

Recent Conceptual and Empirical Advances in Participation Measurement

**Gale Whiteneck, PhD
Director of Research
Craig Hospital
Englewood, Colorado, USA**



Presentation Outline

- **Make the case for participation measurement**
- **Describe NIDRR-funded research that I have been involved in to measure participation**
- **Mention current NIH-funded efforts related to participation measurement**
- **Summarize conceptual and methodological issues in the measurement of participation**



Why Measure Participation

- **Participation is a key concept in the ICF**
- **Classification alone is not adequate to advance disability research**
- **Measures of ICF concepts are needed to determine the strengths of the arrows in the ICF**
- **Participation is the ICF outcome of greatest interest to people with disability, their families, and society**
- **Participation measurement is less advanced compared to impairment and activity measurement**
- **No consensus yet exists about how to measure participation**



Participation Research in the NIDRR-funded Traumatic Brain Injury Model Systems

- **Original TBIMS participation measure—Community Integration Measure (CIQ) had been scrapped due to poor psychometric properties**
- **A priority was placed on replacing the CIQ with a better measure of participation**
- **The developers of four other participation measures were Project Directors in the TBIMS**
- **They agreed to pool the items from the four measures in a collaborative study to determine which measure or new combination of items would form the best tool**



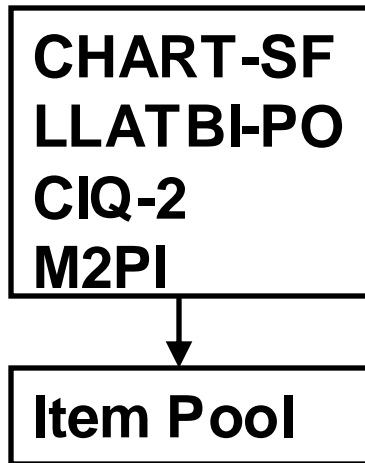
Four TBIMS Participation Measures

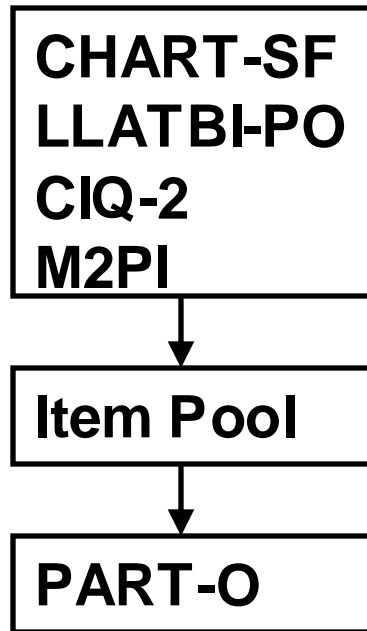
- **Craig Handicap Assessment and Reporting Technique (CHART) Whiteneck et. al.**
- **The Participation Objective Subscale of Living Life After TBI (LLATBI-PO) Gordon et. al.**
- **The Community Integration Measure Version 2 (CIQ-2) Dijkers et. al.**
- **The Mayo Portland Participation Index (M2PI) Malec et. al.**

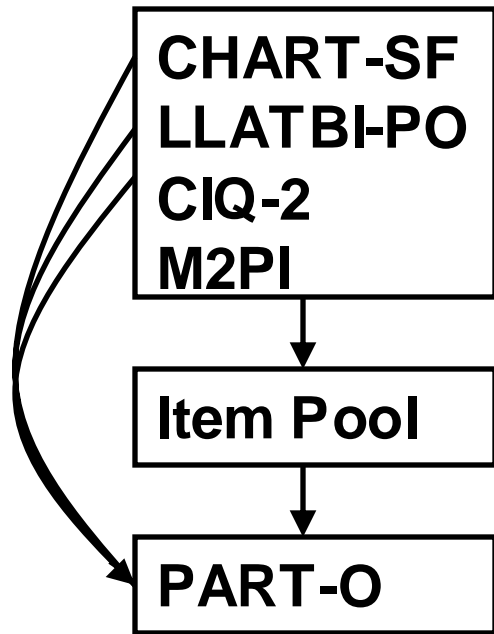


**CHART-SF
LLATBI-PO
CIQ-2
M2PI**









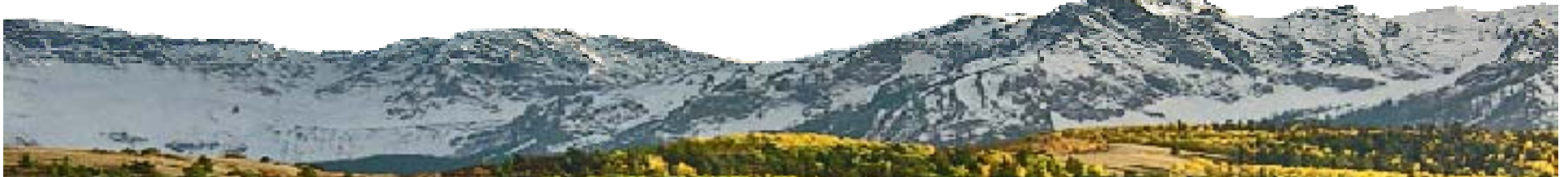
PART-O

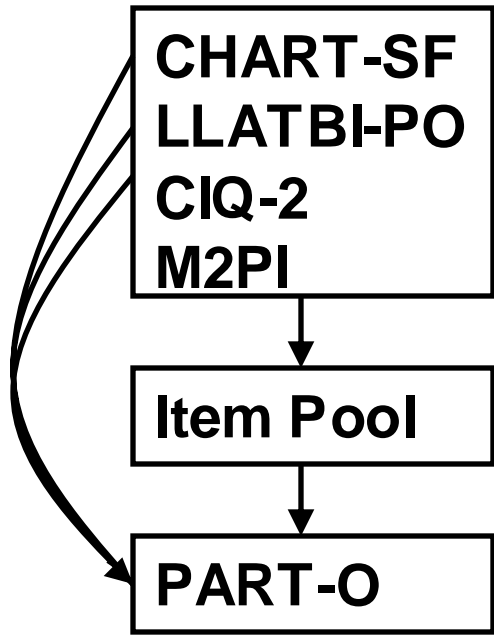
- **Items selected from three of the four participation measures based on factor analysis, Rasch analysis, conceptual coverage yielded a superior measure**
- **Participation Assessed with Recombined Tools – Objective (PART-O)**
- **Referred to as “objective” because all items sought relatively observable objective counts or frequencies of participation components (hours spent ..., number of..., times per month...)**
- **Criticized for judging participation based on societal norms**



