

Sickle Cell Disease Implementation Consortium

Marsha Treadwell, PhD

Principal Investigator

UCSF Benioff Children's Hospital Oakland

Ellen M. Werner, PhD, MA

Senior Science Officer in Data Science

Program Director, Blood Epidemiology and Clinical Therapeutics

National Heart, Lung, and Blood Institute/NIH

HealthMeasures User Conference

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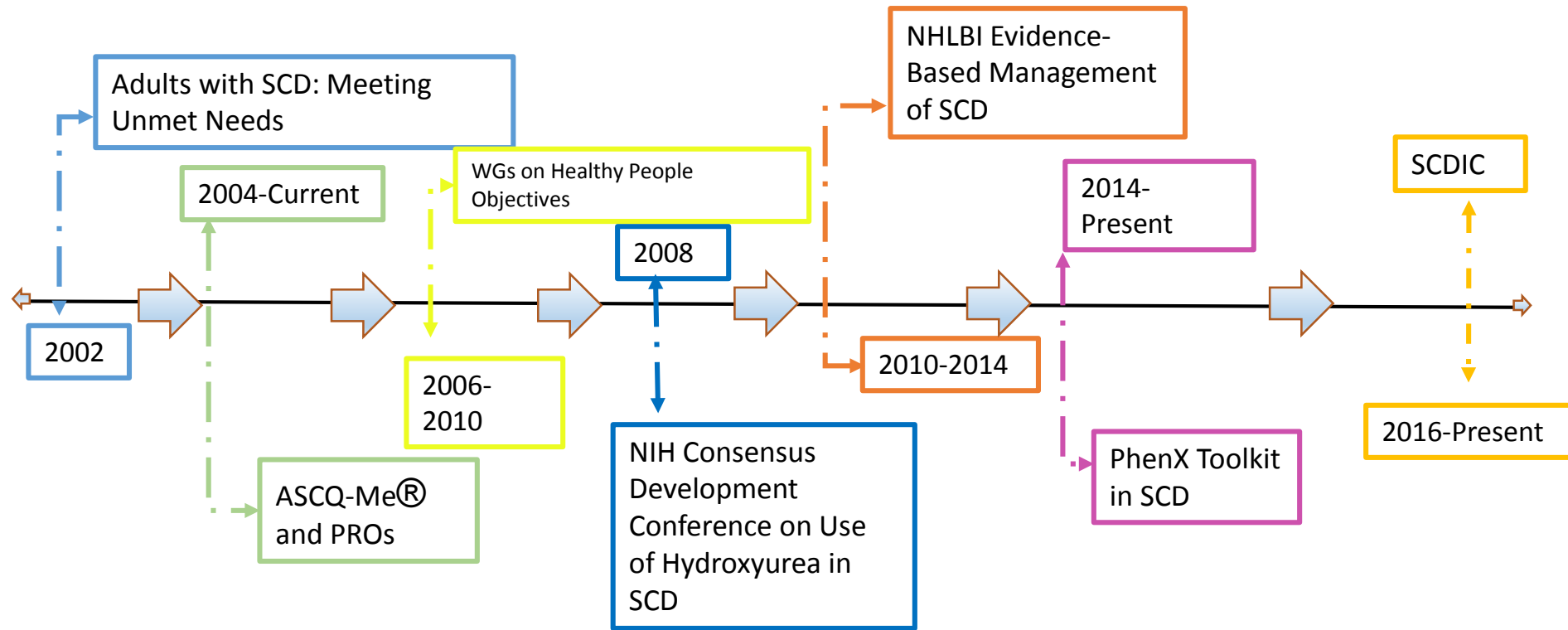


Objective

- ▶ To describe the development of a uniform system of common data elements (CDEs), including Patient Reported Outcomes (PROs) for data collection within the Sickle Cell Disease Implementation Consortium (SCDIC) needs assessment and registry

