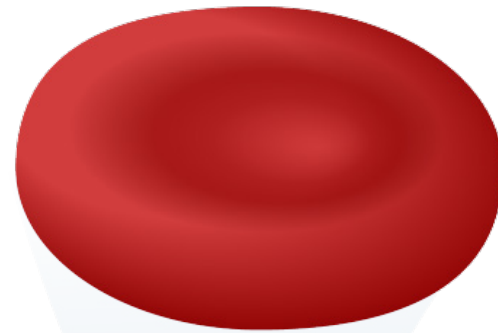


The complex patient in a complex system

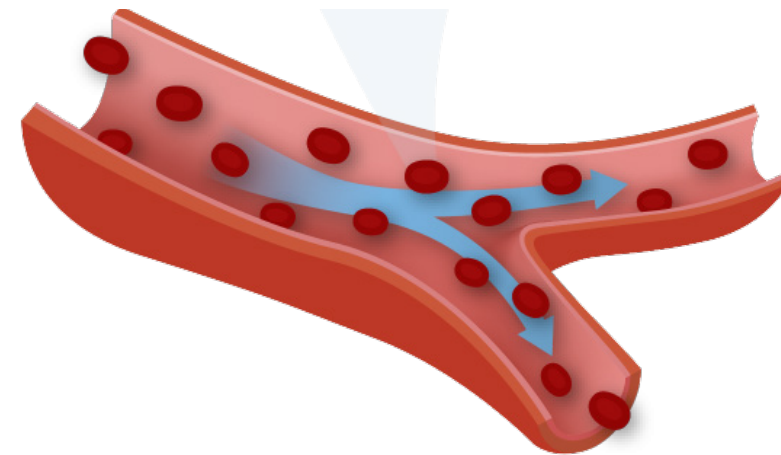
The story of sickle cell patient care

Let's talk about sickle cell disease

Healthy cells



Normal red blood cell

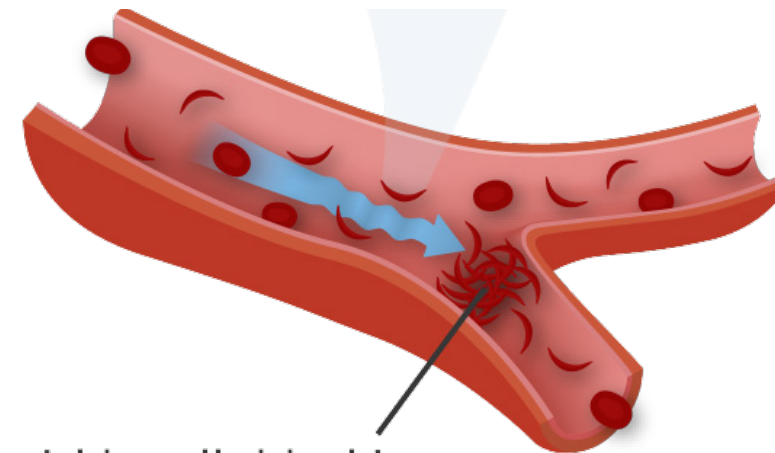


unrestricted blood flow

Sickle cell



Sickle red blood cell



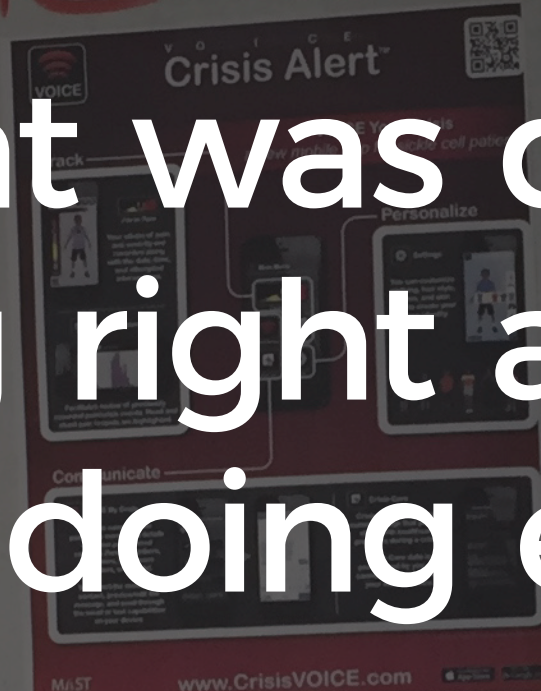
sickle cells blocking
blood flow

The condition is
unpredictable



The patient was doing everything right and her care team was doing everything right for her

Sickle Cell Patients



ATTENTION

Patients for Clinic will be seen according to
SCHEDULED appointment time.

NOT time of **ARRIVAL**.

