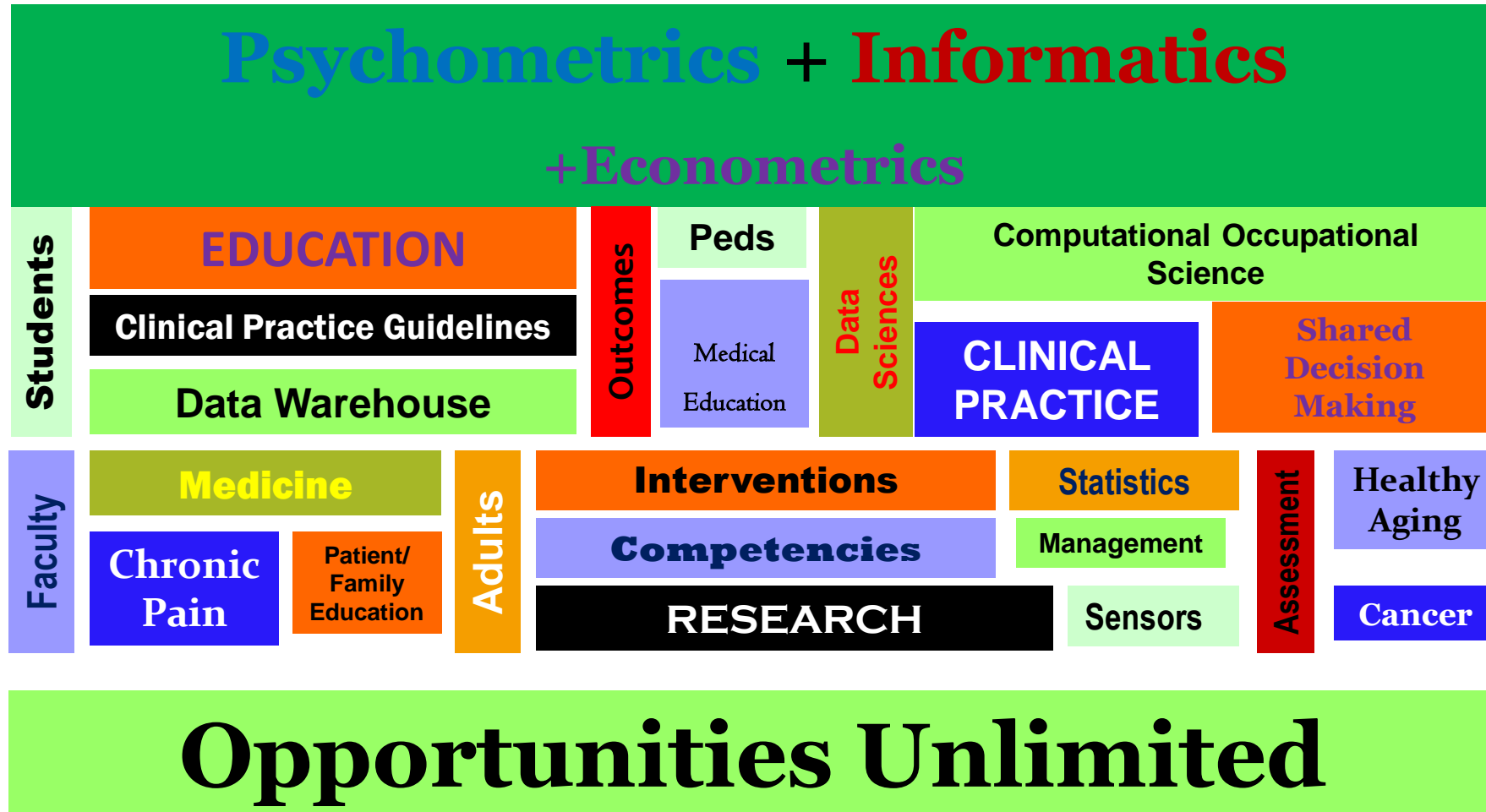
- Conduct research without an IRB and see raw data in real-time - MDClone synthetic data is 100% unidentified
- Reduce HIPAA risks and exposure
- Share data and insights without any risk of patient re-identification

“Evidence-Based Medicine” Component

- Apply the best available evidence gained from the scientific methods and clinical practices to clinical decision making
- Clinical Practice Guidelines (CPG)
- Clinician Preferences
- *Knowledge Transfer (KT)*