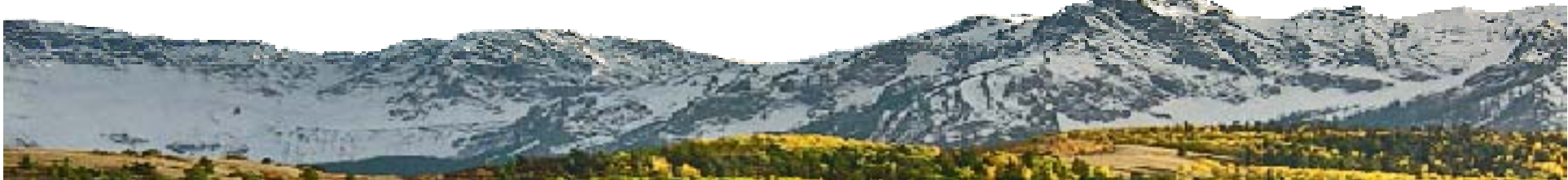
Participation Research in the NIDRR-funded RRTC on Rehabilitation Outcomes

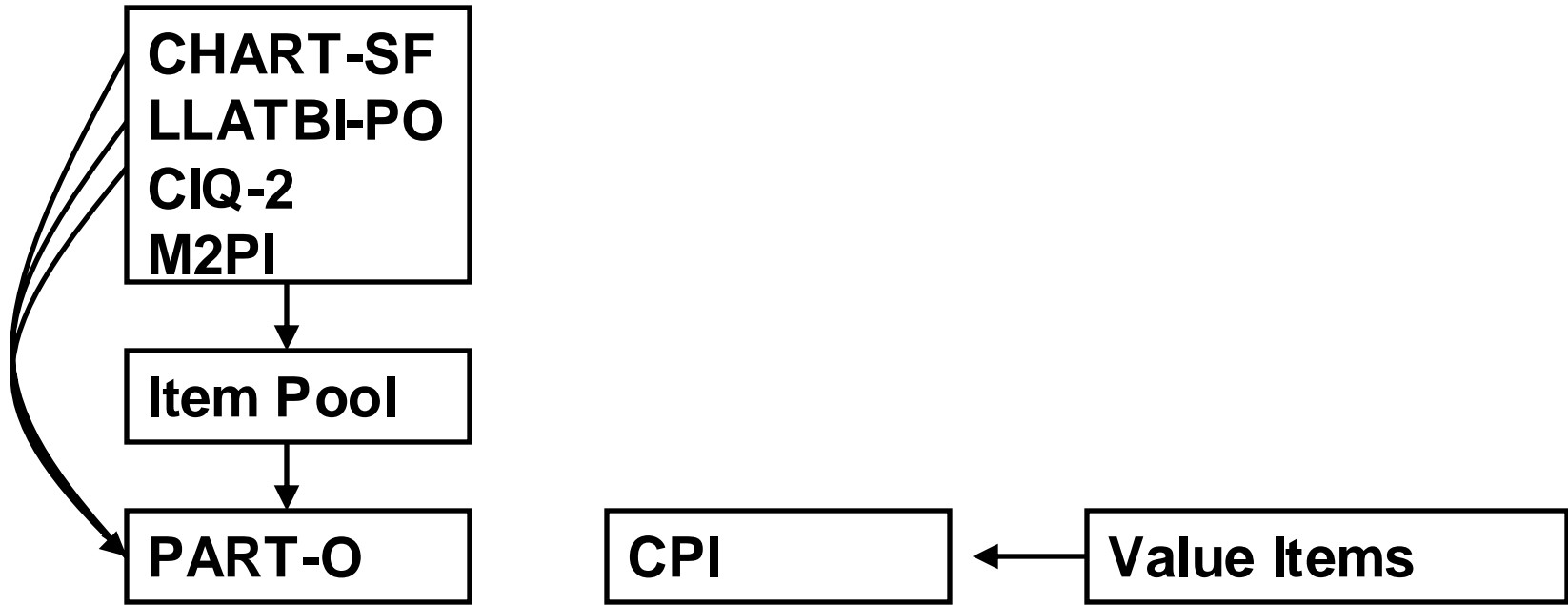
- Proposed to build a participation measure based on the perspectives of constituency groups
- Conducted 18 focus groups of 218 people with disability, their families and caregivers, service providers, insurance payors, and policy makers asking their view of participation
- Process yielded subjective “value items” addressing issues of choice and control, access and opportunity, meaningful engagement, inclusion, responsibilities, and having an impact
- These items formed the basis for a major section of the Community Participation Indicators (CPI) Heinemann et.al

