

Adult Sickle Cell Clinic at MLK Jr Outpatient Center



**On site of infamous
hospital, L.A. County
tries new approach
to serving health
needs of area's poor**

Los Angeles Times 10/8/2016



Dr. Susan Claster, left, and Dr. Bernadette Manalo, right, talk to patient Philadelphia Philpot at the MLK Jr. Outpatient Center's new sickle cell clinic. (Marcus Yam / Los Angeles Times)



Affiliations and Disclosures

- ▶ Judith R. Baker, D.Ph., MHSA: Director of Public Health, Center for Inherited Blood Disorders (CIBD), Santa Ana, CA; Policy Director – Pacific Sickle Cell Regional Collaborative; and Assistant Adjunct Professor, University of California Los Angeles
- ▶ Susan Claster, MD: Professor of Medicine at University of California, Irvine; Center for Inherited Blood Disorders, Hematologist MLK Sickle Cell clinic
- ▶ Ellen Rothman, MD: Chief Medical Officer at MLK Jr Outpatient Center, division of Los Angeles County Department of Healthcare Services
- ▶ The presenters have no disclosures.



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Objectives

- To articulate the **impetus** for the new Adult Sickle Cell Disease clinic – why and how we started.
- To assess the strengths and weaknesses of the **medical home model to address complex healthcare needs**
- To introduce a **new delivery model** that *integrates primary care, hematology and behavioral health.*



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Adults with Sickle Cell Disease

- Chronic renal failure
- CNS Dementia – multiple strokes
- Chronic leg ulcers
- PHTN/Cardiac failure – small vessel
- **Permanent damage:** brain, heart, lungs, kidneys, liver, bones and spleen.
- Retinopathy
- Iron overload
- Chronic pain – severe & unpredictable
- Psychosocial, vocational, socio-economic challenges

Limited options for adults with SCD

- Shortage - adult hematologists w/special expertise
- PCPs - limited experience
- Non-specialists uncomfortable prescribing Hu
- PCPs and hematologists – uncomfortable managing chronic pain
- Heavy reliance on Medicaid

Erin Marcus – *Our healthcare systems abandons adults with Sickle Cell Disease*

Washington Post 3/21/2016



Sickle Cell Today in the US

Dismal Unacceptable
National Embarrassment

Treatable
Treatable
Treatable !!!

Massive Societal Indifference at all levels

Preventable deaths and morbidities cannot be allowed to be considered the norm - Craig Hooper, PhD., Director, CDC Division of Blood Disorders, Thrombosis and Hemostasis Societies of North America – April 2016

Disclaimer: The findings and conclusions are those of the author and do not necessarily represent the official position of the Center for Disease Control and Prevention.

Why Los Angeles?

51% of Californian adults with SCD live in L.A.

SCD mortality higher in L.A. than rest of the country

Powars Medicine 2005

No comprehensive clinic besides Kaiser



Longitudinal Data Collection
for Sickle Cell Disease in California:
History, Goals and Challenges



Sickle Cell Disease – Southern California

	Total	Pediatric	Adults
Los Angeles	2065	920	1145
Orange	121	56	65
San Bernardino	286	111	175
Riverside	280	102	178
San Diego	286	111	175
TOTAL	3038	1300	1738

**20-80% of
patients
Hispanic in
some cities**

Transition from Pediatric to Adult Services is Risky

- Teen and young adults suffer from more frequent SCD-related complications than younger patients
- Increased ED utilization after transition
- Longer travel distance to an adult SCD center is a risk factor for unsuccessful transition
- Until now, there has been no public clinic offering tailored, coordinated services to the adult SCD population in Los Angeles County

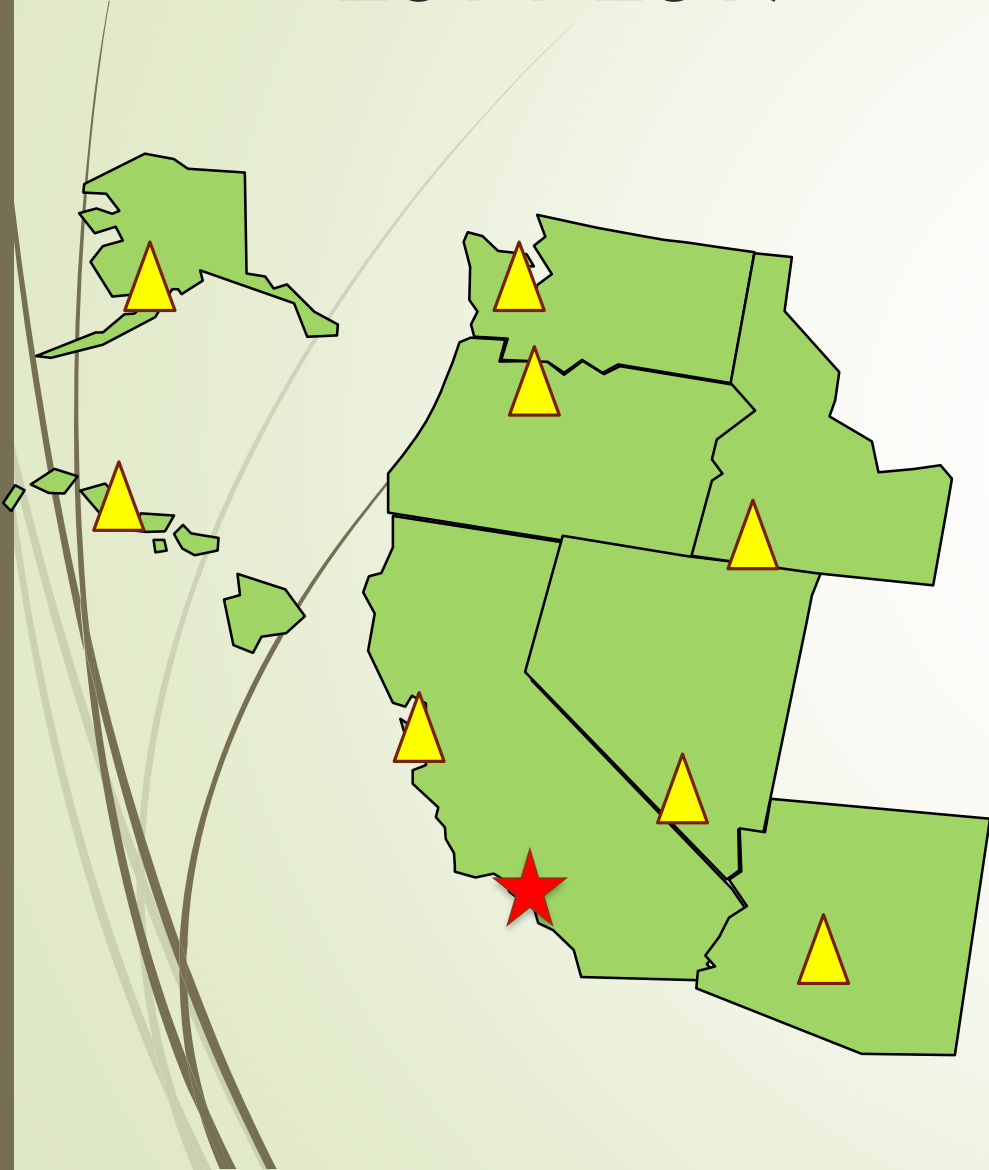
HRSA Pacific Sickle Cell Regional Collaborative 2014-2017

<http://pacificscd.org/>

Goals

- Increase provider knowledge
- Increase evidence based therapy - hydroxyurea
- Improve access to care

