Sickle Cell Care Coordination Initiative: Needs Assessment Results

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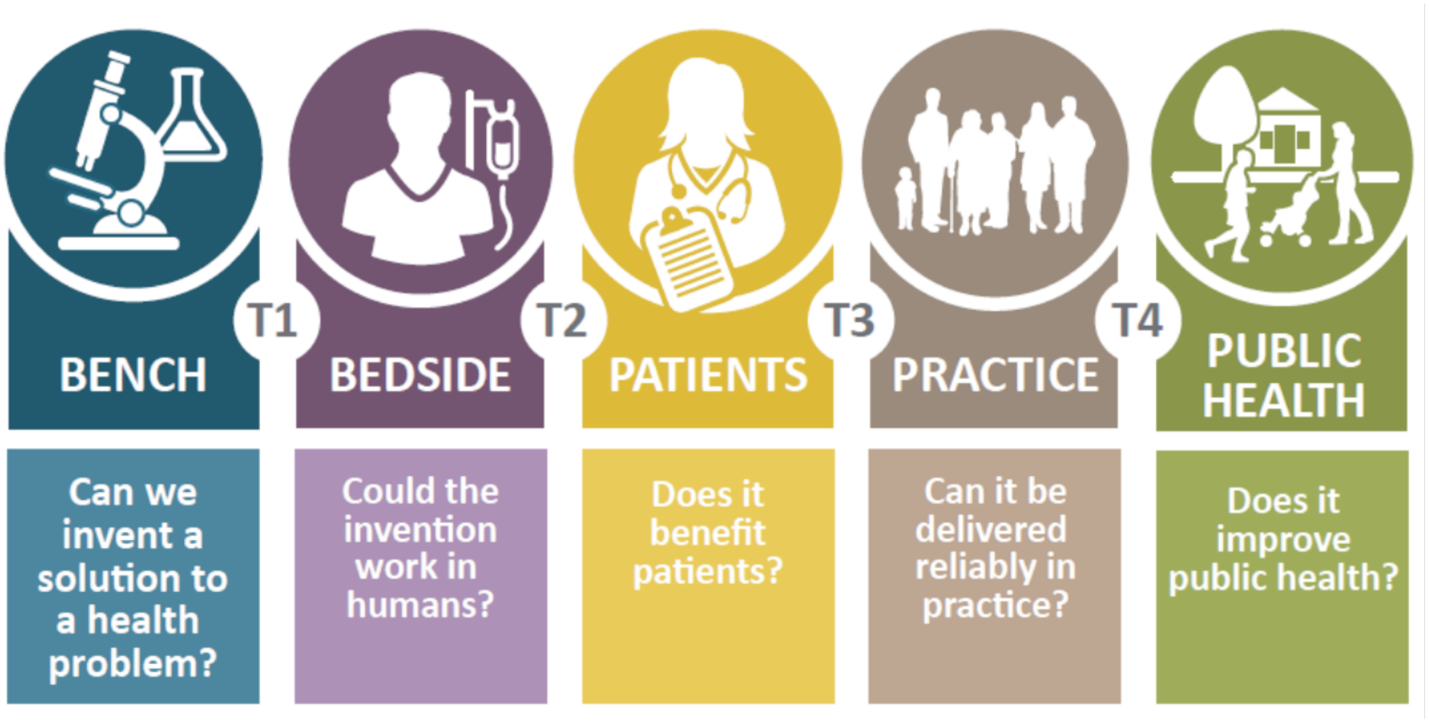
From Evidence to Practice



BENCH

Can we invent a solution to a health problem?

T1

BEDSIDE

Could the invention work in humans?

T2

PATIENTS

Does it benefit patients?

T3

PRACTICE

Can it be delivered reliably in practice?

