

Sickle Cell Care Coordination Initiative

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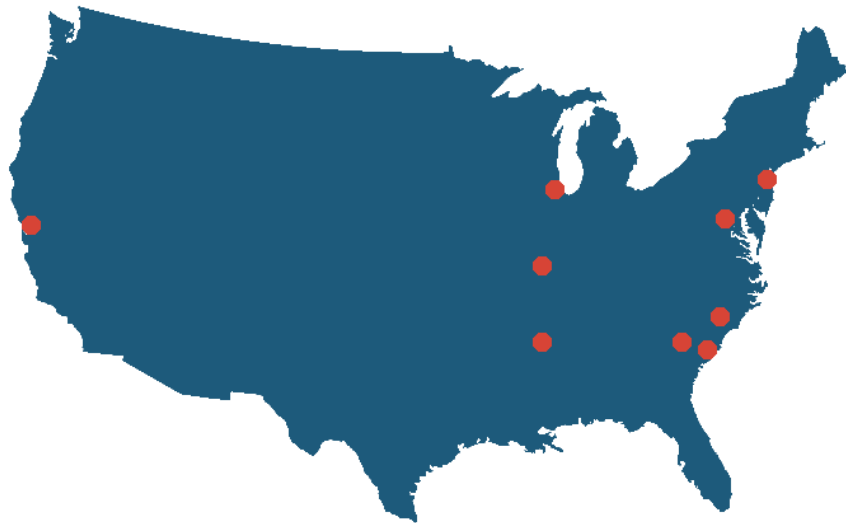
From Research to Practice

- ▶ The fraction of discovery science reaching patients in clinical practices is very low
 - ▶ It takes an average of **17 years** for **only 14%** of new scientific discoveries to enter day-to-day clinical practice
 - ▶ Americans receive, on average, **only half** of recommended preventive, acute, and long-term quality health care
- ▶ This proportion for SCD is even lower

Implementation Science

- ▶ A means to address healthcare inequities
- ▶ Broader scope than traditional clinical research, encompassing patient, provider, organizational and policy levels of health care
- ▶ IS research engages multi-sector/multi-modality interventions to overcome the barriers to health care
- ▶ NHLBI made commitment in 2014 to funding research into the implementation of evidence-based therapies in heart, lung and blood disorders





- ▶ Using implementation science to address known disparities related to SCD
 - ▶ Decreased survival compared with general and African American populations
 - ▶ Diminished quality of life for adults
 - ▶ Failure to put existing guidelines into practice

Goal of SCDIC is to accelerate use of NHLBI guidelines and make their use more widespread



SCDIC Project Phases

Phase I: 2 years

Needs Assessment

- Medical, patient, community stakeholders
- Identify barriers and gaps to healthcare

Registry

- Common data elements
- Drawn from data science tools

Administrative Review

Phase II: 4 years

Implementation Studies

- Multi-modal
- Multi-sector
- Informed by needs assessment

Registry continues



Sickle Cell Care Coordination Initiative



- ▶ Targeting five counties
- ▶ Needs Assessment nearing completion
 - ▶ 55 individuals with SCD interviewed and surveyed from every county
 - ▶ 45 providers interviewed from 4 counties
 - ▶ 29 providers surveyed from every county
 - ▶ 5 key informants interviewed
- ▶ Beginning analysis of this diverse input