GRANTEE: The Center for
Inherited Blood Disorders



Mobilizing the Partners

Internal - Pacific Region

- **Alaska:** Providence Hospital, Anchorage
- **Arizona:** University of Arizona Cancer Center, Tucson
- **California:** Center for Inherited Blood Disorders*, UCSF Benioff Children's Hospital Oakland, UC Davis
- **Hawaii:** Kapi'olani Medical Center, Honolulu
- **Idaho:** St. Luke's Mountain States Tumor Institute, Boise
- **Nevada:** Children's Specialty Center, Las Vegas
- **Oregon:** Oregon Health Sciences University, Portland
- **Washington:** Seattle Children's Hospital, Seattle
- **Guam:** Department of Health & Social Services
- **CBO:** Sickle Cell Disease Foundation of California

* Backbone organization – Regional Grantee

External

- Government – federal, state, local
- Health Professions Societies
- Research Consortia
- CBOs

The Center for Inherited Blood Disorders

- Community Clinic – not for profit. Specialty Center.
- Sickle Cell...Thalassemia...Thrombophilia... Hemophilia...
- Advanced Diagnostic Lab
- Pharmacy
- **Federal Grantee** – *HRSA's Regional Hemophilia & Sickle Cell Networks*
- **Founder:** Diane J. Nugent, MD, Chief Hematology, CHOC Children's
- *Sickle Cell Disease Foundation of California on BOD*



<http://cibd-ca.org/>

Regionalization: Hemophilia's success

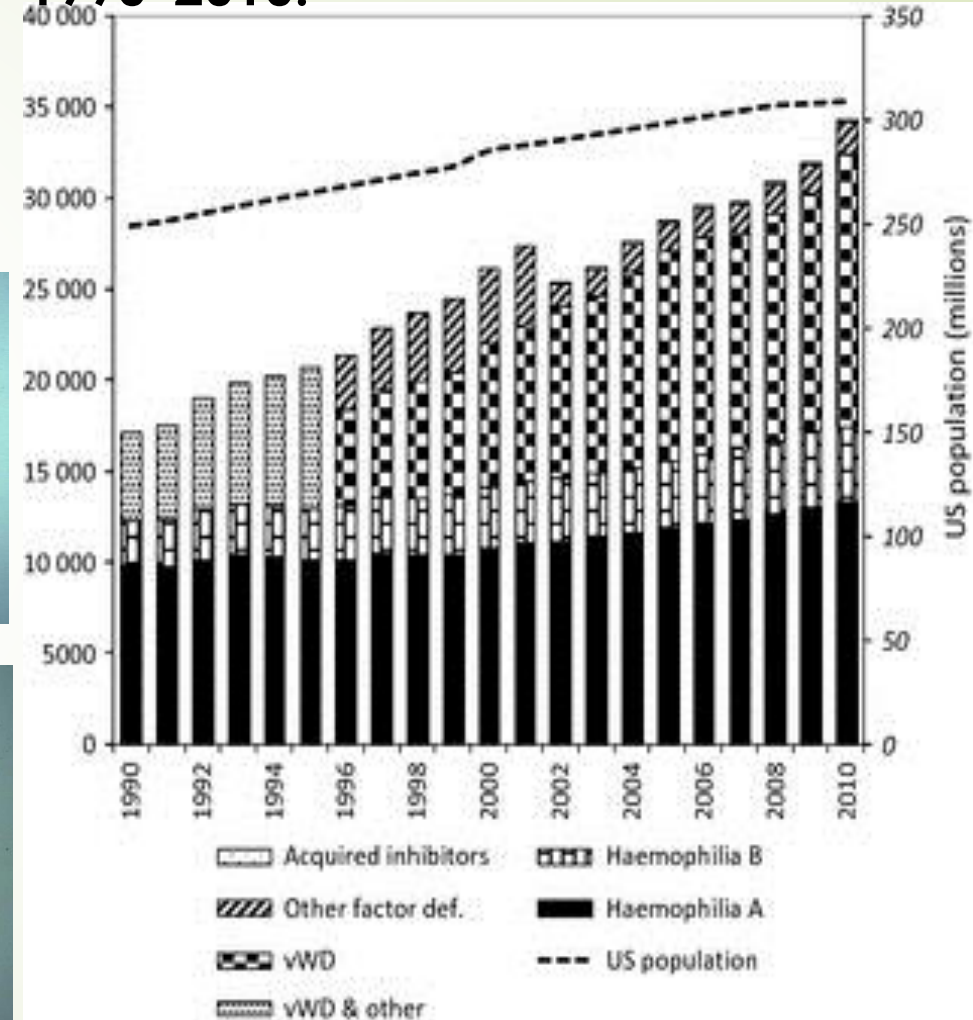
Team based care in regional
US Hemophilia Treatment
Centers:

40% reduction in mortality¹ &
morbidity²

Soucie et al., *Blood* 2000¹ and *Haemophilia* 2001²

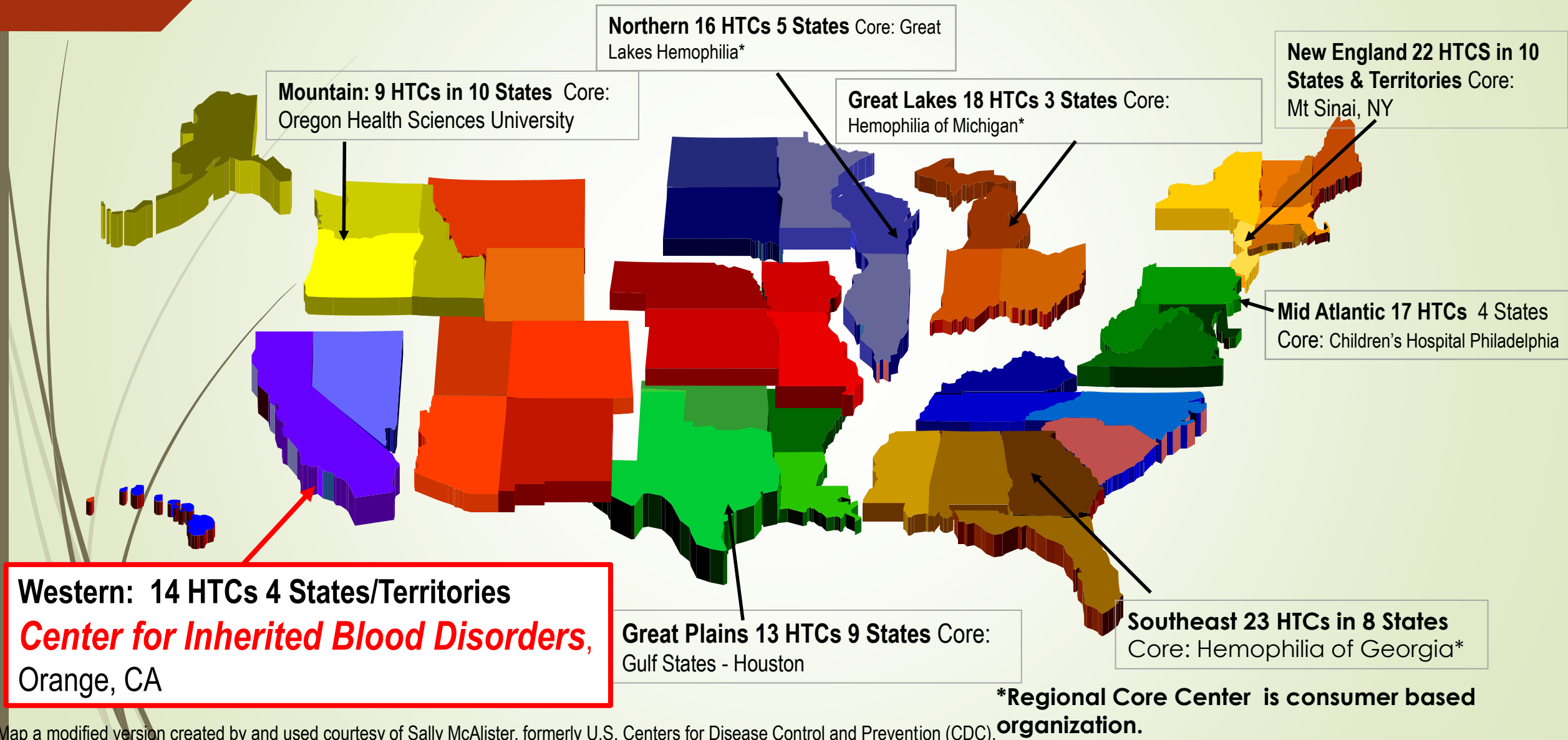


US Haemophilia treatment center patient population by diagnosis 1990–2010.



