

ASCQ-Me and PROMIS in  
the Sickle Cell Disease  
Implementation  
Consortium: Follow Up

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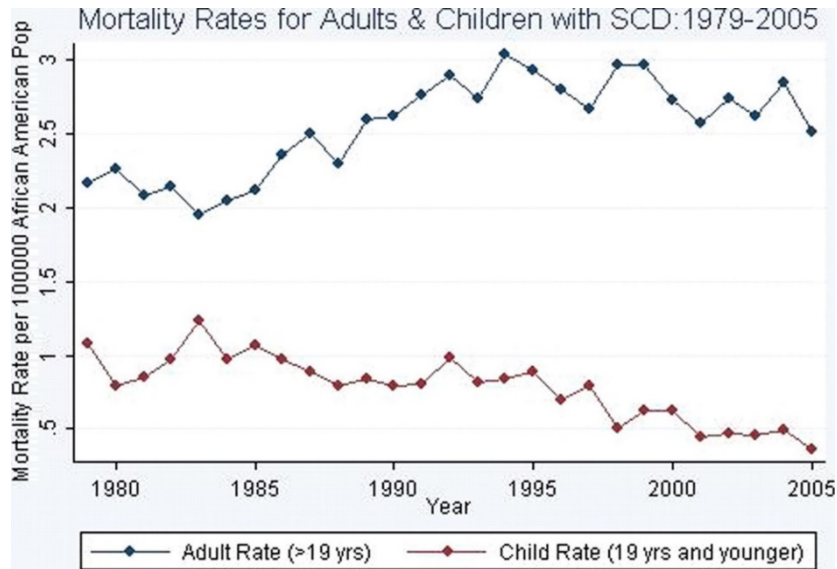


# From Evidence to Practice

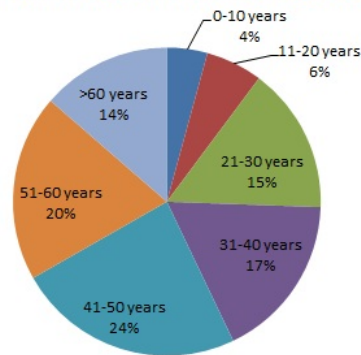
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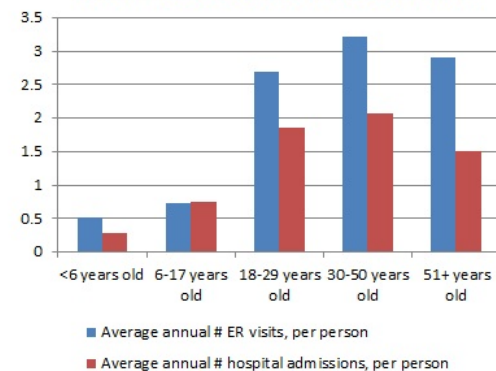
# SCD Age Related Disparities



**California RuSH SCD Cases 2004-08 Age at Death**



**California RuSH SCD Cases 2004-08 Utilization**



# Sickle Cell Disease Implementation Consortium

- First NHLBI research program to use Implementation Science to identify and address barriers to quality care in sickle cell disease



- Multi-modal, multi-sector strategies promote adoption of research findings into healthcare, to address healthcare disparities
- Goals
  - Conduct needs based community assessment of barriers to care
  - Design studies to address barriers
  - Develop SCD Registry

# Needs Assessment Basic Survey

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- ▶ Demographics
- ▶ SCD Genotype
- ▶ Sickle Cell Disease Self-Efficacy



- ▶ Pain Interference

ASCQ-Me

*Adult Sickle Cell Quality of Life Measurement Information System*

- ▶ Pain Episode Frequency
- ▶ Pain Episode Severity
- ▶ Quality of Care
  - ▶ Provider Communication
  - ▶ Emergency Department Care
- ▶ Access to routine and

## Individuals with Sickle Cell Disease (N = 440)

<b>Gender, n (%)</b>	Female	245 (56)
	Male	193 (44)
<b>Age, n (%)</b>	15 - 18 years	92 (21)
	19 - 30 years	176 (40)
	31 - 50 years	172 (39)
<b>Race, n (%)<sup>a</sup></b>	African American/Black	428 (97.5)
	Other	8 (2)
<b>Hispanic ethnicity, n (%)<sup>a</sup></b>	No	414 (95)
	Yes	22 (5)