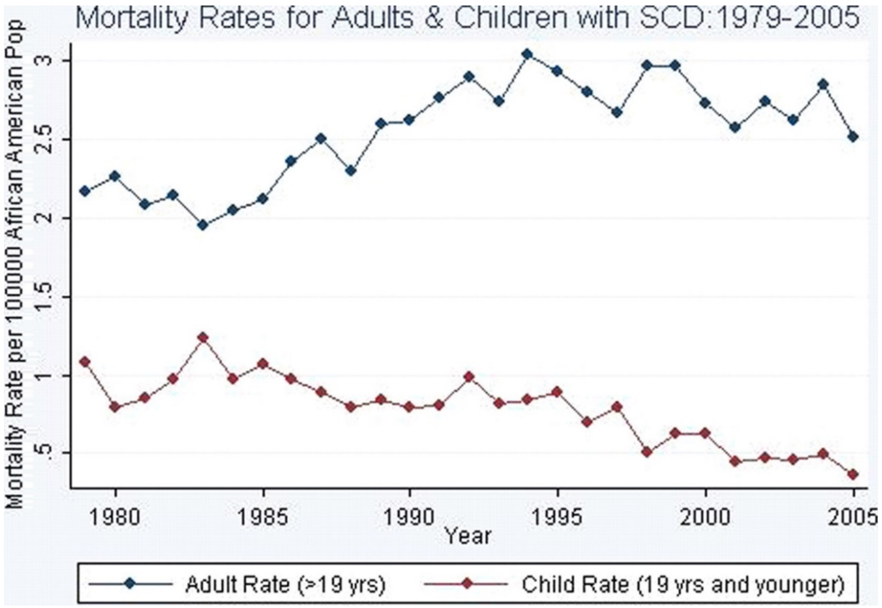
T4

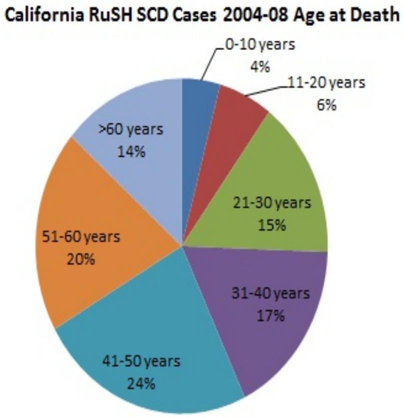
PUBLIC HEALTH

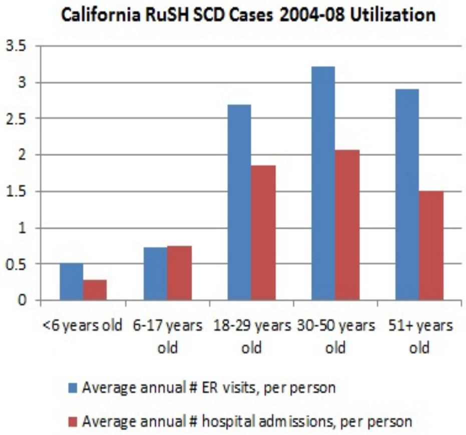
Does it improve public health?