Baker et al., *Haemophilia* 2012

Regional Hemophilia Networks – 140 Centers/8 Hubs



Framework #1 → MLK Adult SCD Clinic

Collective Impact Model

Sectors: Clinicians, Public Health, Consumer Based Org

Leadership team

Collaboration highest levels

Shared decision making

Collective Impact Model

**Mobilize Partnerships →
Catalyze Mutually Reinforcing
Activities *REGION-WIDE***

Commitment of a group of actors from **different sectors** to a **common agenda** for solving a complex social problem.

Kania, Stanford Social Innovation Review 2011

Common Agenda

- Keeps all parties moving towards the same goal

Common Progress Measures

- Measures that get to the TRUE outcome

Mutually Reinforcing Activities

- Each expertise is leveraged as part of the overall

Communications

- This allows a culture of collaboration

Backbone Organization

- Takes on the role of managing collaboration

... but How?

Structuring the Pacific Sickle Cell Regional Collaborative → Departments

- Surveillance and Data
- Clinical Care Capacity
- Provider Education
- Policy / Partnerships
- CBO Capacity



Framework #2 → MLK Adult SCD Clinic

- Different Sectors: Clinicians, Public Health, Consumer Based Org
- *Public Health and Rare Disorders* – responsibility to build capacity outside our agency

Regional Networks - Advance Rare Disorder Public Health



- Surveillance – geographic
- Knowledge – regional networks & databases: share clinical expertise
- Health care - regional centers of clinical expertise – specialty access
- Regional networks of providers - coordinate treatment & reimbursement

Framework #3 → MLK Adult SCD Clinic

- Different Sectors: Clinicians, Public Health, Consumer Based Org
- Regionalization – responsibility to build capacity outside our agency
- 3 Pillars – Finance/Insurance component

*Chronic Care Model – Regional
Adaptation*

Framework for Creating a Regional Healthcare System

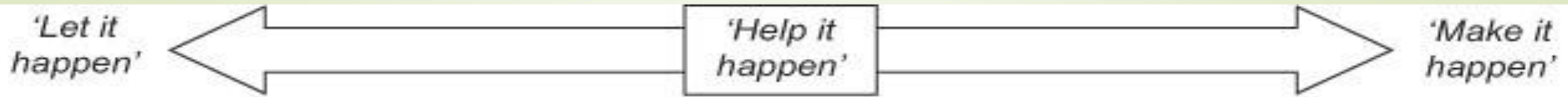


Finance models: for team based care, CHWs, preventive outpatient care, adult immunizations...

Framework# 4 → MLK Adult SCD Clinic

- Different Sectors: Clinicians, Public Health, Consumer Based Org
- Regionalization – responsibility to build capacity outside our agency
- 3 Pillars – Finance/Insurance component
- Make it happen: structured communications w/Leadership
- MLK Planning Team
 - Leadership reach out – commitment to solve problem. Who and how
 - Marketing – Leadership team bios & abstract
 - Bi-weekly meetings to clinic design & PR

Conceptual framework for the spread of innovations in service organizations



Defining features

Unpredictable,
unprogrammed,
uncertain, emergent,
adaptive, self-
organizing

Negotiated,
influenced,
enabled

Scientific, orderly,
planned, regulated,
programmed,
systems 'properly
managed'

Assumed mechanism

Natural,
emergent

Social

Technical

Managerial

Metaphor for spread

Emergence,
adaptation

Knowledge
construction,
making sense

Diffusion

Negotiation

Knowledge
transfer

Dissemination,
cascading

Re-
engineering

LA Department of Healthcare Services: *Initial Buy In*

- ➡ 9/18/15 – JRB to SC: do you know Mitch Katz, MD, Director
- ➡ 9/19/15 – JB drafts script: how to reach out
- ➡ 9/20/15 – SC to MK – Hello – Will you help us w/SCD?
- ➡ 9/22/15 – MK to SC – YES → talk to Hal Yee, MD, PhD
- ➡ 10/2/2015* – Hal Yee, MD, PhD: CMO of LA DHCS – YES → Ellen Rothman, MD, CMO, MLK Jr. Outpatient Center
- ➡ 10/16/2015 – Rothman meeting at MLK – YES!

LA Department of Healthcare Services

Initial Meeting 10/2/2015 – 30''

- Team: Hematologist, Public Health, Sickle Cell CBO ED & Program Director
- Tight structure = we talk for 10'', listen for 20''
- **Materials:** Data, Bio's, Abstract. Logic Model
- Agenda:
 - Intros
 - SCD – the Crisis in Los Angeles
 - Federal Response – HRSA Regional SCDTDP Grant Goals, HRSA NBS, NIH SCD Implementation Science Grant
 - Regional Government Partnerships
 - Los Angeles Partnership Opportunities

MLK Adult SCD Clinic Design Begins

Sectors: Clinicians, Public Health, Consumer Based Org

- **Bi-weekly: clinic design** - identify core clinical team components, services, fill SW/Data Mgr. funding gaps (CIBD), training, CHWs (SCDFC \$)
- **Bi-weekly PR meetings:** mission, vision, value, tagline. Print, Social
- Summer 2016 – Training clinical staff – trauma informed care
- July 2016 – Mock clinic
- August 2016 – Soft opening
- September 2016 – Webinars – pediatric SCD clinics
... and Official Opening