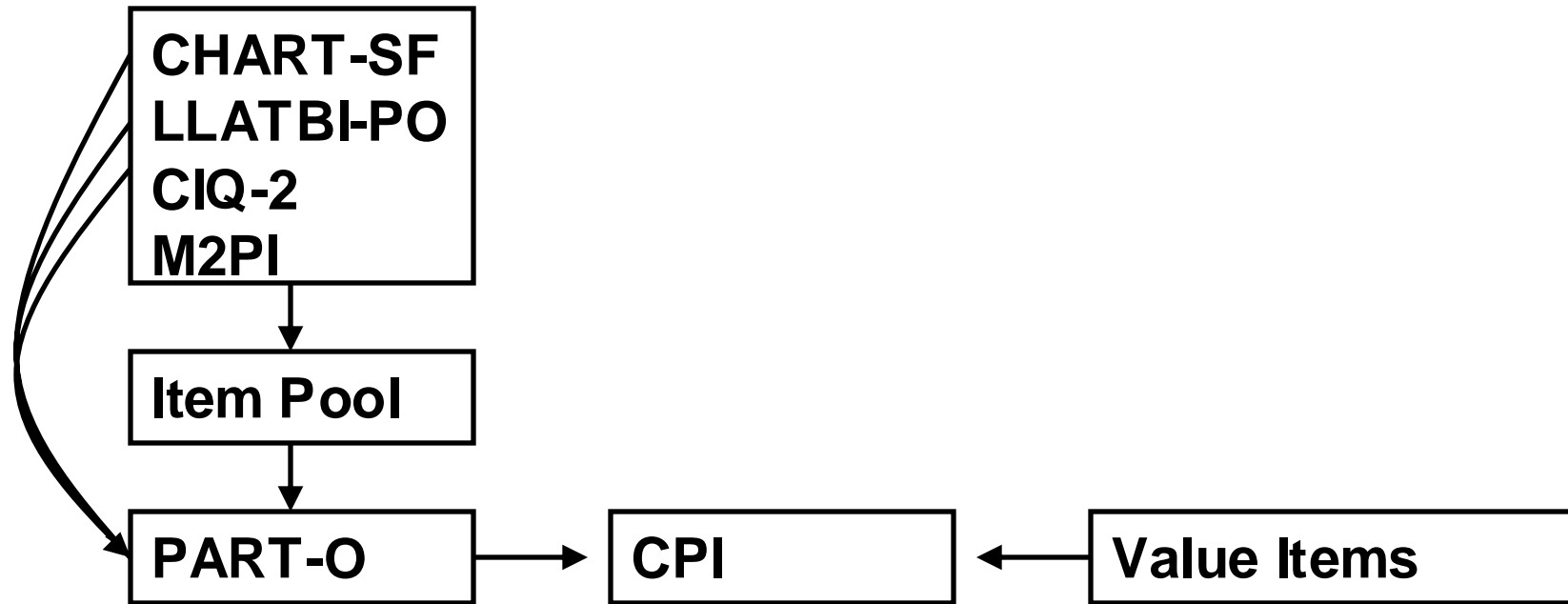


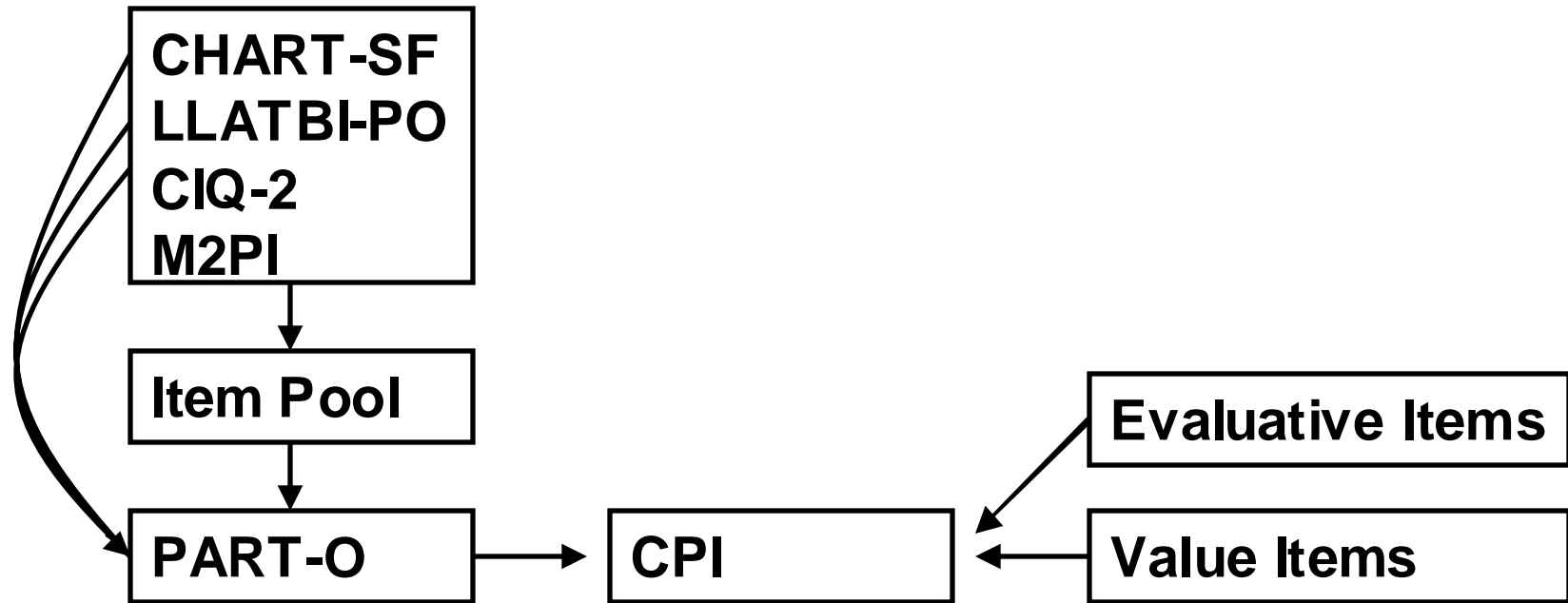


Value Items





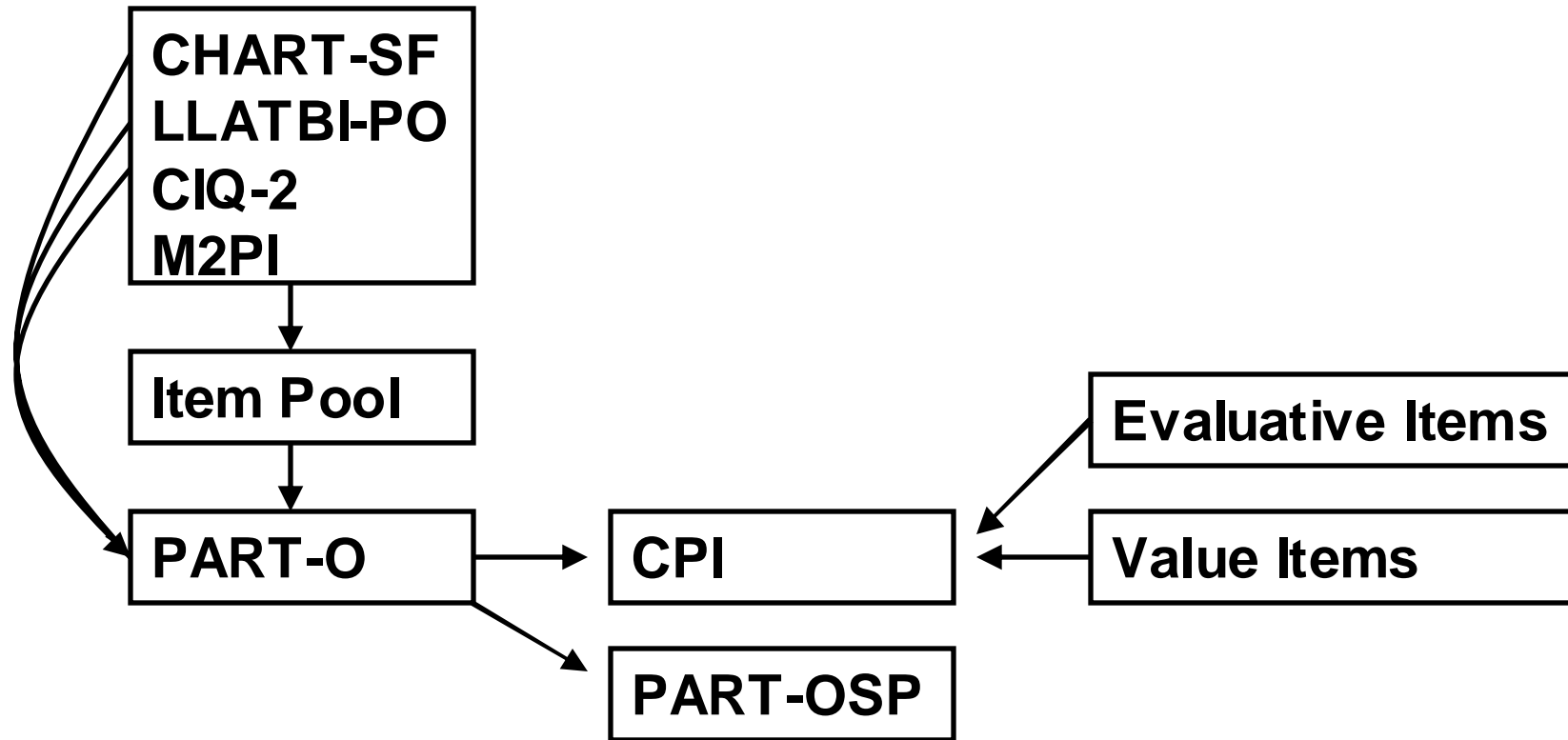


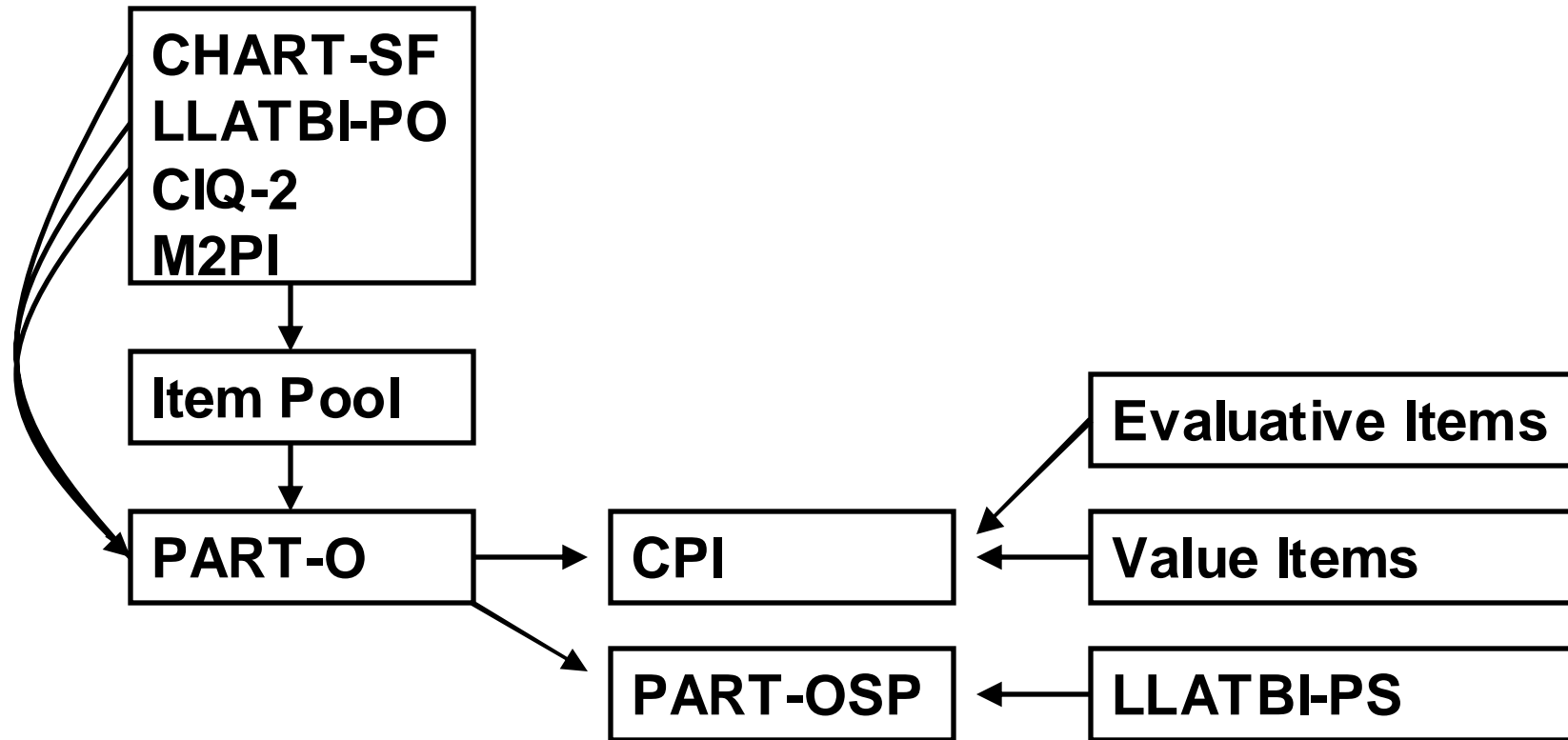


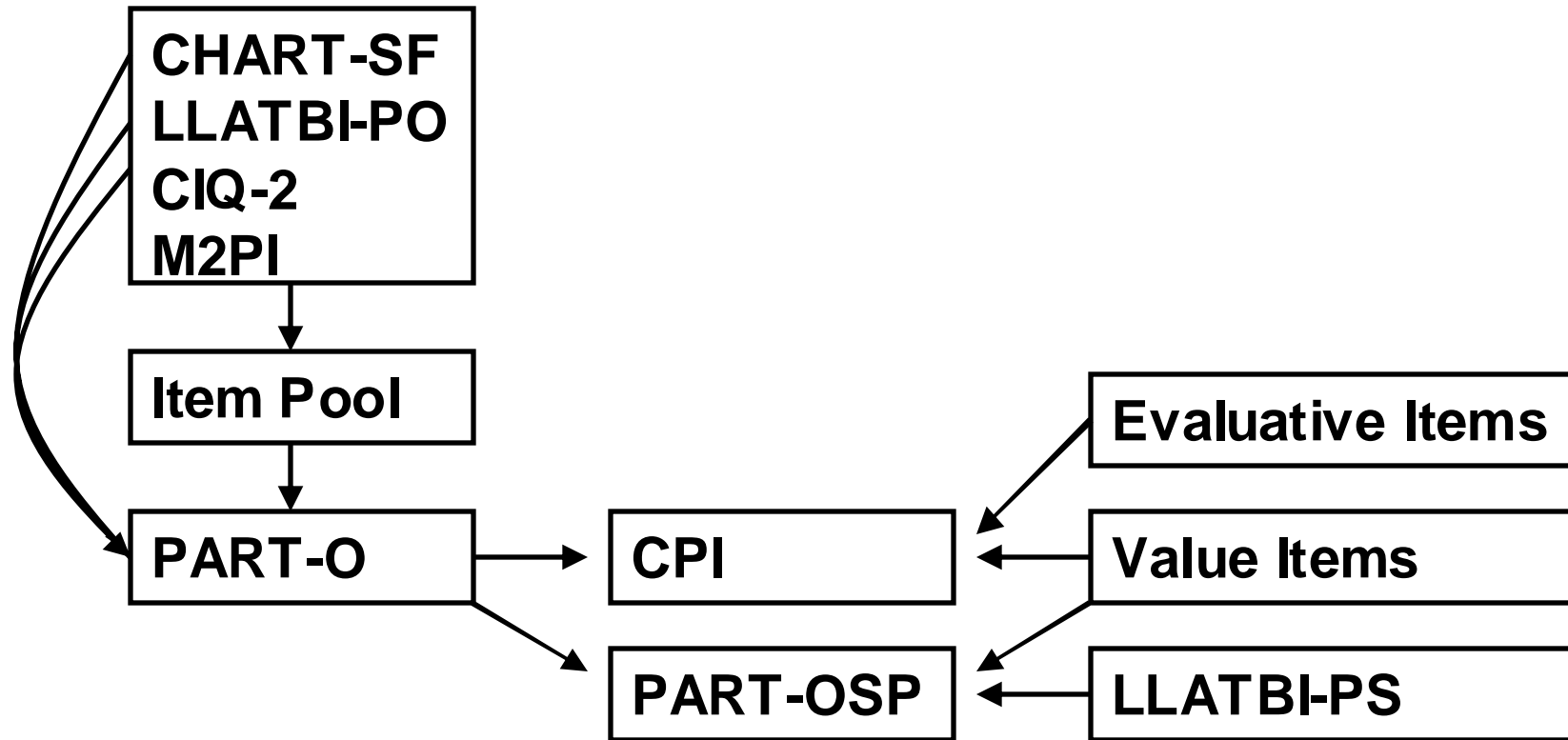
Meanwhile Back at the TBIMS

- A second phase of research was undertaken to add a subjective component to the PART-O
- The Participation Subjective Subscale of the Living Life After TBI (LLATBI-PS) Gordon et. al. was used as the model for the subjective component in which people were asked to rate both the importance of, and their satisfaction with, participation domains
- The resulting tool was called PART-OSP (Objective, Subjective, and Perceptions)