- Uchechukwu et al *J Am Coll Cardiol* 2016; 68: 517-24

SCD Age Related Disparities


Mortality Rates for Adults & Children with SCD:1979-2005


California RuSH SCD Cases 2004-08 Age at Death


California RuSH SCD Cases 2004-08 Utilization

- Lanzkron, Haywood *Blood* 2010;116:736

Paulukonis et al *Pediatr Blood Cancer* 2017; 64

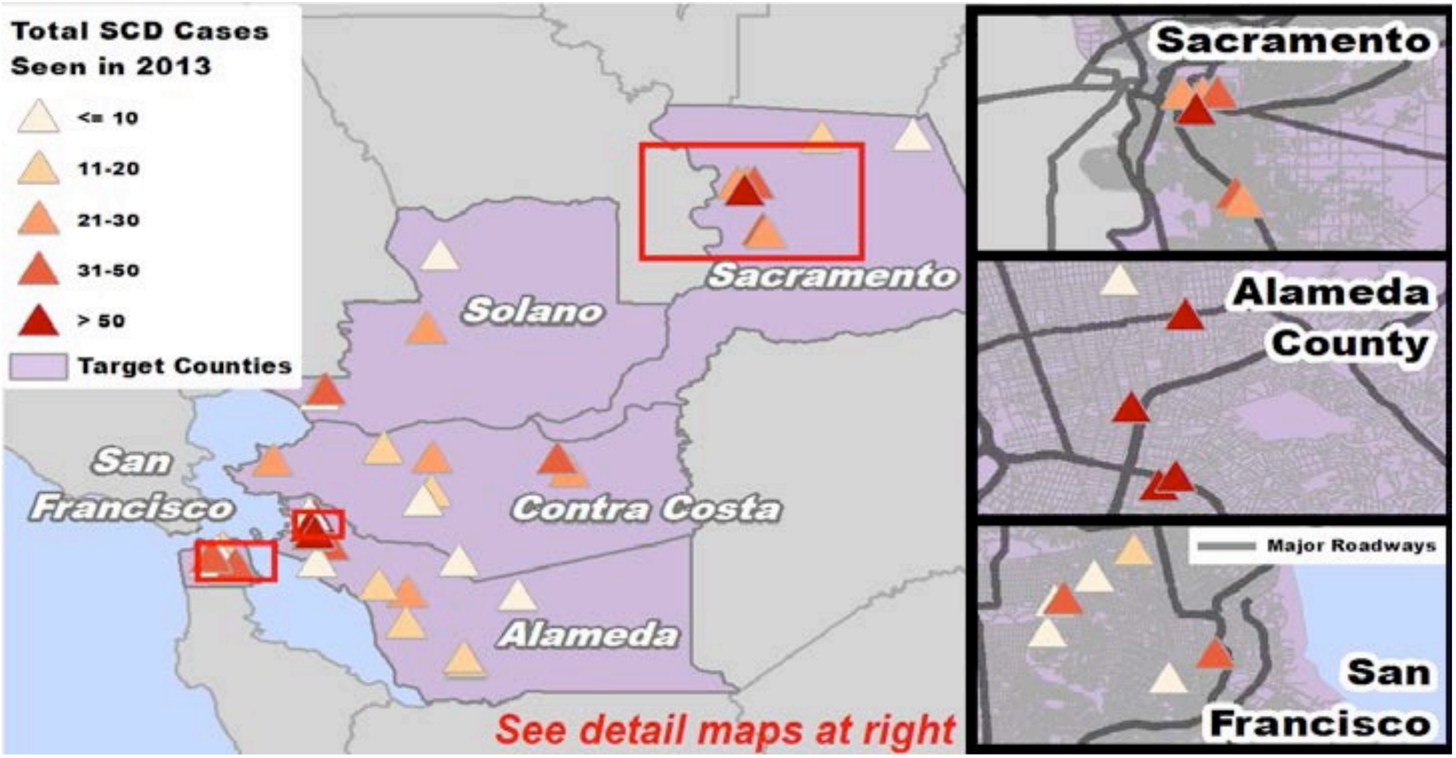
Sickle Cell Disease Implementation Consortium

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

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

Baumann, King et al *BMC Health Serv Res* 2018;18:500

SCCCI 5 County Catchment Area



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

Sickle Cell Care Coordination Initiative

UCSF Benioff Children's Hospitals

UC DAVIS HEALTH

Goals

- Increase number of youth and adults with SCD who receiving preventive care
- Increase provider adherence to evidence-based guidelines, to decrease preventable morbidity and mortality
- Improve timely and appropriate pain management in the ED, thereby enhancing patient satisfaction with care

Methods

- Surveys using standardized instruments
  - PhenX
  - PROMIS Pain Interference
  - ASCQ-Me Quality of Care
  - Barriers to Care
  - Sickle Cell Self-Efficacy Scale
- Structured focus group and individual interviews

Individuals with Sickle Cell Disease (N = 58)		
Gender, n (%)	Female	33 (57)
	Male	25 (43)
Age, n (%)	15 – 25 years	18 (31)
	26 – 35 years	21 (36)
	36 – 48 years	18 (31)
Race, n (%)	African American/Black	54 (93)
	Other	7 (12)
	White	1 (2)
Hispanic ethnicity, n (%)	No	51 (88)
	Yes	5 (9)
County of Residence, n (%)	Alameda	20 (34.5)
	Contra Costa	12 (21)
	Sacramento	6 (10)
	San Francisco	6 (10)
	Other (includes 2 from Solano)	11 (19)