▶ <sup>a</sup>Percentages do not always add up to 100 due to non-responders

## Individuals with Sickle Cell Disease (N = 440)

<b>Head of Household educational attainment, n (%)<sup>a</sup></b>	High school graduate or less	142 (36)
	Some college/AA	142 (36)
	College degree or higher	91 (23)
<b>Occupation, n (%)<sup>a</sup></b>	Working now	116 (27)
	Disability Income	131 (30)
	Student	104 (24)
	Other	80 (18.5)
<b>Annual income, n (%)<sup>a</sup></b>	< \$30,000	268 (66)
	> \$30,000	108 (27)

▶ <sup>a</sup>Percentages do not always add up to 100 due to non-responders



## Individuals with Sickle Cell Disease (N = 440)

<b>Insurance, n (%)<sup>b</sup></b>	Medicaid	166 (39)
	MediCare	129 (30)
	Private	70 (16.5)
	Other	21 (5)
	None	9 (2)
<b>Hemoglobin type, n (%)</b>	Hgb SS/ Hgb S $\beta$ zero	306 (70)
	thalassemia	88 (20)
	Hgb SC	18 (4)
	Hgb S beta + thalassemia	2 (0.5)
	Other	21 (5)
	Don't know	

▶ <sup>b</sup>Multiple insurances could be selected

# Psychometric Properties

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- ▶ **Reliability (Cronbach's alpha)**
  - ▶ Pain Interference = 0.95
  - ▶ Self-Efficacy = 0.87
  - ▶ ASCQ-Me QoC = 0.73
- ▶ **Construct Validity (CFA)**
  - ▶ Pain Interference – all items loaded to one factor with factor loadings  $> 0.71$
  - ▶ Self-Efficacy – all items loaded to one factor with factor loadings  $> 0.56$



# Psychometrics (cont'd)

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- ▶ **Construct Validity (CFA)**
  - ▶ ASCQ-Me QoC – items loaded to two factors (Provider Communication and ED Care), excluding item asking about access to outpatient appointments
  - ▶ RMSEA = 0.07; Bentler CFI = 0.94



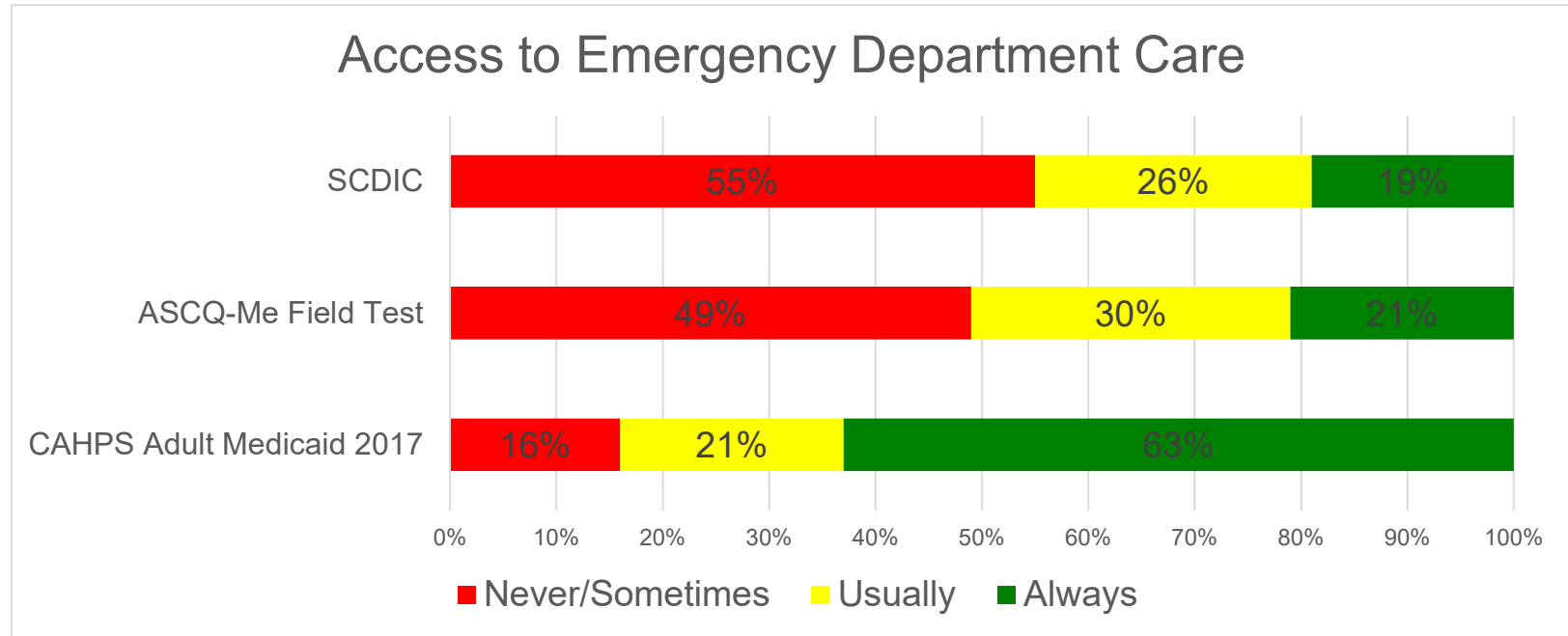
# Factors Associated with Pain Interference and Self-Efficacy