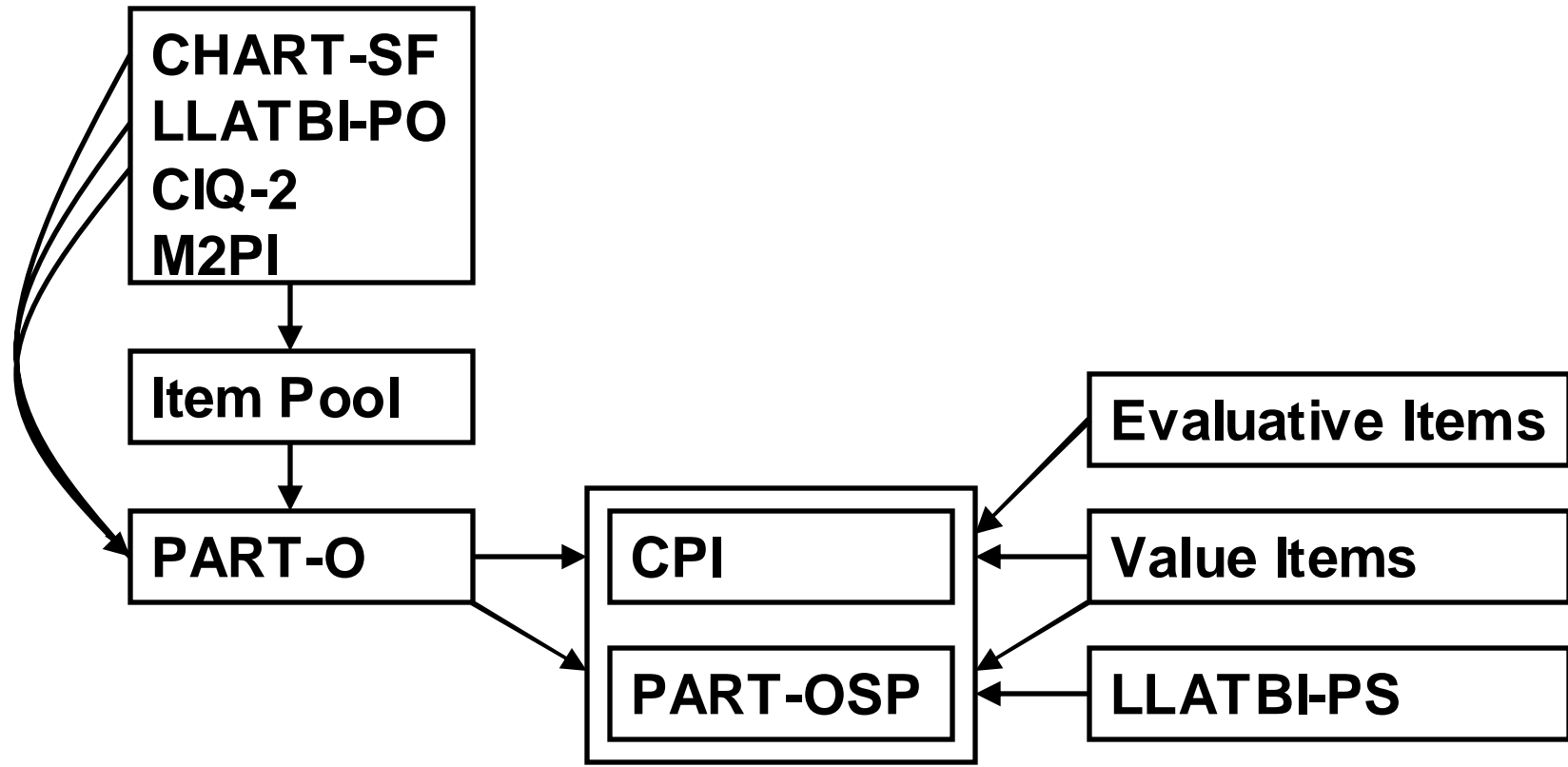


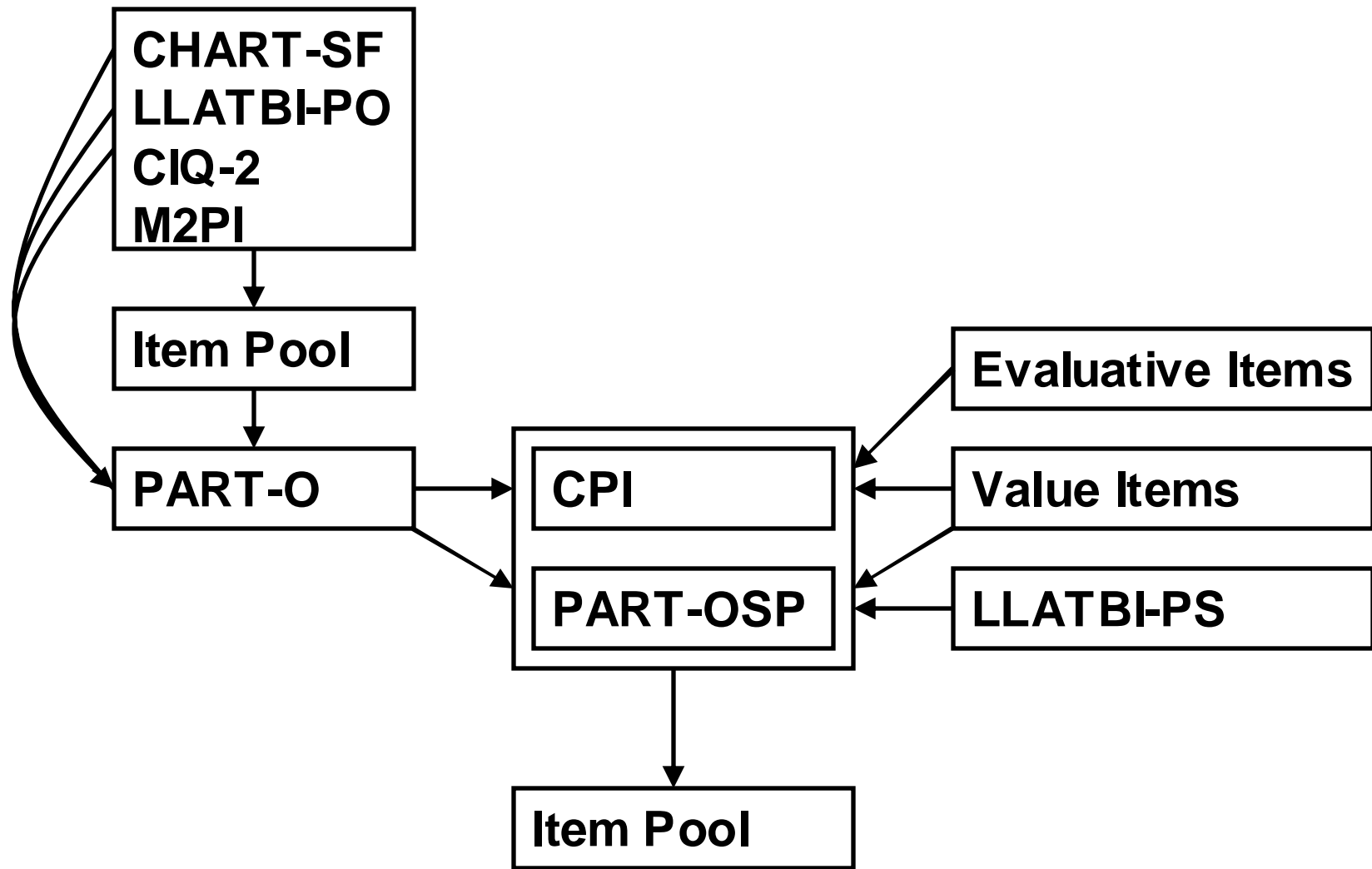


Participation Research in the NIDRR-funded Spinal Cord Injury Model Systems

- In a strategy similar to the TBIMS, the SCIMS are testing a pool of items from five participation measures
- The CPI and PART-OSP have a majority of items in common and they start the item pool