Identifying Sickle Cell Challenges from Needs Assessment

Youth/Adults with SCD

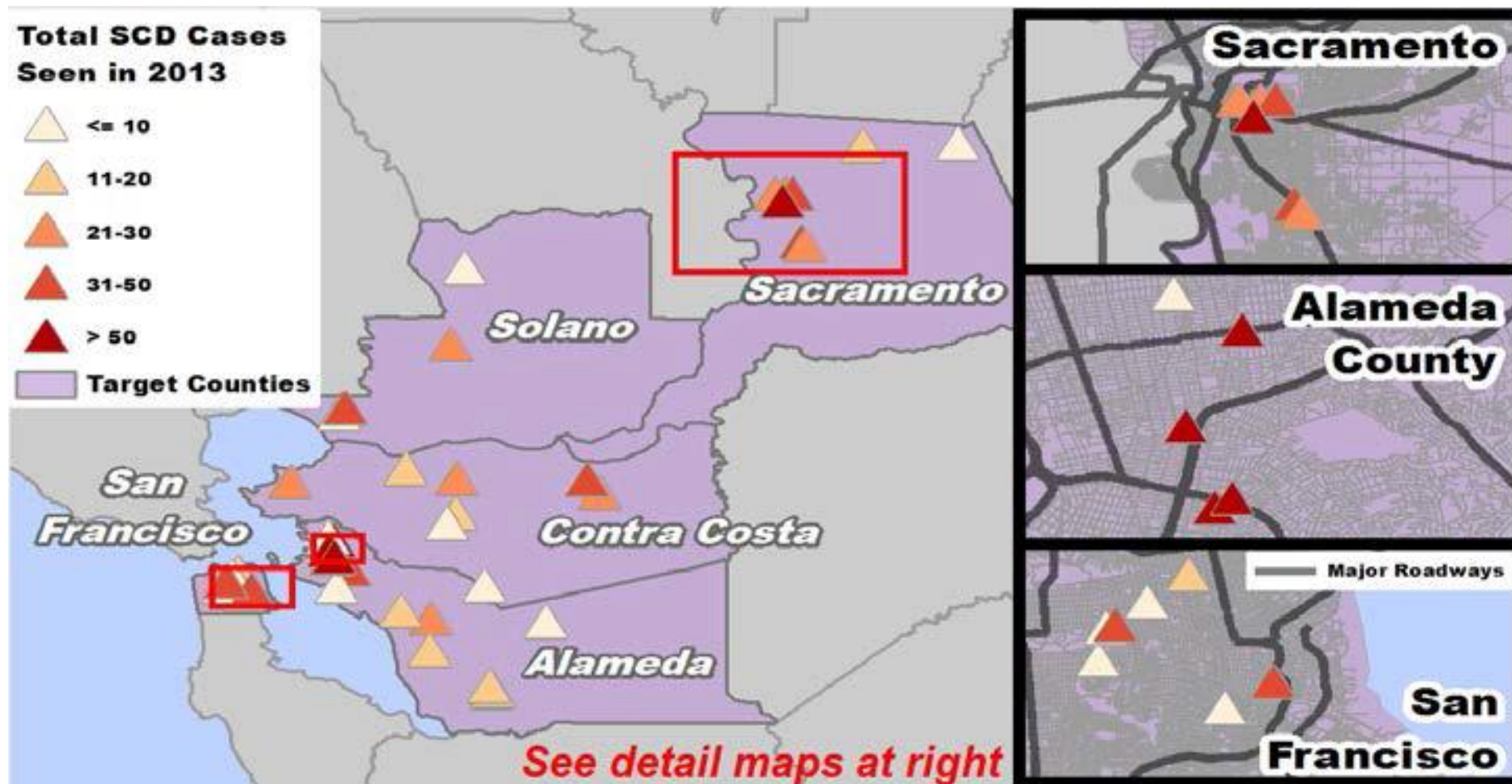
- ▶ Living with SCD
- ▶ Experiences with receiving care
 - ▶ What works, what does not work
- ▶ Experiences with hydroxyurea
 - ▶ Barriers/facilitators
 - ▶ What would help to improve care