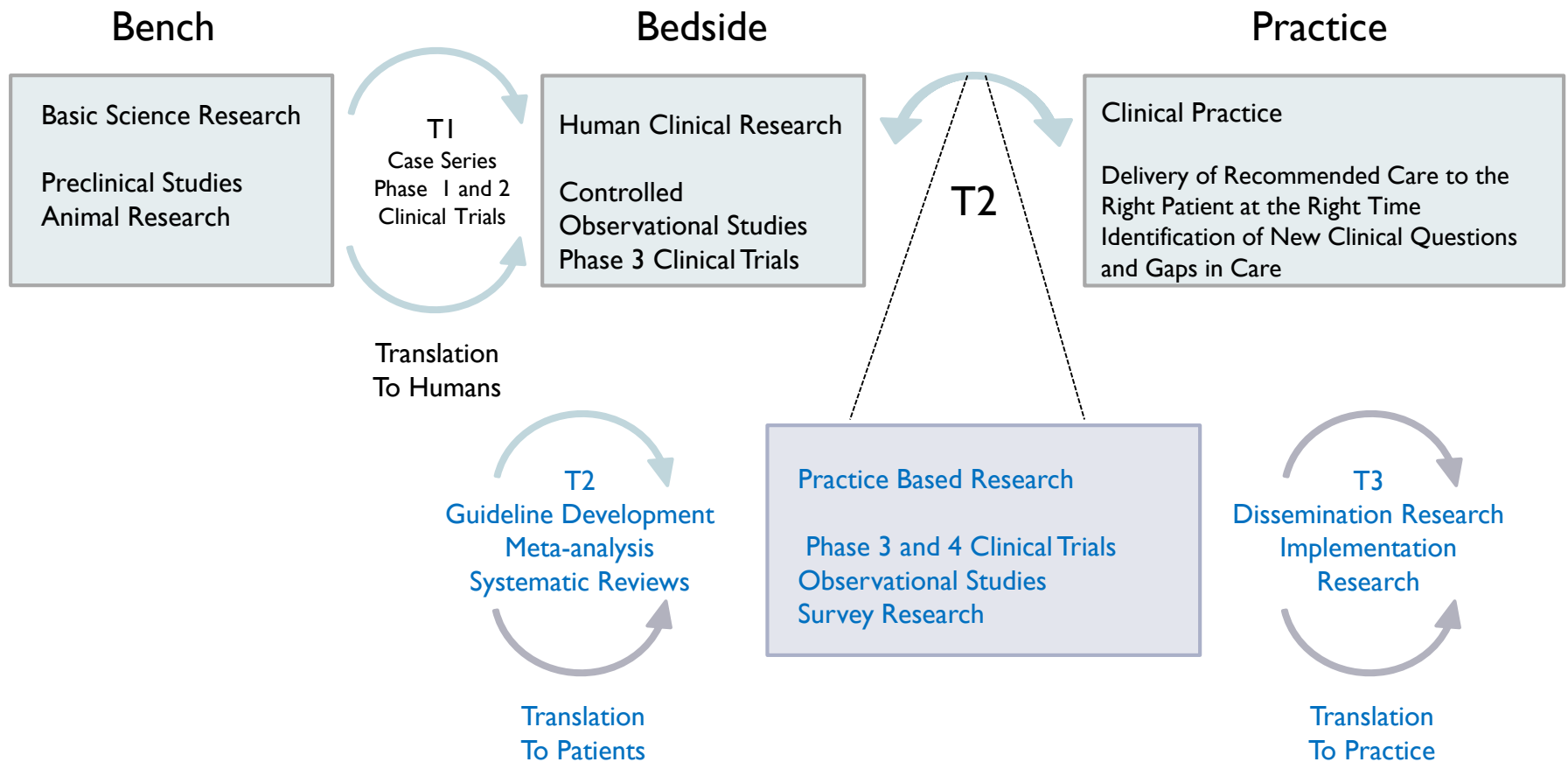


Genesis of the SCDIC 2002-Present

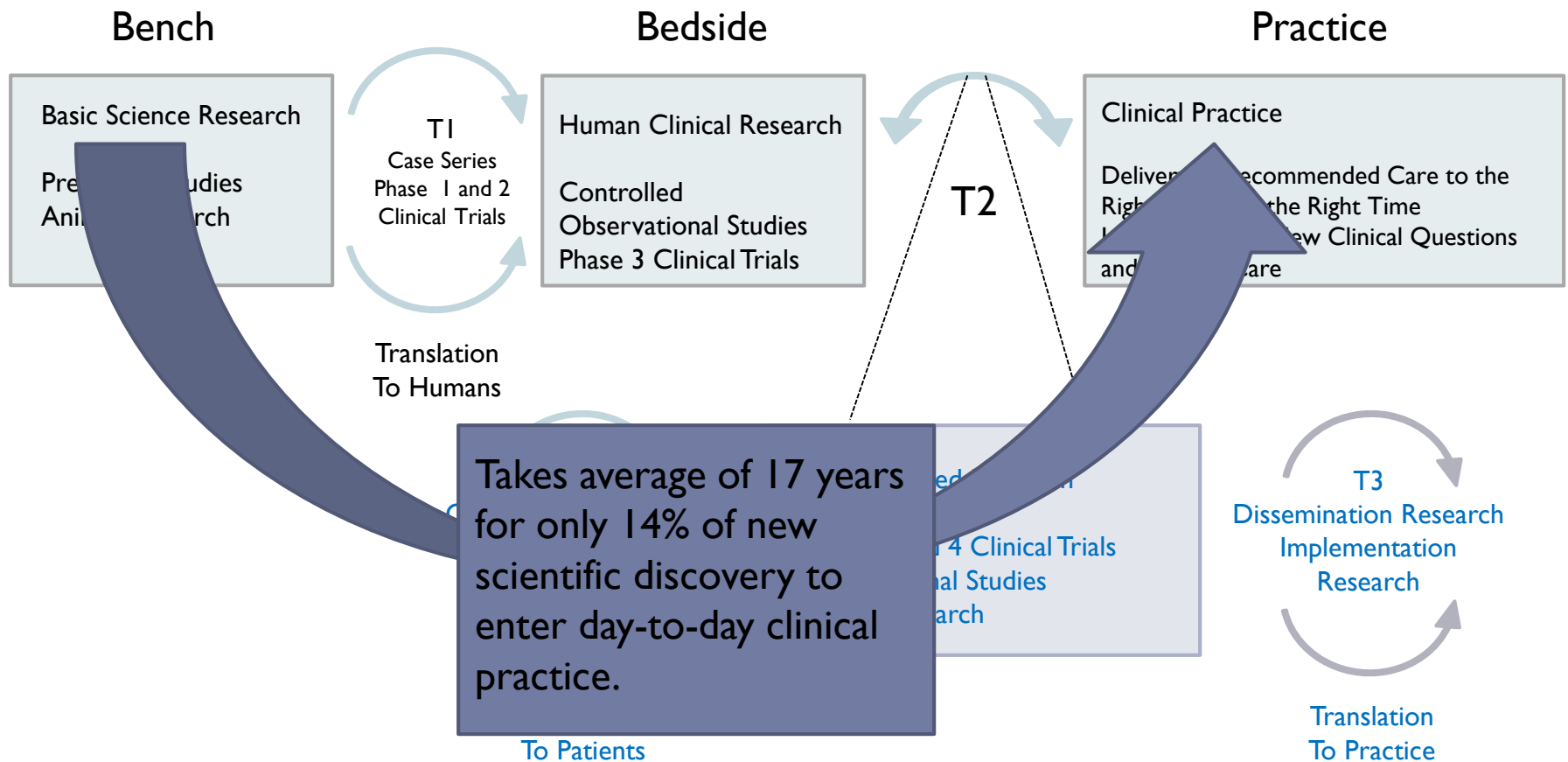


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From Research to Practice



From Research to Practice



Implementation Science



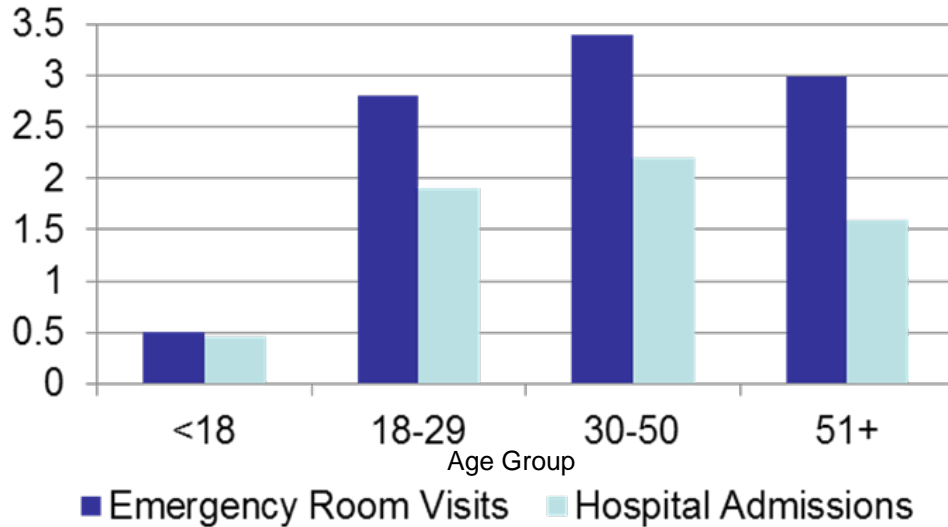
NHLBI's Sickle Cell Disease Implementation Consortium