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- ▶ In linear regression models, increased pain interference associated with female gender, older age, lower income, disabled status, public or no insurance, increased frequency and severity of pain episodes, higher ED and inpatient utilization, severe pain with no healthcare
- ▶ Decreased self-efficacy associated with older age, lower income, disabled status, increased frequency of pain episodes, higher ED and inpatient utilization, severe pain with no healthcare

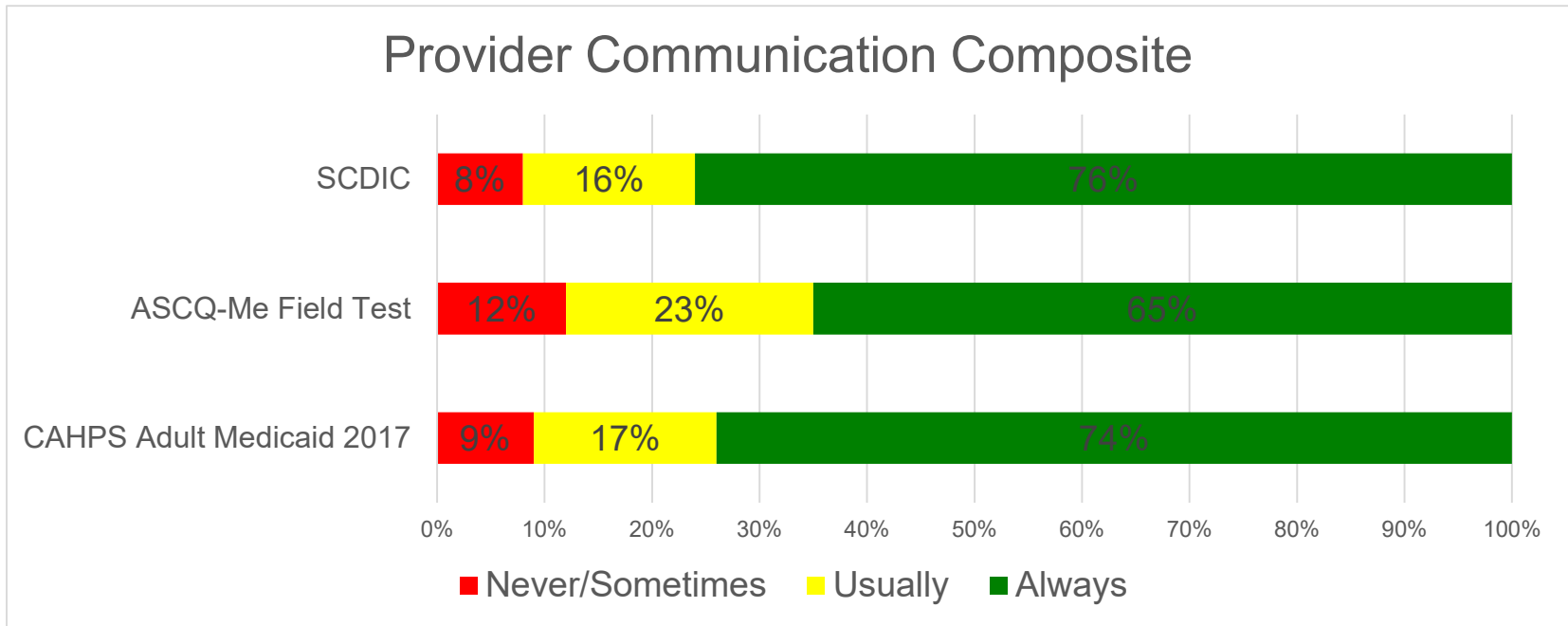


# Known Groups



- ▶ 67% of 379 respondents reported delayed or avoided going to the ED when they thought they needed care in the past 12 months