Providers/Key Informants

- ▶ Experiences with providing care
 - ▶ What works, what does not work
 - ▶ What would help
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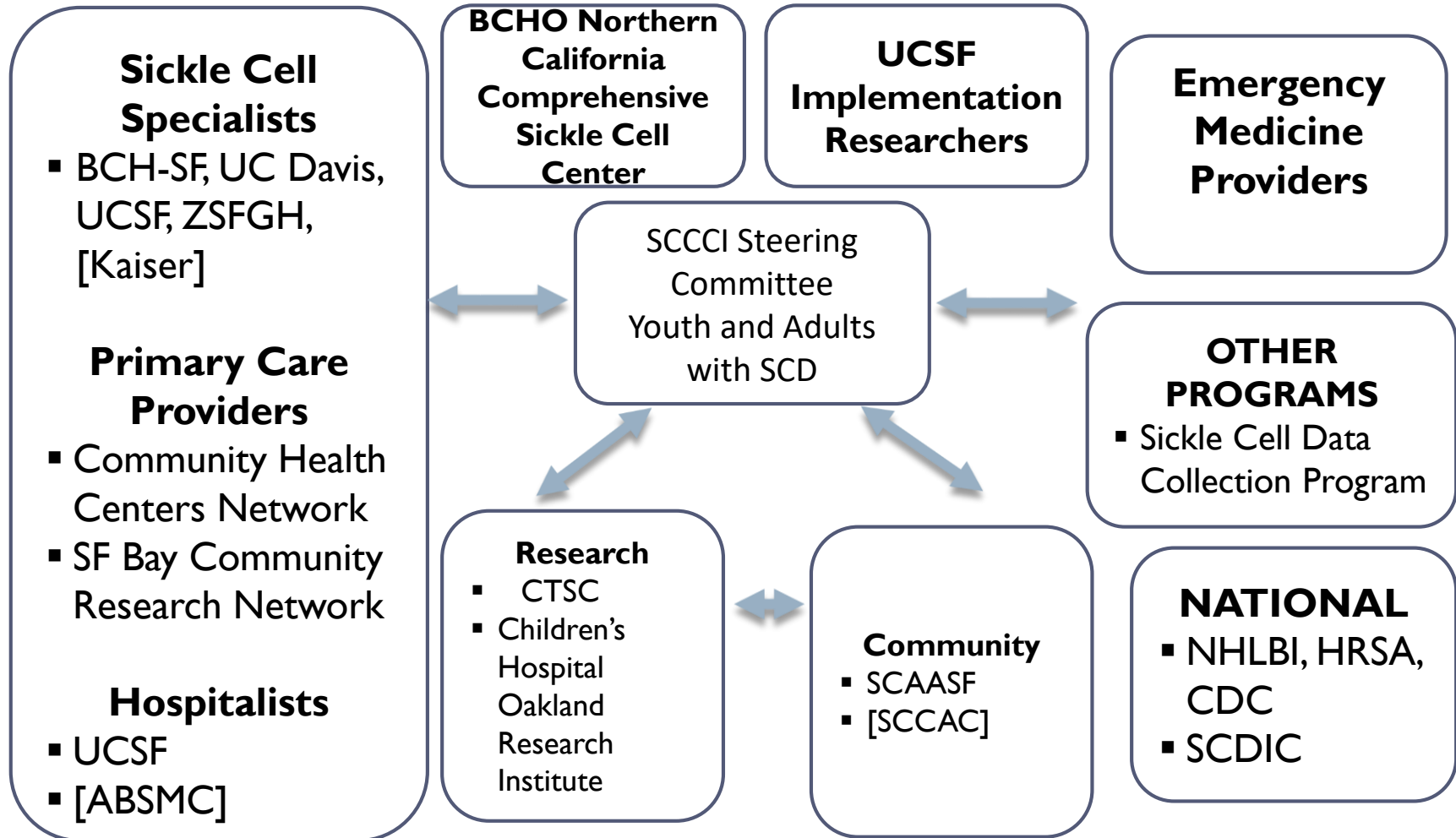


SCCCI 5 County Catchment Area Total SCD Cases - 2013



▶ N = 1120 unique patients in targeted age group; planned registry enrollment n = 300

SCCCI Partners



Potential Interventions

- ▶ **Care Redesign**

- ▶ Creating and improving partnerships between primary care providers and sickle cell specialists
- ▶ Bringing unaffiliated patients into care with sickle cell specialists
- ▶ Improving ED care
- ▶ Improving transition from pediatric to adult care