- ▶ NHLBI committed to funding research into the implementation of evidence-based therapies in heart, lung and blood disorders
 - ▶ Established NHLBI Center for Translational Research and Implementation Science in 2014
- ▶ Focus on disparities in healthcare and accelerations in advances needed in SCD
 - ▶ Patients often live in challenging social contexts, with poorly understood barriers to care
 - ▶ Youth and adults experience high mortality, severe pain, progressive decline in functional status, underutilization of evidence based therapies, lack of access to knowledgeable care

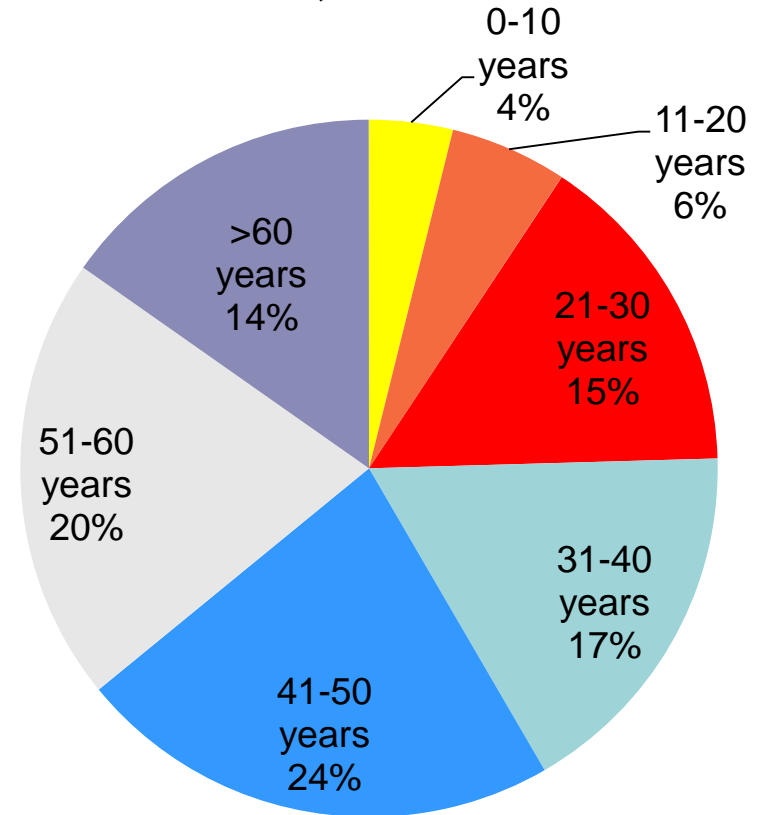


Transition from Pediatric to Adult Care

Healthcare Utilization



Age at Death for People with SCD, 2004-2008



- Hospital admissions and ED visits rise dramatically after age 18
- Over 40% of deaths occurred in patients 40 years and younger