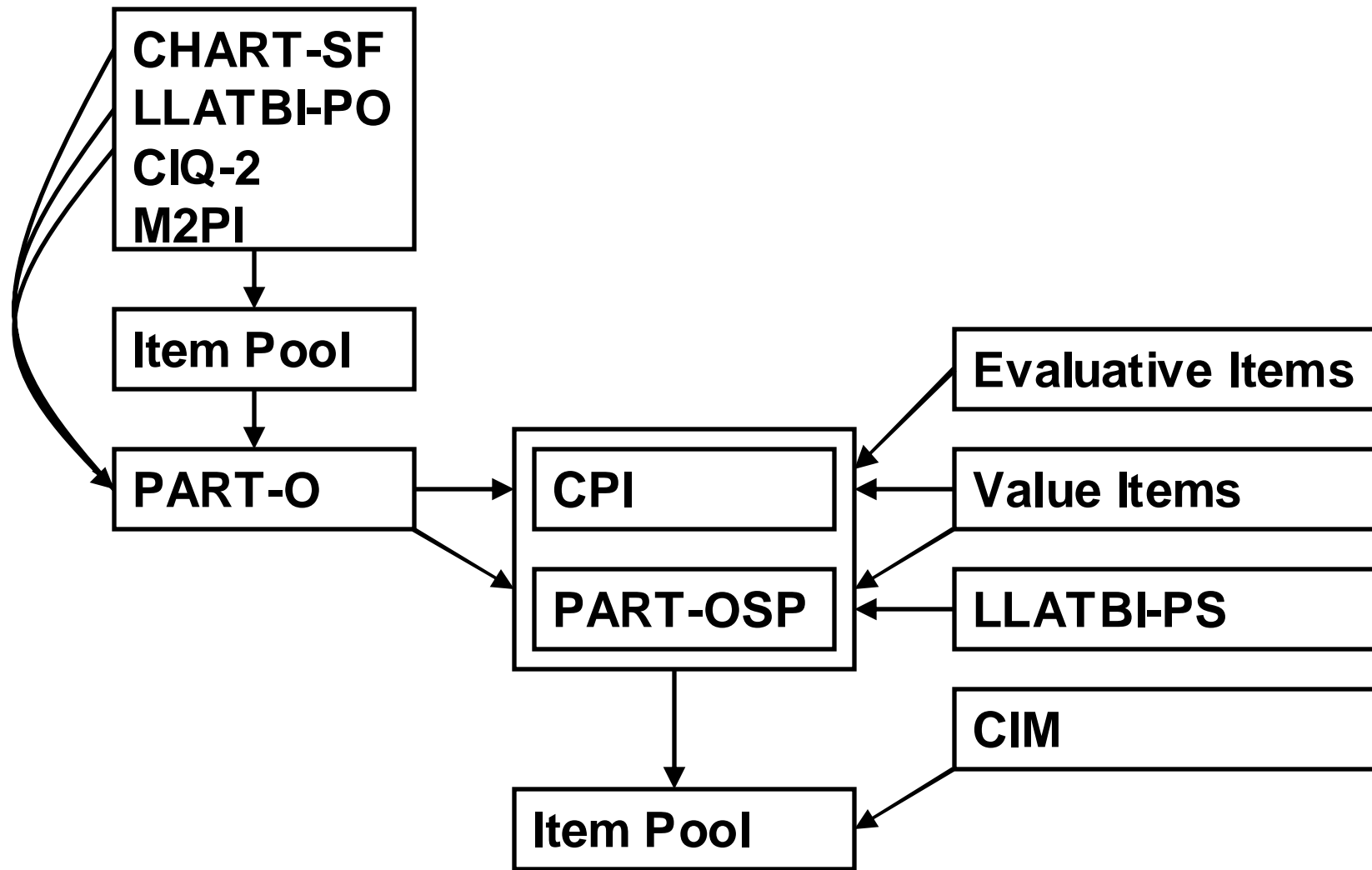


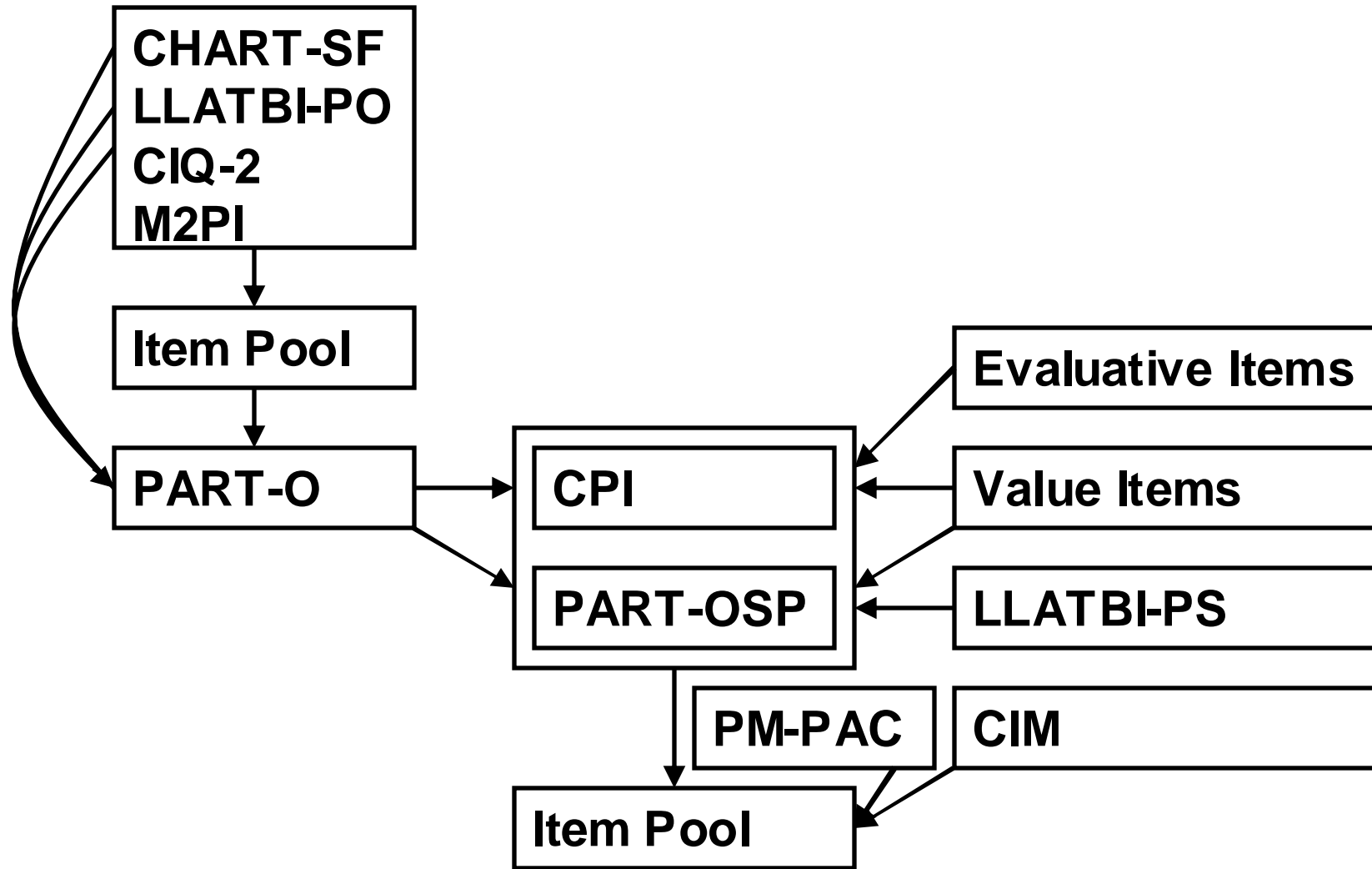