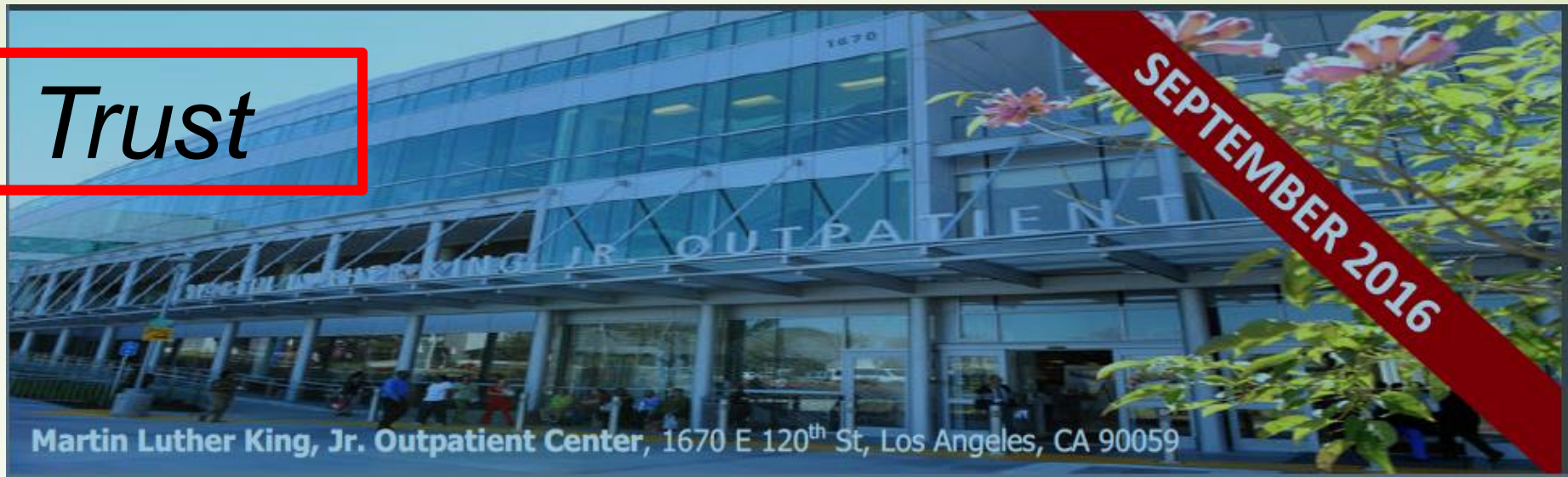




SCD Capacity Building at MLK OPC

- Co-locate team members with SCD experience alongside team members who are new to this realm of healthcare
 - Completed 5 sessions training the new health team about SCD, health maintenance, & team resilience in anticipation of opening
 - Completed a mock clinic with SCD patient volunteers to test workflows
 - Experienced nurse Charlotte Dixon from SCD Foundation of Southern California provides ongoing education
 - Hematologist provides SCD expertise and ongoing consultation for all team members

CBO – Trust



New! Sickle Cell Clinic at MLK Jr. Outpatient Center

Adults with Sickle Cell Disease...We can provide
the care you have always wanted!



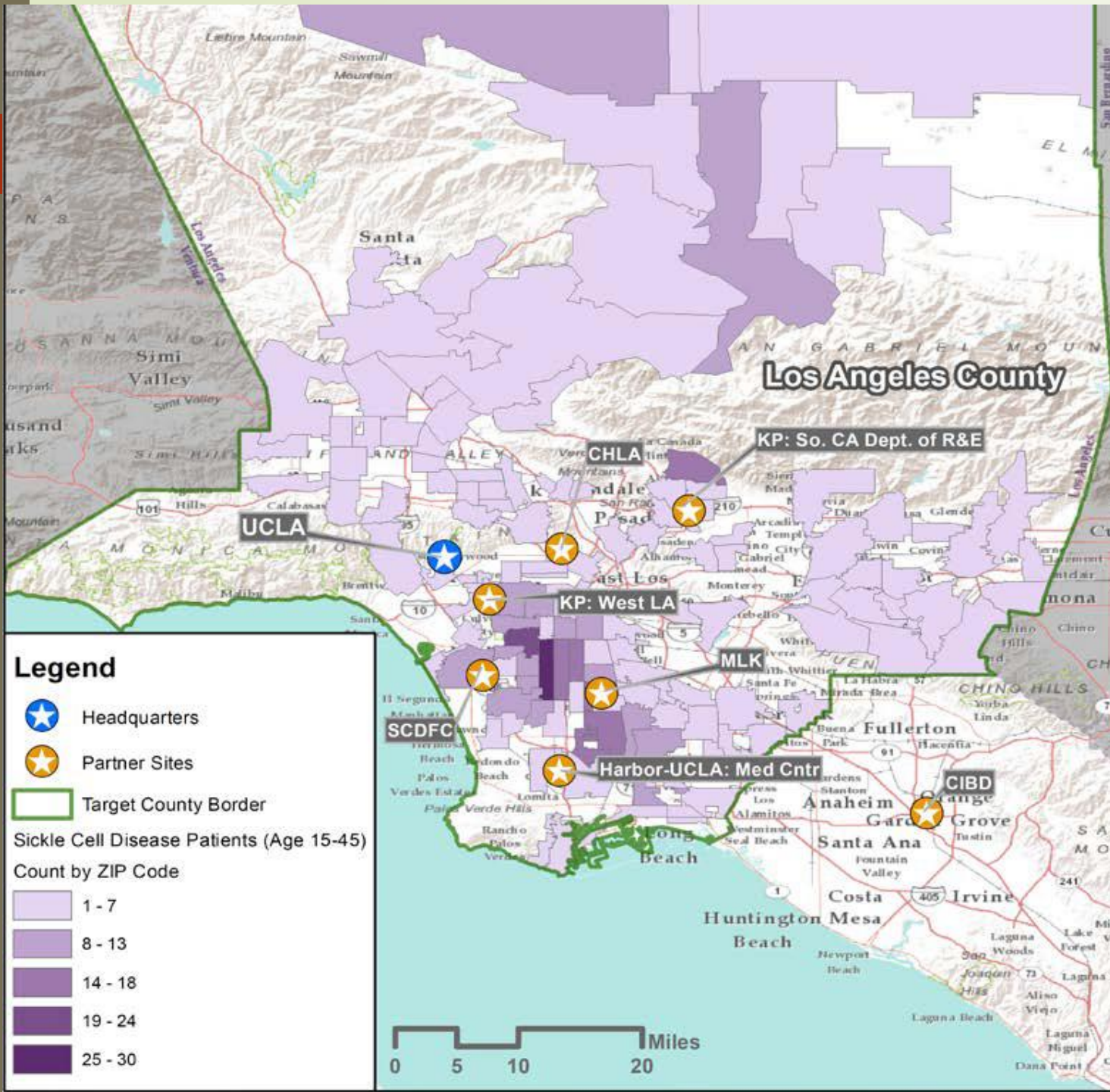
"Adults with sickle cell disease deserve health care providers that understand the disease, its complications, and their pain. Knowing the people who worked hard to open this clinic gives me confidence it will meet the community's needs."

**Mary Brown, President & CEO
Sickle Cell Disease Foundation of**

Los Angeles Residents with Sickle Cell Disease age 15-45

Zip code of Residence, 2015.

CBO – Data



Data sources: Sickle Cell Disease Foundation of California, and Center for Inherited Blood Disorders.

Map created by UCLA CTSI as part of *PRISM-SCD: Promoting Implementation Science Methodologies for Sickle Cell Disease* RFA-HL-16-010

Framework #5 → MLK Adult SCD Clinic

- Different Sectors: Clinicians, Public Health, Consumer Based Org
- Regionalization – responsibility to build capacity outside our agency
- 3 Pillars – Finance/Insurance component
- Make it happen: structured communications
- Complexity – multiple determinants of innovation adoption

Conceptual model for considering determinants of diffusion, dissemination and implementation of innovations in HS Service delivery and organization

THE INNOVATION
 Relative advantage
 Compatibility
 Low complexity
 Trialability
 Observability
 Potential for reinvention
 Risk
 Task issues
 Nature of knowledge required (tacit/explicit)
 Technical support

COMMUNICATION AND INFLUENCE
DIFFUSION
 (Informal, unplanned)

↑
 Social networks
 Homophily
 Peer opinion

↓
 Marketing
 Expert opinion
 Champions
 Boundary spanners
 Change agents

DISSEMINATION
 (formal, planned)

THE OUTER CONTEXT
 Socio-political climate
 Incentives and mandates
 Inter-organisational norm-setting & networks
 Environmental stability

SYSTEM ANTECEDENTS FOR INNOVATION

Structure
 Size/maturity
 Formalisation
 Differentiation
 Decentralisation
 Slack resources

Absorptive capacity for new knowledge
 Pre-existing knowledge/skills base
 Ability to find, interpret, re-codify and integrate new knowledge
 Enablement of knowledge sharing via internal and external networks