Sickle Cell Disease Implementation Consortium

Site	PI(s)
University of Illinois at Chicago	Gordeuk/Hsu
St Jude Children's Research Hospital	Hankins/Klesges
Washington University School of Medicine	King
Georgia Regents University	Kutlar/Gibson
Medical University of South Carolina	Melvin/Kanter
Icahn School of Medicine at Mount Sinai	Richardson/ Glassberg
Duke University	Tanabe/Shah
UCSF Benioff Children's Hospital Oakland	Vichinsky/Treadwell

Coordinating Center – RTI

Steering Committee Chair – Alexis Thompson, MD

NHLBI Project Officer – Sharon Smith, PhD



SCDIC Phases

Phase I Needs Assessment

- ▶ Qualitative and quantitative data collection agreed upon
- ▶ Needs Assessment underway

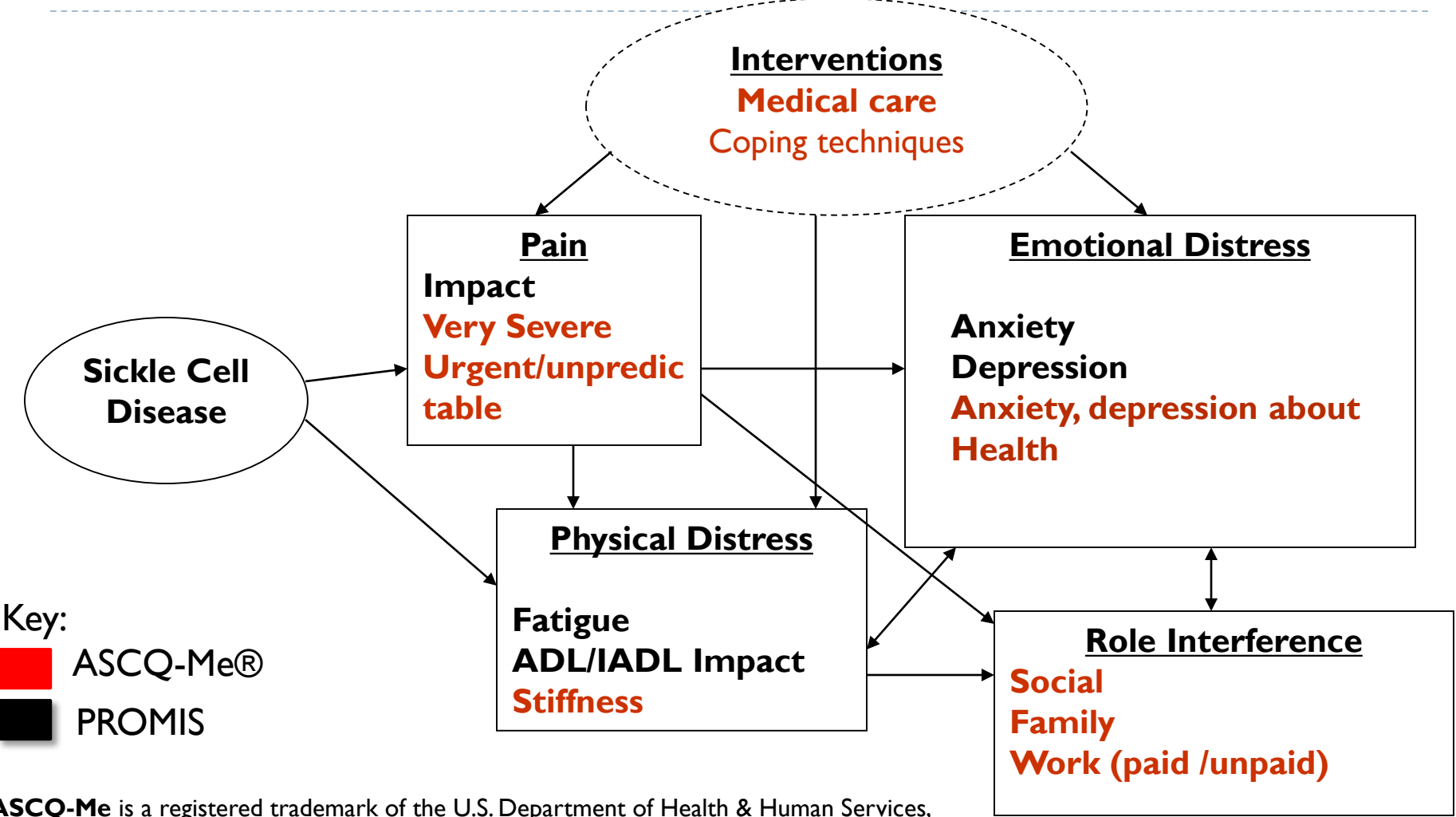
Phase II Registry

- ▶ Uniform system of common data elements including PROs determined
- ▶ Sites beginning data collection

Phase III Implementation Studies

- ▶ Planning studies:
 - ▶ Care Redesign
 - ▶ Emergency Department Care
 - ▶ Reducing # of unaffiliated patients

Conceptual Model for HRQOL in SCD

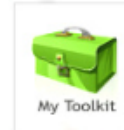


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▶ Treadwell et al *Clin J Pain* 2014;30:902-14
 Keller et al *Health Qual Life Outcomes* 2014;12:125



PhenX Toolkit



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Welcome to the PhenX Toolkit

Mental Health Research Collection - Early Psychosis is now available [here!](#)

The PhenX (consensus measures for **Phen**otypes and **eX**posures) Toolkit is a catalog of recommended, standard measures of phenotypes and environmental exposures for use in biomedical research. PhenX measures can be used to expand a study design beyond the primary research focus. Use of PhenX measures facilitates cross-study analysis, potentially increasing the scientific impact of individual studies. The PhenX Toolkit is a Web-based resource and is available for use at no cost. [More >>](#)





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COLLECTION: Sickle Cell Disease Research 