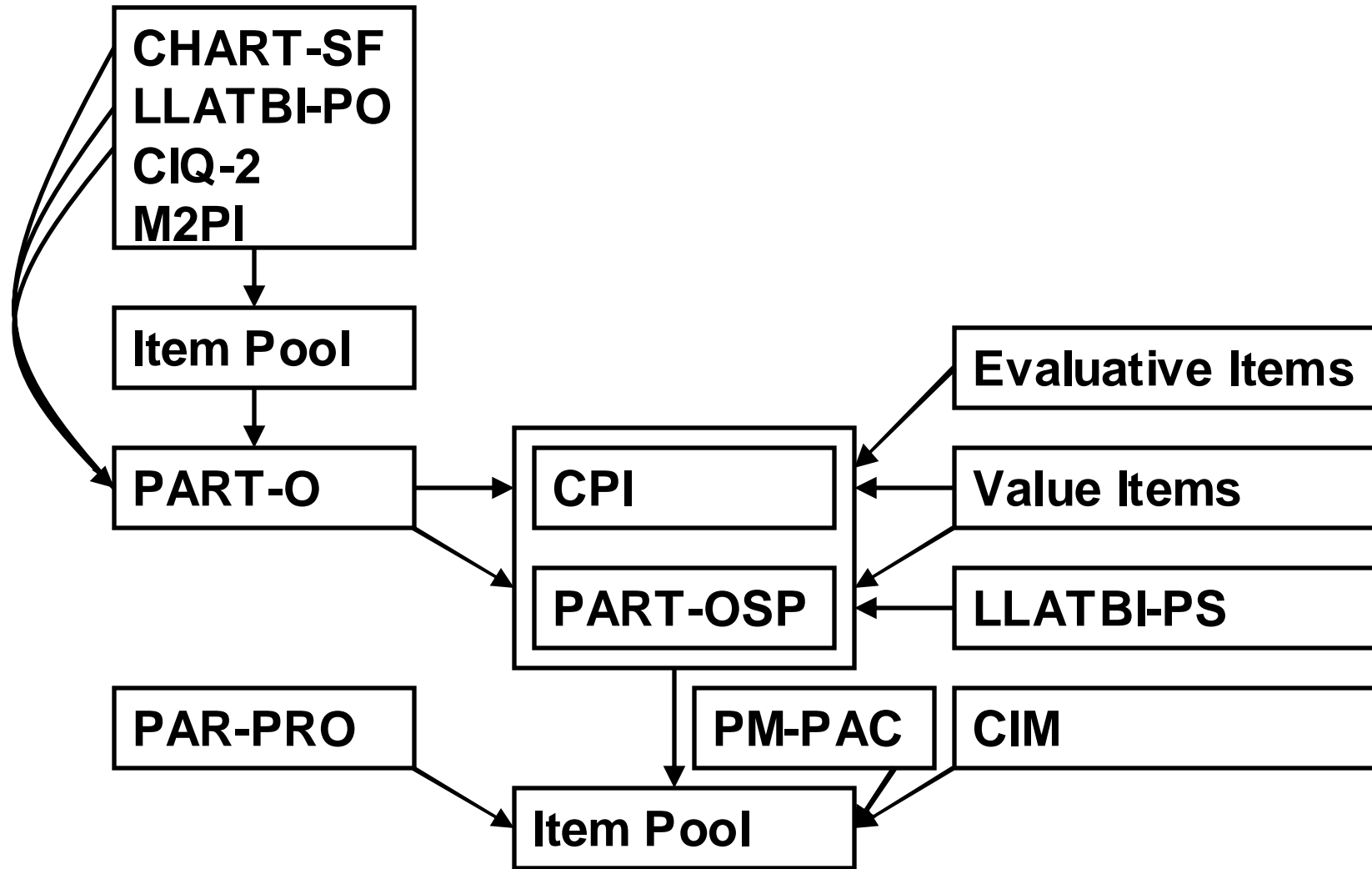
Participation Research in the NIDRR-funded Spinal Cord Injury Model Systems