Receptive context for change
 Leadership and vision
 Good managerial relations
 Risk-taking climate
 Clear goals and priorities
 High quality data capture

SYSTEM READINESS FOR INNOVATION

Tension for change
 Innovation-system fit
 Power balances
 (supporters vs opponents)
 Assessment of implications
 Dedicated time / resources
 Monitoring and feedback

THE ADOPTER

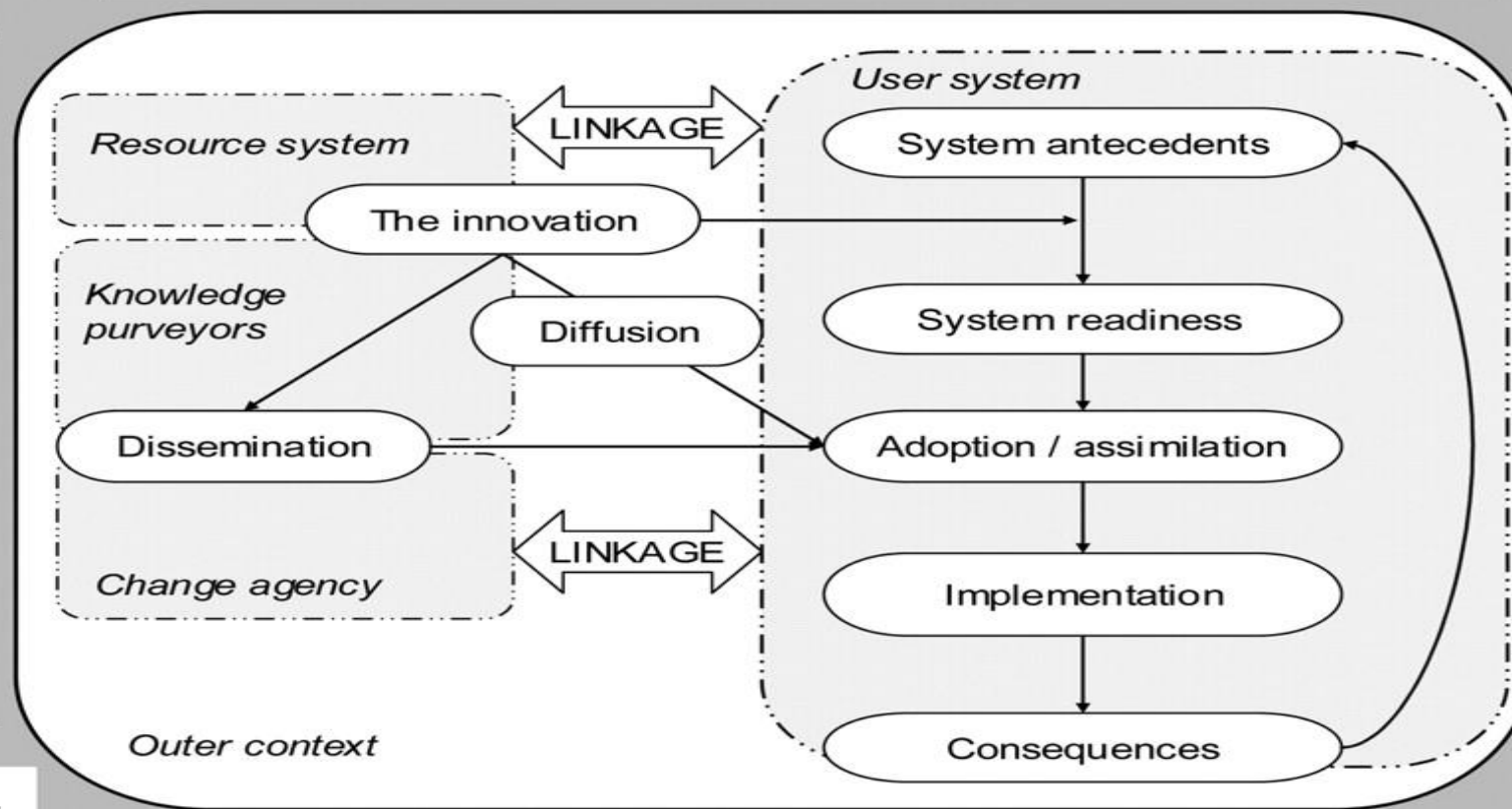
Needs
 Motivation
 Values and goals
 Skills
 Learning style
 Social networks

ASSIMILATION

Complex, non-linear process
 'Soft periphery' elements

THE IMPLEMENTATION PROCESS

Decision-making devolved to front line teams
 Hands-on approach by leaders and managers
 Human resource issues, especially training
 Dedicated resources
 Internal communication
 External collaboration
 Reinvention/development
 Feedback on progress



LINKAGE

Design stage

Shared meanings and mission
 Effective knowledge transfer
 User involvement in specification
 Capture of user-led innovation

Implementation stage

Communication and information
 User orientation
 Product augmentation e.g. technical help
 Project management support



Martin Luther King, Jr. Outpatient Center, 1670 E 120th St, Los Angeles, CA 90059

New! Sick Cell Clinic at MLK Jr. Outpatient Center

Adults with Sick Cell Disease...We can provide the care you have always wanted!

Clinic is open

- Monday to Friday
- Sickle cell clinic: Tuesdays 9 a.m. – 5 p.m.

Services

- Physicians, Nurse Practitioners, and Hematologists experienced in sickle cell care
- Social workers and patient navigators for linkage to services and counseling
- Comprehensive and alternative approaches

Who is eligible?

We accept Medi-Cal and Medi-Cal Managed Care, and HealthyWay LA. Options are available to individuals without insurance as well. Other plans may be covered. Please visit the dhs.lacounty.gov website for further details.

¡Nueva! Clínica de células falciformes en MLK Jr. Outpatient Center

Adultos con enfermedad de células falciformes...¡Podemos proporcionar la atención que siempre ha querido!

Clínica está abierta

- De lunes a viernes
- Clínica de células falciformes: martes 9 a.m.-5 p.m.

Servicios

- Médicos, enfermeras y hematólogos con experiencia en el cuidado de células falciformes (SCD)
- Trabajadores sociales y navegantes de paciente de la vinculación con los servicios y el asesoramiento

¿Quién es elegible?

Aceptamos Medi-Cal, Medi-Cal Managed Care, y HealthyWay LA. Opciones están disponibles para las personas sin seguro también. Otros planes pueden estar cubiertos. Por favor, visite el sitio web dhs.lacounty.gov para más detalles.

WEBINAR FOR PEDIATRIC SICKLE CELL CLINICIANS

*New Adult Sickle Cell Clinic at
MLK Jr. Outpatient Center in Los
Angeles opens September 2016*



LEARNING OBJECTIVES:

- To articulate the impetus for the new Adult Sickle Cell Disease clinic – why and how we started.
- To introduce a new delivery model that integrates primary care, hematology and behavioral health.
- To highlight hematology expertise and delineate specialty care opportunities.
- To identify referral criteria and eligibility requirements.
- To understand the role of the SCDCC in the new clinic.