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Sickle Cell Disease Research Working Group 2: Neurology, Quality of Life, and Health Services Specialty Collection - [View Roster](#)

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SCD Measures in PhenX



Needs Assessment Domains

- ▶ Patient Experience
- ▶ Patient Health Metrics
- ▶ Barriers to Care
- ▶ Demographics
- ▶ Medical History
- ▶ Health Literacy
- ▶ Utilization
- ▶ Treatments



Needs Assessment – Basic Survey

- ▶ phenX Toolkit
 - ▶ Demographics
 - ▶ SCD Genotype
 - ▶ Sickle Cell Disease Self-Efficacy
- ▶ PROMIS
 - ▶ Pain Interference
- ▶ ASCQ-Me®
 - ▶ Pain Episode Frequency
 - ▶ Pain Episode Severity
 - ▶ Quality of Care
 - ▶ Provider Communication
 - ▶ Emergency Department Care
 - ▶ Access to routine and emergency care



ASCQ-Me

Adult Sickle Cell Quality of Life Measurement Information System

Needs Assessment – Optional Measures

- ▶ **ASCQ-Me[®]**
 - ▶ Emotional Impact
 - ▶ Social Functioning Impact
- ▶ **PROMIS**
 - ▶ Global Health – PROMIS 29
- ▶ **HRSA SCDTDP**
 - ▶ Barriers to Care
- ▶ **CAHPS**
 - ▶ Prescription Medicine Costs
 - ▶ Health Literacy
 - ▶ Care from Specialists
 - ▶ Cultural Competency
 - ▶ Patient Centered Medical Home (Access)

Registry - Common Data Elements

- ▶ **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

▶ NeuroQoL

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Research Questions

- ▶ Complications/Co-Morbidities
- ▶ Treatments
- ▶ Access to Care
- ▶ Quality of Life and PROs
 - ▶ Social determinants of health and HRQoL
 - ▶ Pain experiences, healthcare utilization as a function of age, gender
 - ▶ Geo-mapping and disability attributable to SCD
 - ▶ Longitudinal changes in HRQoL



Conclusion

- ▶ **Comprehensive HealthMeasures systems, PhenX Toolkit**
 - ▶ Provide foundation for understanding patient needs then developing and evaluating multi-modal, multi-sector interventions to address longstanding and pervasive disparities that youth and adults with SCD face in accessing quality healthcare