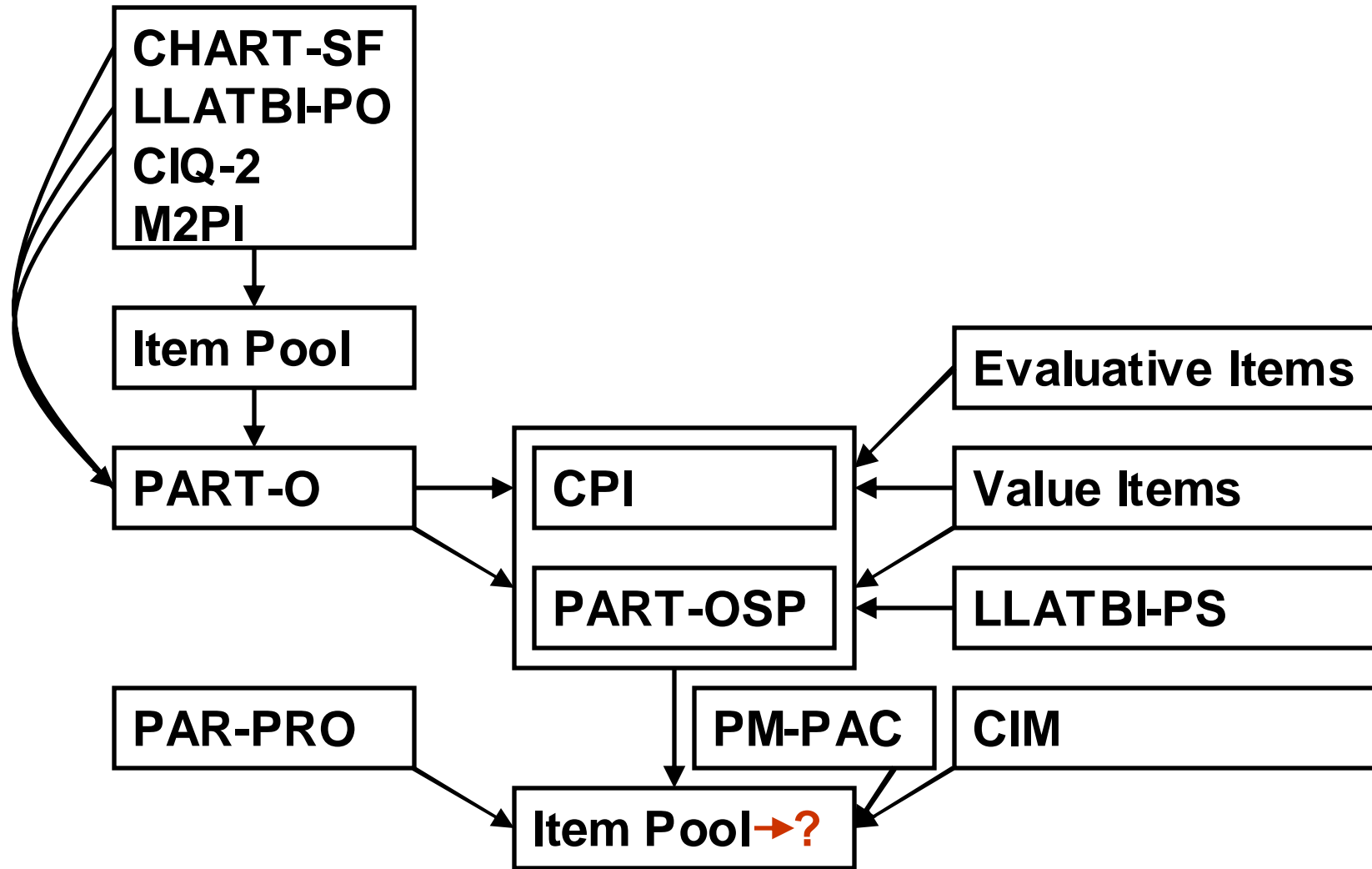
- Three additional measures were added to the pool representing other new participation measures
- A totally subjective measure was added with items of a similar nature to the CPI but containing different content—the Community Integration Measure (CIM) McColl et. al.
- The Participation Measure for Post Acute Care (PM-PAC) Jette et. al. was added addressing difficulty of participating
- Finally, the very objective Participation Profile (PAR-PRO) Granger et. al. was added











Participation Research Funded by NIH

- **Two very large item banking efforts are underway at NIH designed to use computer adaptive testing**
- **The Patient Reported Outcomes Measurement Information System (PROMIS) includes two relevant item banks within the Social Health domain—Role Participation Limitations and Role Participation Satisfaction**
- **The Neurological Quality of Life Project (NeuroQual) includes two relevant item banks—Social Role Performance and Social Role Satisfaction**



Key Conceptual Participation Issues

- **Is participation unidimensional?**
- **Should a subjective dimension be included?**
- **Are there identifiable dimensions of objective participation?**
- **Initial evidence suggests three objective domains:**
 - Economic engagement (productivity)**
 - Micro-social engagement (family and friends)**
 - Macro-social engagement (community)**
- **And two subjective domains:**
 - Evaluation of engagement (satisfaction)**
 - Enfranchisement (extent individual is valued by society)**



Key Methodological Participation Issues

- To what degree does participation meet the assumptions underlying modern psychometric theory and methods?
- Do individual preferences for selecting particular modes of participation (even within a domain) render analytic strategies such as item response theory and factor analysis less than ideal?
- Is a clinometric approach to measuring participation more appropriate than a psychometric approach?
- What item stems and responses will prove most effective? (frequency, satisfaction, difficulty, agreement)



Thank you
For further information contact

Gale Whiteneck
gale@craig-hospital.org
303-789-8204