**Friday,
September 16th**

**10:00 – 10:30 am &
1:00 – 1:30 pm**
(content to repeat)

PRESENTERS:

- Ellen Rothman, MD, Chief Medical Officer, MLK Jr. Outpatient Center
- Susan Claster, MD, Adult Hematologist, Adult Sickle cell Clinic at MLK Jr. Outpatient Center
- Mary E. Brown, President & CEO, Sickle Cell Disease Foundation of California and lead Community Based Organization – HRSA Pacific Sickle Cell Regional Collaborative

10:00 – 10:30 am (PST)
[Click Here to Join the meeting via WebEx](#)

Meeting Number:
927 990 018

Meeting Password:
fXWrc246

1:00 – 1:30 pm (PST)
[Click Here to Join the meeting via WebEx](#)

Meeting Number:
925 555 420

Meeting Password:
8eRq9Pc4

JOIN BY PHONE

(866) 546-3377

Audio Passcode: 843314

Framework #6 → MLK Adult SCD Clinic

- Different Sectors: Clinicians, Public Health, Consumer Based Org
- Regionalization – responsibility to build capacity outside our agency
- 3 Pillars – Finance/Insurance component
- Make it happen: structured communications
- Complexity – multiple determinants of innovation adoption

Haines: Framework for Successful clinical networks External support, perceived leadership, internal management key

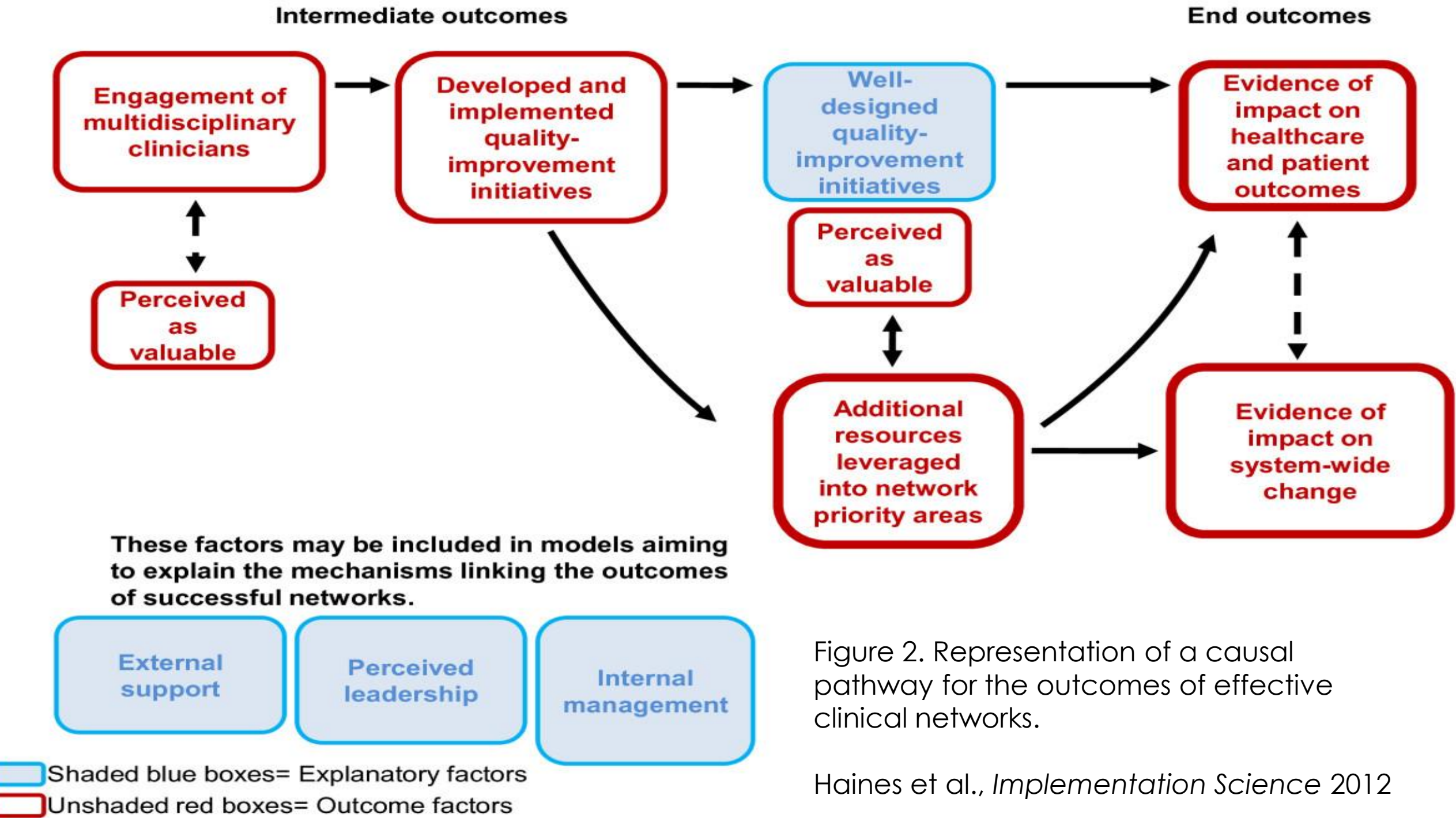


Figure 2. Representation of a causal pathway for the outcomes of effective clinical networks.

Haines et al., *Implementation Science* 2012

Framework #7 → MLK Adult SCD Clinic

- Different Sectors: Clinicians, Public Health, Consumer Based Org
- Regionalization – responsibility to build capacity outside our agency
- 3 Pillars – Finance/Insurance component
- Make it happen: structured communications
- Complexity – multiple determinants of innovation adoption
- Successful networks: External support, perceived leadership, internal management key
- Boundary spanning – key to effective collaborations.

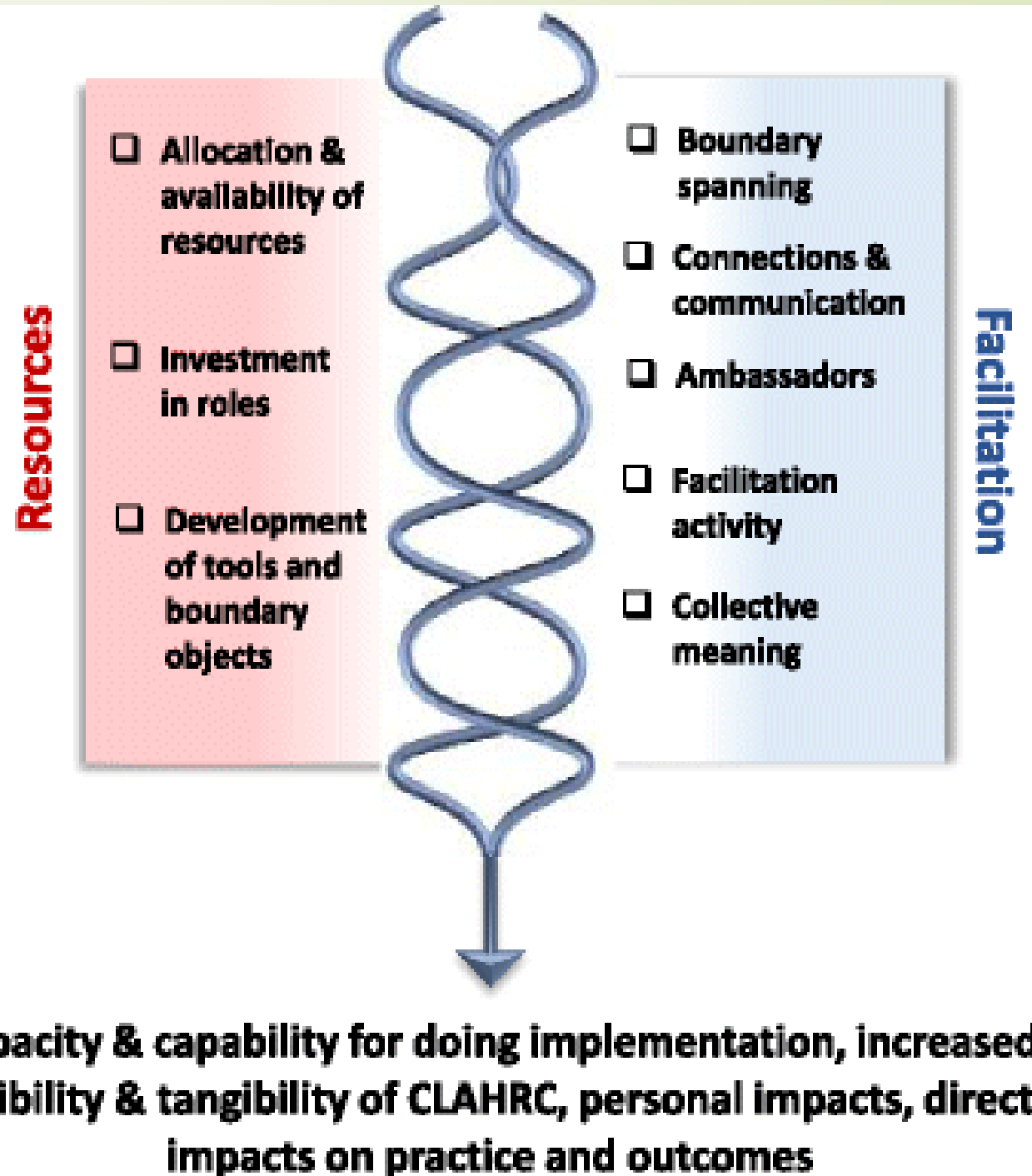
Collective Action for Implementation: A realist evaluation of organizational collaboration in healthcare

