1. How does health literacy impact the collection and interpretation of patient reported data/patient reported outcomes?



Local The Global Digital Divide



Figure 1. Internet Use Among Hispanics, Whites, and Blacks		
100% (Online	
Non-Hispanics	Hispanics	
Black College Graduates (93%) White College Graduates (91%) Whites, Ages 18-29 (86%)	Hispanic College Graduates (89%)	
Blacks, Ages 18-29 (77%)	English-Dominant Hispanics (78%) Native-Born Hispanics (76%)	
ALL WHITES (71%)		
	Hispanics, Ages 18-29 (67%)	
ALL BLACKS (60%)	ALL HISPANICS (56%)	
	Foreign-Born Hispanics (43%)	
Whites, No High School Degree (32%)	Spanish-Dominant Hispanics (32%) Hispanics, No High School Degree (31%)	
Blacks, No High School Degree (25%)		
	Hispanics, Ages 71+ (17%)	
Blacks, Ages 71+ (7%)		
0% Online		

Education Age **English proficiency Overall-race ethnicity**

Pew internet and American life project, 2007 www.pewhispanic.org

Single Item Health Literacy Evaluation: CCHHS



~140k patient encounters~Dichotomized: "Extremely" or "Quite a bit"

- Chew LD et al., Fam Med. 2004
- Wallace LS et al., JGIM. 2006

Effect of Age on Reasoning



*Past experiences minimize the decline in task performance Older patients with low SES have less exposure to computers

Technology & Health Literacy

- Shared demographics
 - Limited English proficiency
 - Older age
 - Lower education attainment

 As researchers gravitate toward electronic assessments, systems and processes need to be developed to accommodate individuals with low health literacy. 2. What approaches are used to collect patient reported data? How might these approaches be impacted by patient/family health literacy?

Response Latency: ACASI

Characteristic	Difference (seconds) ^a	95% CI	P-value
Language			
English	Referent		
Spanish	3.9	2.9 to 4.9	< 0.001
Computer in Home ^b			
Yes or unknown	Referent		
No, or not used	3.2	2.7 to 3.8	< 0.001
Physical symptom burden ^c			
Less than 0.5	Referent		
≥ 0.5	0.6	0.0 to 1.3	0.06
Self-Reported Health, Mental ^d			
Above mean score	Referent		
Less than or equal to mean	0.6	0.0 to 1.1	0.05
Age, years			
19 to 49	Referent		
50 to 59	1.4	0.7 to 2.1	< 0.001
60 to 69	3.4	2.6 to 4.1	< 0.001
70 to 79	5.3	4.2 to 6.3	< 0.001
80 to 89	5.4	4.0 to 6.9	< 0.001

Trick, Applied Clinical Informatics, 2015

Proxy Respondents

	Caregiver		
ADL item	Spouse (n = 278-283)	Son/daughter (n = 340-347)	
Physical			
Eating	0.65 (0.55-0.75)	_c	
Dressing	0.43 (0.33-0.53)	0.49 (0.40-0.58)	
Personal care	0.44 (0.34-0.54)	0.46 (0.37-0.55)	
Walking	0.61 (0.50-0.72)	0.48 (0.39-0.57)	
Getting out of bed	0.28 (0.18-0.38)	0.56 (0.47-0.65)	
Taking bath	0.61 (0.51-0.71)	0.55 (0.46-0.64)	
Using toilet	0.40 (0.32-0.48)	0.55 (0.46-0.64)	
Instrumental			
Getting to distant places	0.60 (0.50-0.70)	0.44 (0.36-0.52)	
Using telephone	0.55 (0.46-0.64)	0.45 (0.36-0.54)	
Going shopping	0.60 (0.50-0.70)	0.61 (0.53-0.69)	
Preparing own meals	0.57 (0.48-0.66)	0.47 (0.39-0.55)	
Doing housework	0.50 (0.41-0.59)	0.53 (0.45-0.61)	
Taking medicine	0.52 (0.43-0.61)	0.48 (0.40-0.56)	
Managing own money	0.61 (0.51-0.71)	0.40 (0.32-0.48)	
ADL rating	0.60 (0.52-0.68)	0.53 (0.46-0.60)	

mHealth assessments in low literacy populations?

Human Computer Interface





"If it won a design or art award, older users will hate it."

Hawthorn, Interacting with computers, 2000

What approaches would you recommend in the future?

What additional research is needed in this area?

ACASI: General Medicine Clinic



For Clinician: Interview Responses

Symptoms & severity

	Symptom	03/11/11	04/15/10	
Decreas	ed sexual interest	++	++++	
	Lack of energy	++	+	
	Pain	++	++	
	Bloated	+	+	
	Cough	+	+	
	Drowsy	+	++	
	Dry mouth	+	?	
	Itching	+	-	
Sł	nortness of breath	+	+	
	Change in taste	-	+	
	Constipation	-	-	
	Diarrhea	-	-	
	Dizziness	-	-	
	Loss of appetite	-	-	
	Nausea	-	+	
	Vomiting	-	-	
	Weight loss	-	-	
None, -	A little, +	Somewhat, ++	Quite a bit, +++	Very much, ++-

Two-item depression screen: Patient response for past two weeks (03/11/11)

Q1: Little interest or pleasure in doing things?
Q2: Feeling down, depressed, or hopeless?

Response: More than half the days Response: Several days

Interpretation: Possible major depression

Tobacco use (03/11/11)

The patient has skipped the questions about tobacco use

Quality of Life Scores (Scores > 50 above U.S. mean; < 50 below mean)

Component	03/11/11	04/15/10	
Mental	38.8	33.8	
Physical	42.3	34.9	

Clinical Implementation

Table 2: Barriers and facilitators to implementing patient-reported outcomes in an electronic health record

Barriers		Facilitators		
Uncertain clinical benefit	Time, work flow, and effort constraints	Process automation	Usable system interfaces	Right patient at the right time
"Can of worms"	"Slow down productivity"	"Self registration"	"Smart phrases"	"PROs paired to visit"
"Hate us for patients	"Time pressures"	"notes into EHR"		
wanting to discuss pain."				

Clinical Relevance of Data Collection

Instruments	Intervention Opportunities
<i>Behavioral Health</i> Tobacco use Substance use (ASSIST)	 Smoking cessation counseling. List of smokers willing to quit sent to health educators Brief interventions for at-risk use, specialty referral for dependent use
Clinical assessments Symptom burden (MSAS) Depression screen (PHQ-2)	 Provision of symptom-specific coping strategies Join pharmacy data, alerts for common side effects (e.g., cough and ACE inhibitor) Offer psychiatrist or psychologist evaluation
Patient-reported outcomes Self-reported health (NIH-PROMIS)	 Augmented care for patients who have decrements in self reported health Longitudinal assessments available to evaluate intervention strategies. Outcome routinely collected for comparative effectiveness research

Future Approaches

- Mobile technologies
- Computer adaptive testing
- Patient and clinician input on instruments & workflow
- Link to EHR
- Provision of interventions
- Biometric identification with secondary confirmation

Research Needs

- Increase clinician acceptance
 - Bridge instruments to improved clinical outcomes
 - Automate interventions based on responses
- Mobile technologies
 - Accessibility
 - Poor literacy, cognitive impairment, physical limitations
 - Person identification