# Known Groups

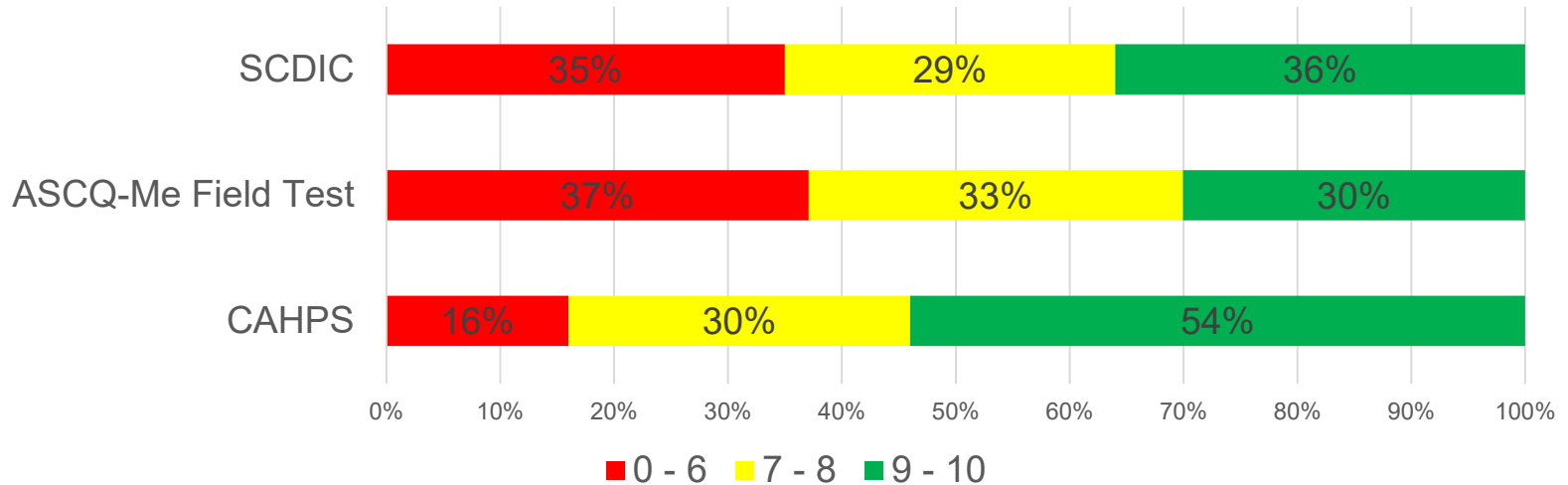


- ▶ 83% of 361 respondents reported they have a usual care provider who generally treats “a lot of patients with SCD”

# Known Groups

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## Overall Ratings Quality of Care



- ▶ Pain severity/frequency impacted satisfaction with non-acute care; limited demographics associated with satisfaction with ED care
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# Summary

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- ▶ SCDIC needs assessment provided opportunity to contribute additional information about the validity and reliability of ASCQ-Me and PROMIS measures with a geographically diverse SCD sample
  - ▶ Measures appear reliable for our sample, with good construct, face validity
  - ▶ ASCQ-Me QoC demonstrated different factor structure compared with field test





# Summary

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- ▶ Findings highlight pervasive disparities in outcomes and access to resources for the population, underscoring the importance of the work of the consortium



# SCDIC Proposed Interventions

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- IS aims focus not only on evaluating clinical effectiveness of interventions but focus on understanding the context of the interventions
- IS outcomes include focus on acceptability and feasibility of interventions, as well as barriers and facilitators to implementation
- Example:
  - ED Care protocol will intervene at the level of the patient (improve access to, and motivation to use, individualized medication prescribing and monitoring protocol (IPP)) and provider (knowledge barriers to pain management and access to IPP) and will consider differences in contexts across sites

# SCDIC Registry - Data Elements

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## ▶ phenX Toolkit

- ▶ Sickle Cell Disease Core Tier 1 and Core Tier 2 demographics

## ▶ PROMIS

- ▶ Pain Quality
- ▶ Emotional Distress - Depression
- ▶ Fatigue

## ▶ Neuro-QOL

- ▶ Cognitive Function

## ▶ ASCQ-Me

- ▶ Pain Episode Frequency
- ▶ Pain Episode Severity
- ▶ SCD Medical History Checklist
- ▶ Emotional Impact
- ▶ Pain Impact
- ▶ Sleep Impact
- ▶ Social Functioning Impact



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