Boundary spanning – key to effective collaborations

Interplay of resources (context) and facilitation (mechanism).

Credible individuals → cross boundary work, facilitation and direct impacts.

Boundaries: Organizational, philosophic, semantic, professional, geographic





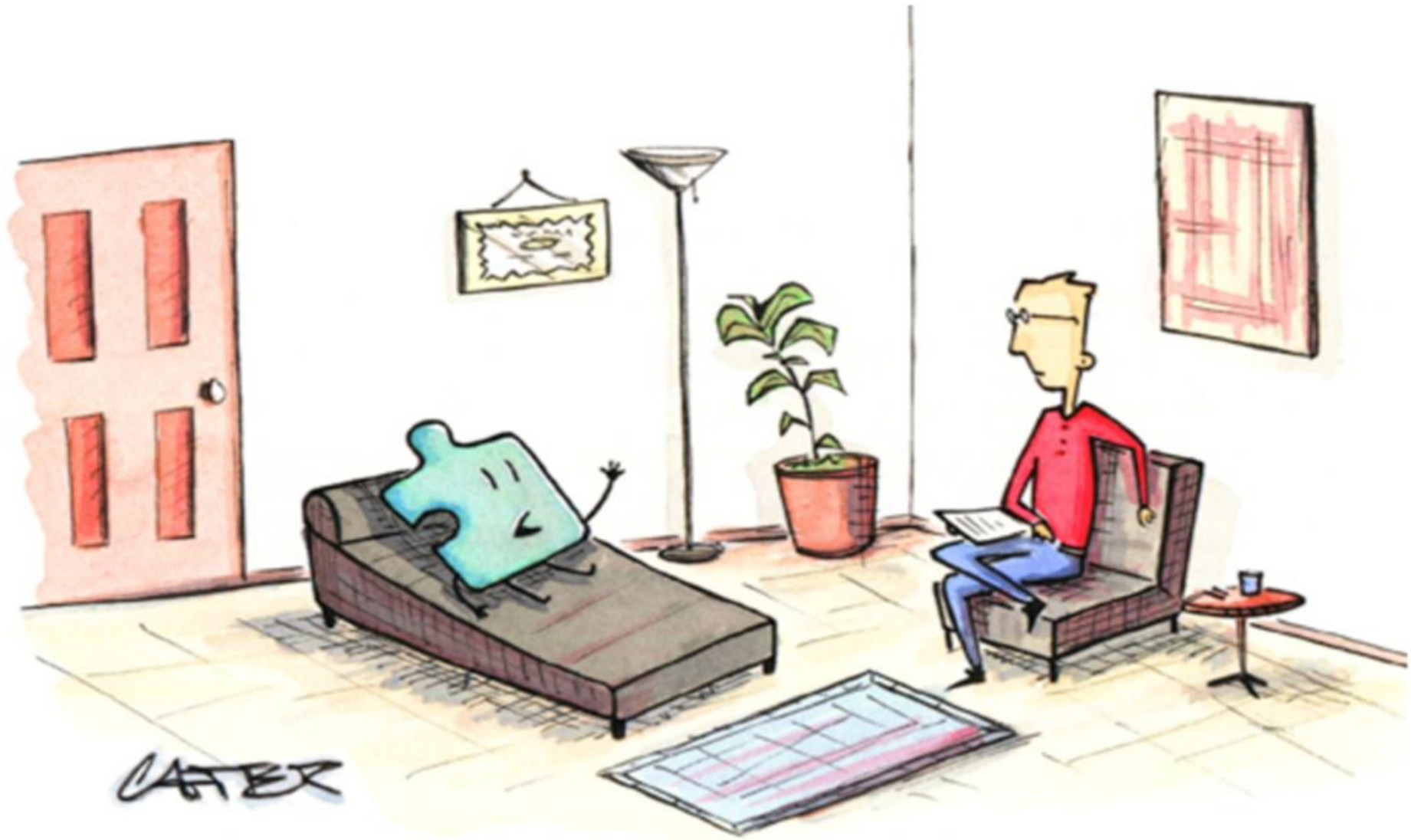
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- To assess the strengths and weaknesses of the **medical home model to address complex healthcare needs**
- To introduce a **new delivery model** that *integrates primary care, hematology and behavioral health.*



Patient-Centered Medical Home: Core Elements

- Comprehensive
 - Coordinated
 - Continuous
 - Accessible
 - Patient-centered
 - Culturally appropriate
- 



"Did you ever feel like you're part of something greater than yourself?"





How effective is the PCMH Model?

Questions remain about its value

- Literature - mixed quality
- Affordable Care Act included support of CMS demonstration projects to study this model
- Comprehensive Primary Care Initiative, large CMS-funded demonstration
 - followed 497 adult practices in 7 regions
 - at the midway point in the *study*(NEJM 2016):
 - No savings in expenditures
 - Minimal improvements in quality and experience metrics



How effective is the PCMH Model?

Some promising findings for our setting

- Moderate support for hypothesis that medical homes provide improved health-related outcomes for children with SCD
- PCMH is able to partially, but not completely, alleviate disparities in care encountered by African American children with complex health care needs compared to their white counterparts as measured by ED utilization



Why is Primary Care Critical?

- Adults with SCD over 40 years of age have different healthcare needs
 - More visits related to end-organ damage and failure
 - More visits related to routine health conditions like diabetes and heart disease
 - Preventive healthcare and adult immunizations are important and often missed in specialty care



Specialty Care Medical Homes?