Individuals with Sickle Cell Disease (N = 58)		
Educational attainment, n (%)	Less than high school	2 (2)
	High school graduate	14 (24)
	Some college/AA	29 (50)
	College degree	6 (10)
	Beyond college	3 (5)
Occupation, n (%)	Working now	23 (40)
	Unemployed	11 (19)
	Disability Income	19 (33)
	Student	4 (7)
	Other	10
Marital status, n (%)	Married/living together	10 (17)
	Separated/Divorced	7 (12)
	Never married	41 (71)

Individuals with Sickle Cell Disease (N = 58)		
Annual income, n (%)	<30,000 30 to <60,000 60,000 or more	23 (39.7) 14 (24.1) 19 (32.8)
Insurance, n (%)	Medicaid/MediCal MediCare Private CCS/GHPP	40 (69) 16 (28) 13 (22) 8 (14)
Hemoglobin type, n (%)	Hgb SS Hgb SC Hgb S beta + thalassemia	41 (71) 12 (21) 2 (3)

Pain and Utilization (N = 58)

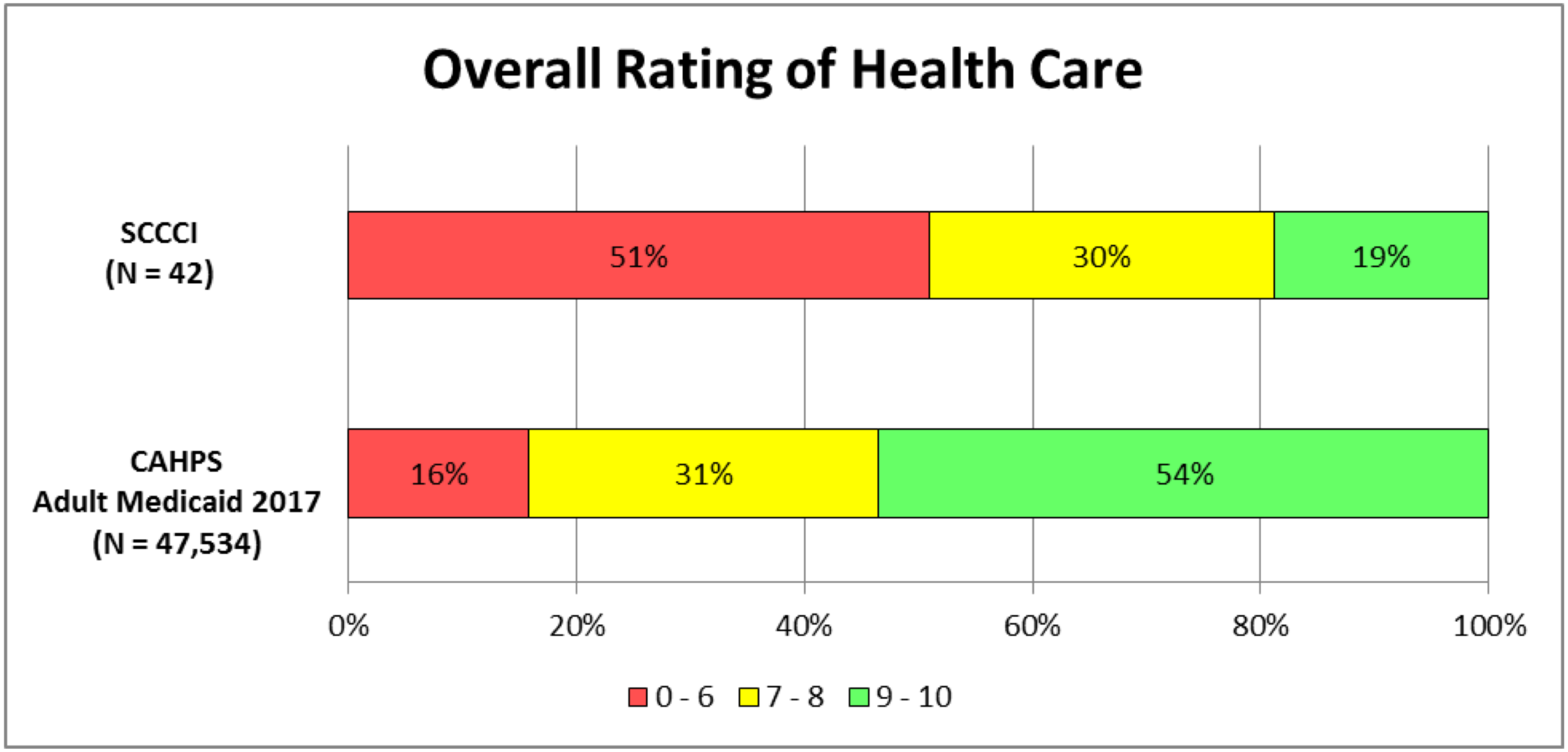
ED visits for pain, past 6 months, n (%)	0	18 (31)
	1-2	20 (34)
	3-4+	17 (19)
Admissions for pain, past 12 months, n (%)	0	17 (29)
	1-2	16 (28)
	3-4+	21 (36)
Severe pain without healthcare utilization past 6 months, n (%)	Yes	49 (84)
	No	6 (10)
# of these episodes, past 6 months, n (%)	Less than 4	15 (26)
	4 or more	34 (59)
Downtime due to pain, past 6 months, n (%)	Less than one week	10 (17.2)
	One week or more	39 (67.2)