Clinical Infometrics Has Great Potential



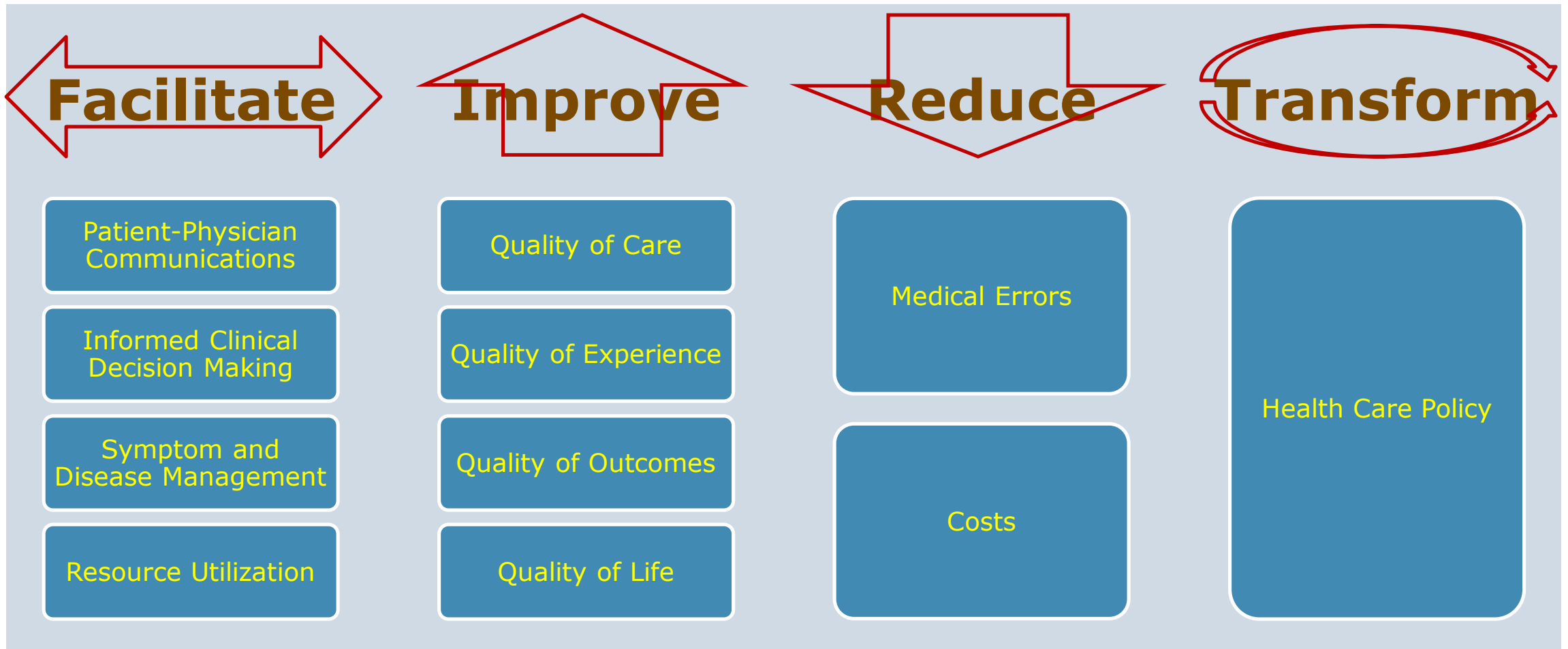
The Needs to Implement Health Measurement in Clinical Practice

- Clinical practice can be enhanced by the integration of the assessment of patient-reported symptoms and concerns into the electronic health record (EHR) and clinical workflows.
 - Facilitate patient-clinician communications
 - Set up realistic treatment goals
 - Facilitate precision medicine implementation

Implementation Strategies to Make Precision Medicine Possible

- Incorporate and integrate health measurement into written protocol document
- Make health-related assessment mandatory
- Obtain “buy-in” across all levels of organization
- Train users in test administration and data transmission
- Develop brief, clear, and easy-to-administer forms
- Attend to patient barriers
 - Performance status (energy level)
 - Severity of illness (prognosis)
 - Language
 - Literacy
 - Time

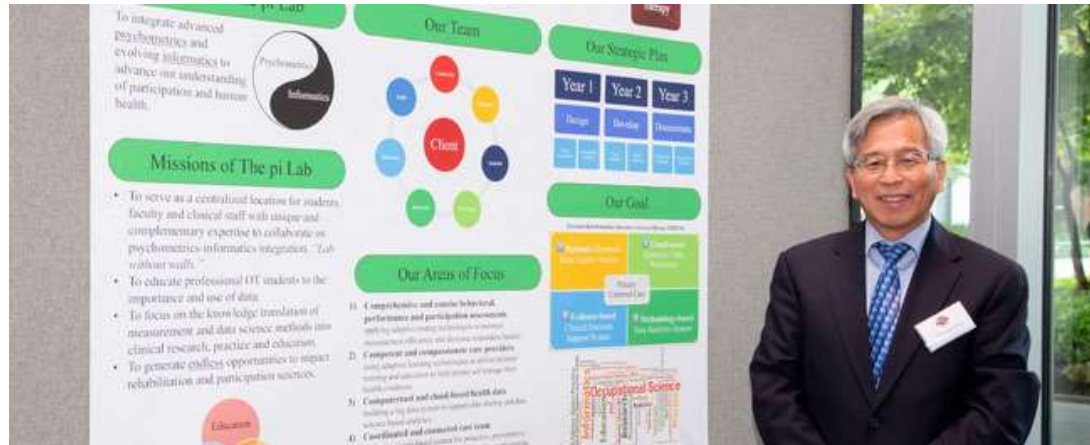
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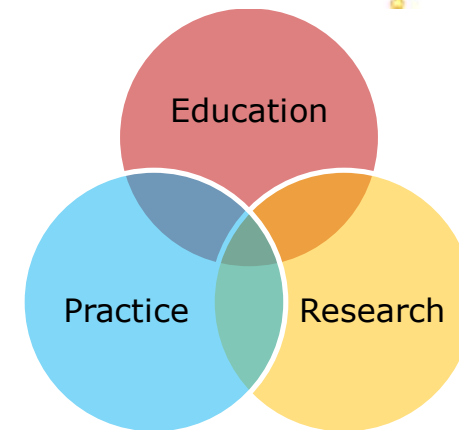
Team Science Based Health Care

**“You can do what I cannot do.
I can do what you cannot do.
Together we can do great things.”
-Mother Teresa**

The Psychometrics + Informatics (pi) Lab @ Washington University in St. Louis



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A map of East Asia, showing parts of China, Korea, and Japan. Major cities like Beijing, Seoul, and Tokyo are labeled. The map is used as a background for the title text.

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