Few and far between

- National survey of 372 specialty medical practices with 1-19 physicians
- 85% of the responding practices reported providing primary care services to fewer than 10% of patients
- 10.3% reported providing primary care to 20% of patients
- Only 1.7% reported providing primary care for more than 50% of patients



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MLK Outpatient Center



- 136,500 Square Feet
- 104 Exam Rooms
- 70 clinics serving primary care, specialty and subspecialty care
- Ambulatory Surgery Center with 5 Operating Suites
- Full spectrum Rehabilitation Services
- Pharmacy
- Radiology, Nuclear Medicine, MRI

Advanced Practice Medical Home

- Integrated with primary care & NP
- Hematology specialty care
- Preventive care specific to SCD
- Behavioral health counseling
- Social Worker & Data Management**
- Alternative therapy for pain
- Peer Navigators & Community Health Workers*
- Outpatient, emergency, inpatient care
- Case Management



Specialty Care Services on Campus

- Neurology
- Orthopedics
- Ophthalmology
- Cardiology
- Gastroenterology
- Urology
- Pulmonology and Pulmonary Function Testing
- Women's Health



Additional Services – Harbor UCLA

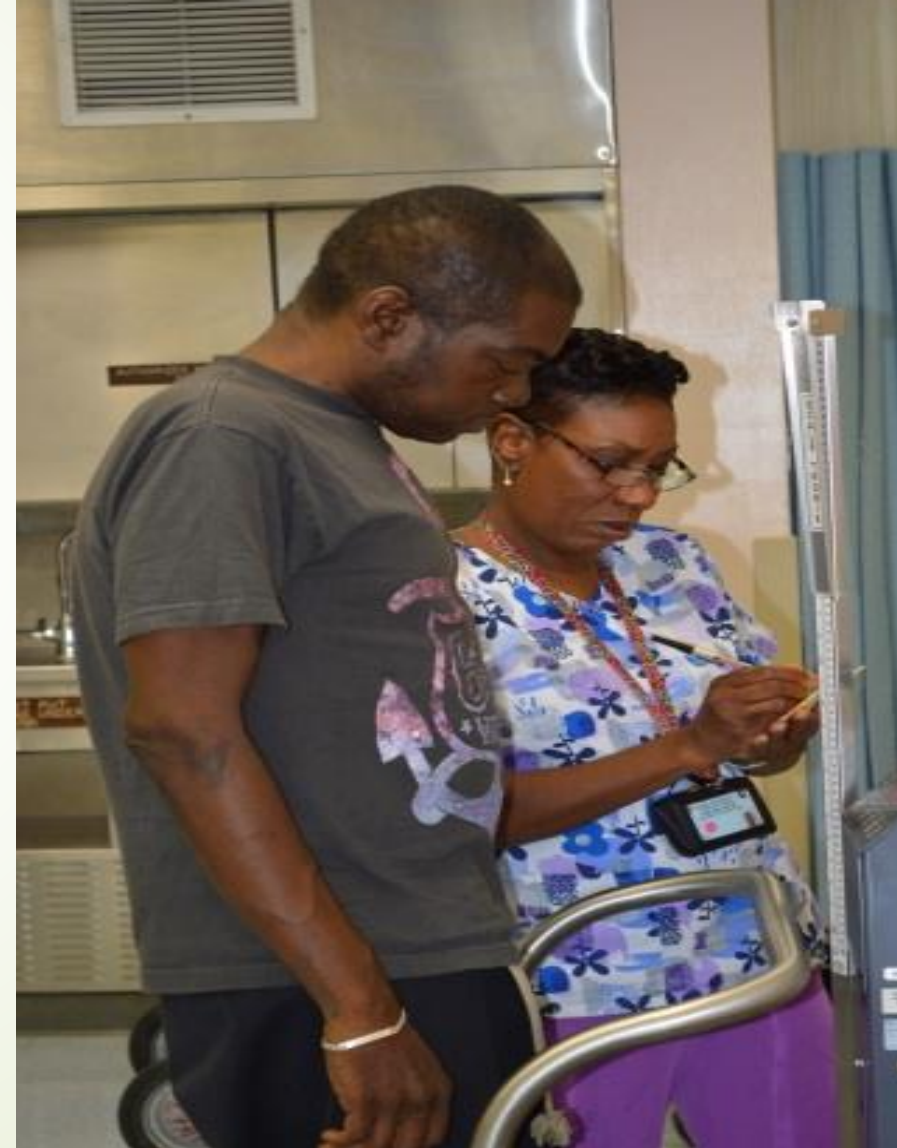
- Transfusions and erythrocytapheresis
- Inpatient admissions and Intensive care
- ER Services
- Additional subspecialty care



Services unavailable on-site at MLK OPC?

These services are provided through linkage with partners.

- Day hospital infusion center
- On-site transfusions or red cell pheresis



Campus Partners

- MLK Jr Community Hospital
- Department of Mental Health
 - MLK Jr Mental Health Urgent Care
 - Augustus F Hawkins Mental Health
- Housing for Health
 - Recuperative Care in the Interns and Residents Building





Department of Healthcare Services Partners

- LAC-USC Medical Center
- Harbor-UCLA Medical Center
- Olive View Medical Center
- Rancho Los Amigos Rehabilitation Center

MLK, JR Community Hospital

- Inpatient Admissions and Intensive Care
- ER Services
- Transfusion



Who Is Eligible?

- Adults with Sickle Cell Disease
- Medicaid eligible or uninsured
- Medicare
- Limited private insurance options
- Willing to participate in LA County Department of Health Center managed care services
- Resident of Los Angeles County



How to refer: sicklecellclinic@scdfc.org or (424) 277-3800



MLK Adult SC Clinic Update

- Opened August 11, 2016
- We continue to build our patient panel
- Integrated Team model includes
 - Community Health Worker
 - Nursing Team
 - Primary Care Nurse Practitioner
 - Hematologist
 - Acupuncturist



Primary Care

- Initial screenings at first health evaluation including screening for mental health, cognitive (MOCA), Quality of Life, overall health and lifestyle assessment
- Immunizations
- Identifying non sickle cell issues and discussing with team regarding impact on SCD
- Co-manages patients with Hematology



Community Health Workers

- Support through intake process
- Contact patients before and after visit
- Support for patients in clinic
- Transportation assistance
- Home visits if needed



Additional Plans

- Yoga is available
- Acupuncture will be available shortly
- Peer support group - early planning
- Workforce development – CIBD / MLK partnership with Charles R. Drew University



Patient Characteristics -1

- All from South LA/Long Beach/SE LA areas
- Mix of genotypes with majority SS disease and the rest SC and S beta thalassemia
- 17 scheduled, 14 enrolled in ongoing care
- ~ 25% are 50+ years of age
- Some: no Hematology care for years



Patient Characteristics -2

- Noticing significant complexities
 - Effects of transfusions over a lifetime: one patient with liver failure and a transplant d/t iron overload
 - Hydroxyurea management poor, some not on drug
 - Inadequate vaccinations
 - Narrow approach to pain management limited to narcotics only



Patient Vignette

- 60 y/o woman from Belize with genotype S beta thalassemia
- No consistent Hematology care
- 3 pregnancies - transfused for this and multiple other times
- Dec 2015- hepatic failure as a result of iron overload
- Jan 2016- liver transplant at UCLA as a result of untreated iron overload




Outcome Measures

- Quality of Life Scale
- ED Utilization Rates
- Hospitalization Rates
- Immunization Rates for flu, pneumococcal, and meningococcal
- Hydroxyurea compliance
- We are planning an observational investigation with a white paper illustrating efficacies and challenges in a highly integrated model



CDC study

- CDC Foundation and California Rare Disease Surveillance
- Administrative data, Newborn screening, vital records, and case reports from 2004-2014
- Study cohort of adults who live in the MLK catchment area before and after clinic opening
- We hope to show that coordinated care improves outcomes



Closing thoughts

- Creating a new adult Sickle Cell Clinic for a very underserved population is achievable
- Planning & Implementation Expertise: Team approach to healthcare delivery transformation for rare complex disorders
 - Public Health, Community Based Organization, Specialty Hematology, Advance practice medical home, health communications
- Regionalization promotes capacity building for rare disorders
- Surveillance to monitor outcomes vital to assessing impact

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Meaningful Partnerships work!

Thank you



PSCRC

The Pacific Sickle Cell Regional Collaborative works to ensure that people with sickle cell disease receive quality care, no matter where they live or seek care.