Barriers to Care (n = 58)

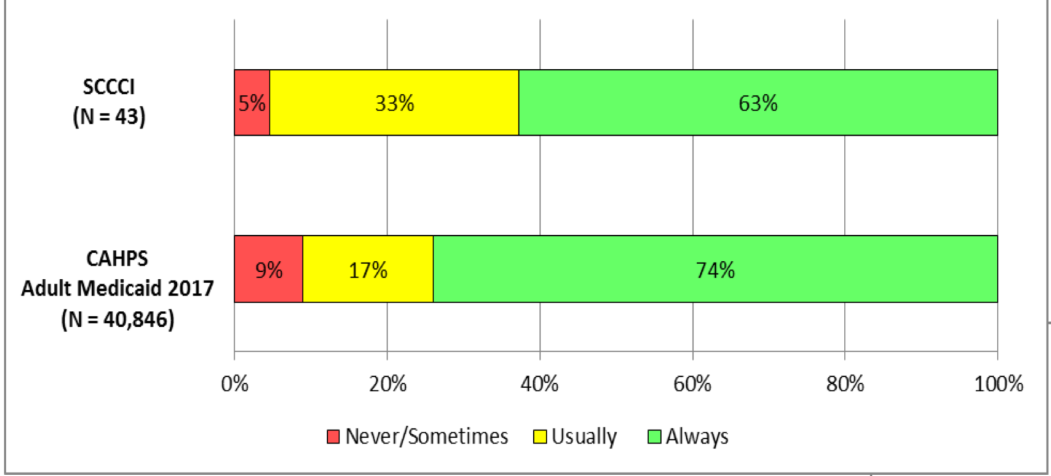
Sickle Cell Disease, n (%)	I am tired	37 (64)
	I am in pain	36 (62)
	Worry/fear	31 (53)
	Frustration/anger	28 (48)
	Lack of confidence	15 (26)
Provider Knowledge/Attitudes, n (%)	Not seen quickly enough when in pain	27 (47)
	Accused of drug seeking	22 (38)
	Provider not knowledgeable/experienced	22 (38)
	Not believed when in pain	20 (34)
	Treated differently from other patients	12 (21)
Transportation, n (%)	Access to a vehicle, costs, other	29 (62)

Barriers to Care (n = 58)

