

Addressing Health Literacy in the Collection and Use of Patient Reported Data and Patient Reported Outcomes in Research

Panel Discussion
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Panelists

- **Russell Rothman MD MPP (Moderator)**
 - Assistant Vice Chancellor, Population Health Research
 - Professor, Internal Medicine & Pediatrics, Vanderbilt University
- **Susan J. Shaw, Ph.D.**
 - Associate Professor, School of Anthropology, University of Arizona
- **Rebecca Sudore MD**
 - Associate Professor, Medicine, UCSF
- **William Trick MD**
 - Director, Collaborative Research Unit, Cook County Health & Hospitals System
 - Professor, Rush University Medical Center
- **Drenna Waldrop-Valverde PhD**
 - *Associate Professor, Emory School of Nursing*
 - Director of Center for Neurocognitive Studies

Background

- Increased national interest in patient-centered research
- Increased focus on patient-reported data (PRD) and patient reported outcomes (PROs) for health system reform and for research.
- Funders such as PCORI, NIH, and others are increasing efforts to collect accurate PRD/PROs.
- Health literacy can influence PRD/PROs, although the exact impact and ways to optimize data collection are still being studied.

Example: Heart Failure QoL

- Trial of literacy sensitive heart failure self-care intervention
- Used the Minnesota Living with Heart Failure (MLHF) Questionnaire as an outcome.
- MLHF included 6-point likert scale items.
- Patients had difficulty with understanding and completing this.
- Developed 4 item Likert with Stars to represent severity



Health Literacy/Numeracy Linked to Poor Understanding

- Over 90% of patients struggle to understand food labels
- Over 2/3 of patients have poor estimation of portion sizes
- Parents had difficulty understanding growth charts, baby formula, WIC guidelines, etc.
- Over 1/2 of parents would inappropriately give OTC cold medicines to children less than 2 years of age.
- In all studies, subjects with lower Literacy/Numeracy had more difficult time understanding health information.

Nutrition Facts		
Serving Size ½ cup (114g)		
Servings Per Container 4		
Amount Per Serving		
Calories 90	Calories from Fat 30	
% Daily Value*		
Total Fat 3g		5%
Saturated Fat 0g		0%
Cholesterol 0mg		0%
Sodium 300mg		13%
Total Carbohydrate 13g		4%
Dietary Fiber 3g		12%
Sugars 3g		
Protein 3g		
Vitamin A 80%	•	Vitamin C 60%
Calcium 4%	•	Iron 4%

* Percent Daily Values are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs:

	Calories:	2,000	2,500
Total Fat	Less than	65g	80g
Sat Fat	Less than	20g	25g
Cholesterol	Less than	300mg	300mg
Sodium	Less than	2,400mg	2,400mg
Total Carbohydrate		300g	375g
Dietary Fiber		25g	30g

Calories per gram:
Fat 9, Carbohydrate 4, Protein 4



Rothman et al, AM J Prev Med, 2006
 Huizinga et al, Am J of Prev Med, 2009
 Kumar et al, Academic Pediatrics, 2010

Lokker et al, Pediatrics, 2009
 Yin et al, Academic Pediatrics, 2012

Health Numeracy Linked to Worse Diabetes Knowledge

- Difficulties performing many literacy and numeracy related diabetes tasks:
 - Over 25% of patients could not interpret glucose meter
 - Over 40% could not calculate carbohydrate intake
 - Over 30% could not dose insulin correctly

A nutrition label for a food product. The label includes serving size, servings per container, and a table of nutrients with their amounts and percent daily values.

Serving Size 1 oz. (28g/About 10 chips)	
Servings Per Container 3.5	
Amount Per Serving	
Calories 140	Calories from Fat 60
% Daily Value*	
Total Fat 6g	10%
Saturated Fat 0.5g	4%
Cholesterol 0mg	0%
Sodium 160mg	7%
Total Carbohydrate 18g	6%

Example: Food Frequency Questionnaire (FFQ)

- 144 primary care patients with type 2 diabetes
- Assessed numeracy with the Diabetes Numeracy Test
- Administered the Block Brief FFQ
- Patients with lower numeracy were significantly more likely to report extremely low or high caloric intake – inconsistent with plausible standards (< 800 or > 4200 kcal/d for men; < 500 or > 3500 kcal/d for women)

Panel Format

- Address 3 Questions
 - For each question panelists will present for 5 minutes
 - 5-10 minutes for *interactive* discussion
- Questions
 - How does health literacy impact the collection and interpretation of patient reported data/patient reported outcomes?
 - What approaches are used to collect patient reported data? How might these approaches be impacted by patient/family health literacy?
 - What approaches would you recommend in the future? What additional research is needed in this area?

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What approaches are used to collect patient reported data? How might these approaches be impacted by patient/family health literacy?

What approaches would you recommend in the future?

What additional research is needed in this area?