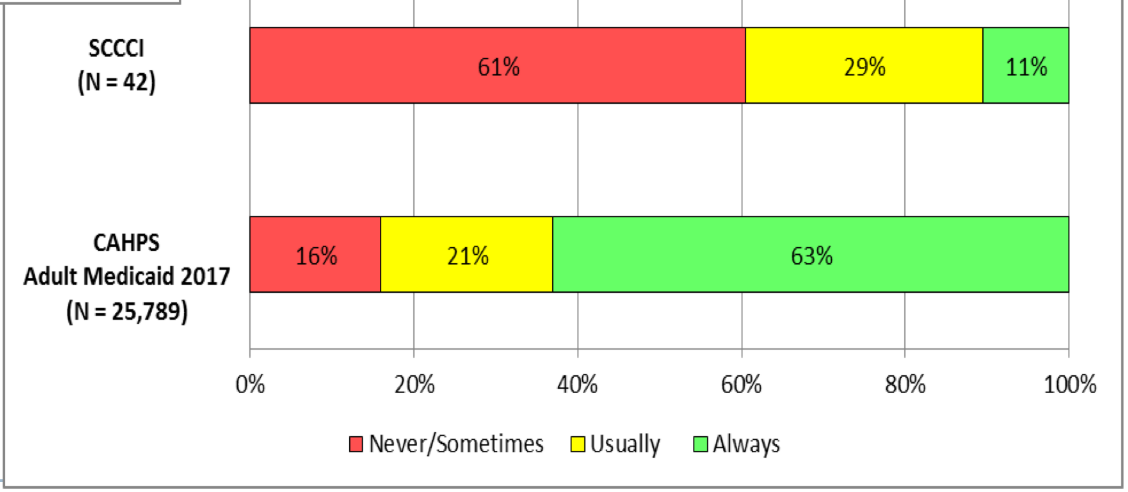
Insurance, n (%)	Costs not covered/co-pays Services, including complementary, not covered Can't go where I would like	20 (34) 15 (26) 12 (22)
Access, n (%)	Places to learn how to stay well not easy to get to	18 (31)
Support, n (%)	Social isolation/don't have enough support Support system burned out Need household help	19 (23) 13 (22) 12 (21)
Individual Barriers, n (%)	Memory problems, hard to follow up Medical system is challenging/ confusing	18 (31) 13 (22)
Barriers to hydroxyurea, n (%)	Worry about side effects Forgetting	19 (33) 17 (29)


Overall Rating of Health Care
SCCCI
(N = 42)
51%
30%
19%
CAHPS
Adult Medicaid 2017
(N = 47,534)
16%
31%
54%
0%
20%
40%
60%
80%
100%
🟥 0 - 6
🟨 7 - 8
🟩 9 - 10

Provider Communication Composite



Emergency Care Access



Qualitative Analyses

"People with sickle cell are Black… and Black pain is never as valuable as White pain."

Young adult with sickle cell disease

Qualitative Analyses – Major Themes

- Barriers to Care
  - Stigma, lack of trust
  - Access to knowledgeable providers
  - Insurance, transportation
  - ED – delays in seeking treatment, delays in being seen, negative experiences, need access to pain plans
- Care Redesign
  - Need alternatives to opioids for pain management, including better self-management
  - Need for compassionate care

Qualitative Analyses – Major Themes

- Transition readiness/need to improve process of transfer to adult care
- Hydroxyurea use
  - Consider sources of support and advice for patients such as family, other patients, navigators, social media
  - Provider support
- Quality of life, community engagement and empowerment
- Need for better care coordination
  - Communication between providers

Limitations

- Despite purposive sampling, participants may not reflect the full diversity of needs and barriers for adolescents and adults with SCD in the Bay Area
  - However, results consistent with the literature and with results from other sites
- Analyses not yet adjusted for age, gender, self efficacy and other covariates
  - Will triangulate findings with those from providers and other SCD stakeholders
- Cross sectional design – no conclusions can be made about temporal relationships between variables

SCDIC Proposed Interventions

- Implementation research aims focus not only on evaluating clinical effectiveness of interventions but focus on understanding the context of the interventions
- Implementation research outcomes include focus on acceptability and feasibility of interventions, as well as barriers and facilitators to implementation
- Example:
  - Care Redesign protocol will intervene at the level of the patient (structural and motivational barriers to adherence with hydroxyurea) and provider (knowledge barriers to prescribing hydroxyurea) and will consider differences in contexts across sites

Baumann A. King A. et al. BMC Health Serv Res. 2018 Jun 27;18(1):500.

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