Thank You for Your Cooperation

Limited treatment options

MANAGING THE CONDITION Hydroxyurea

Sickle Cell Disease

Hydroxyurea: What You Should Know




If you have sickle cell disease, your body makes sickle-shaped, or crescent-shaped, red blood cells. For sickle cell disease, a medicine called hydroxyurea may be able to help. **People who take hydroxyurea must have regular medical care. A doctor who knows about hydroxyurea can tell you about the risks and benefits of taking this medicine.**




Limited treatment options

MANAGING THE CONDITION
Hydroxyurea

MANAGING THE PAIN
Opioids

 Home

 Share

The New York Times

Inside a Killer Drug Epidemic: A Look at America's Opioid Crisis

The opioid epidemic killed more than 33,000 people in 2015. What follows are stories of a national affliction that has swept the country, from cities on the West Coast to bedroom communities in the Northeast.

JAN. 6, 2017



A setting of distrust

“The patient manages himself at home, so [the ED] didn’t know him. They wanted to test him first to see if he actually had sickle cell.”

Social Worker



Patient-system mismatch

Sickle cell patients need to be monitored in time for dosage

ED is not optimized for sickle cell care

Patient-system mismatch

Orphan disease with fewer than 200K people nationwide

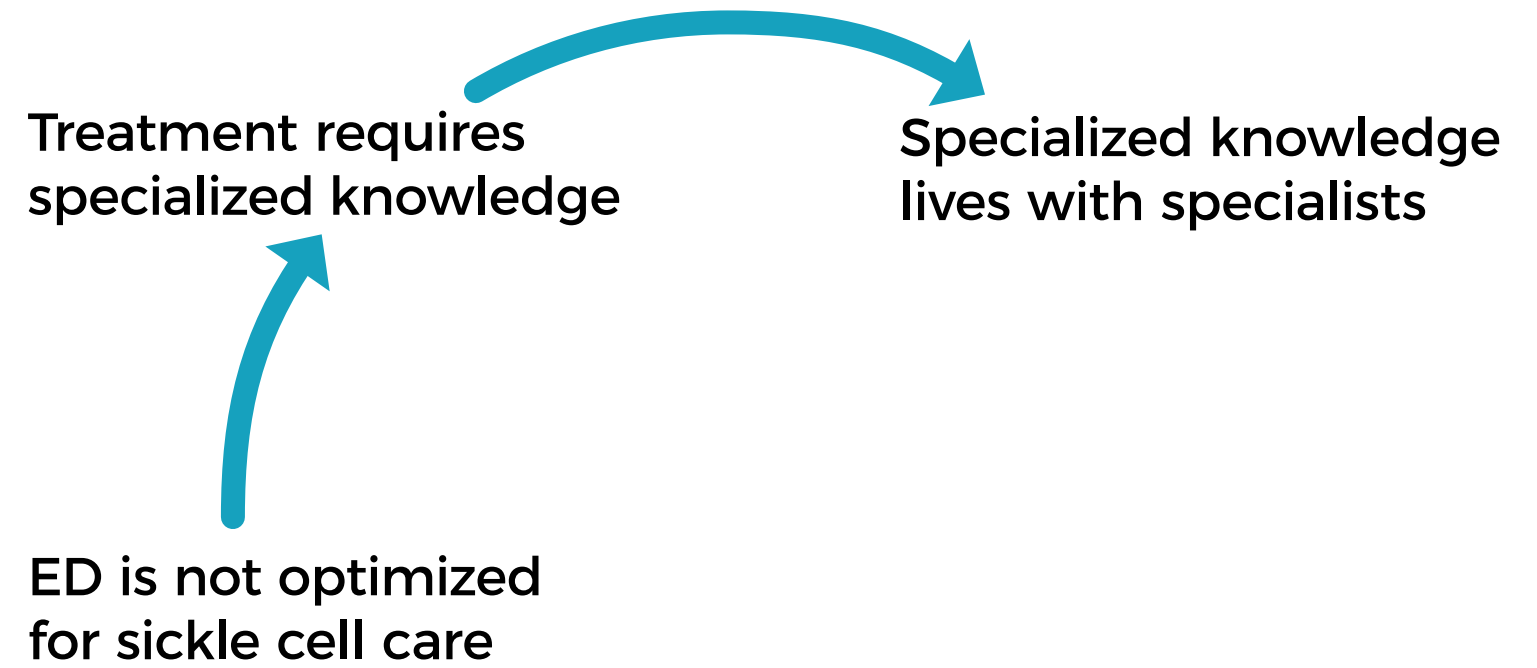
Treatment requires specialized knowledge



ED is not optimized for sickle cell care

Patient-system mismatch

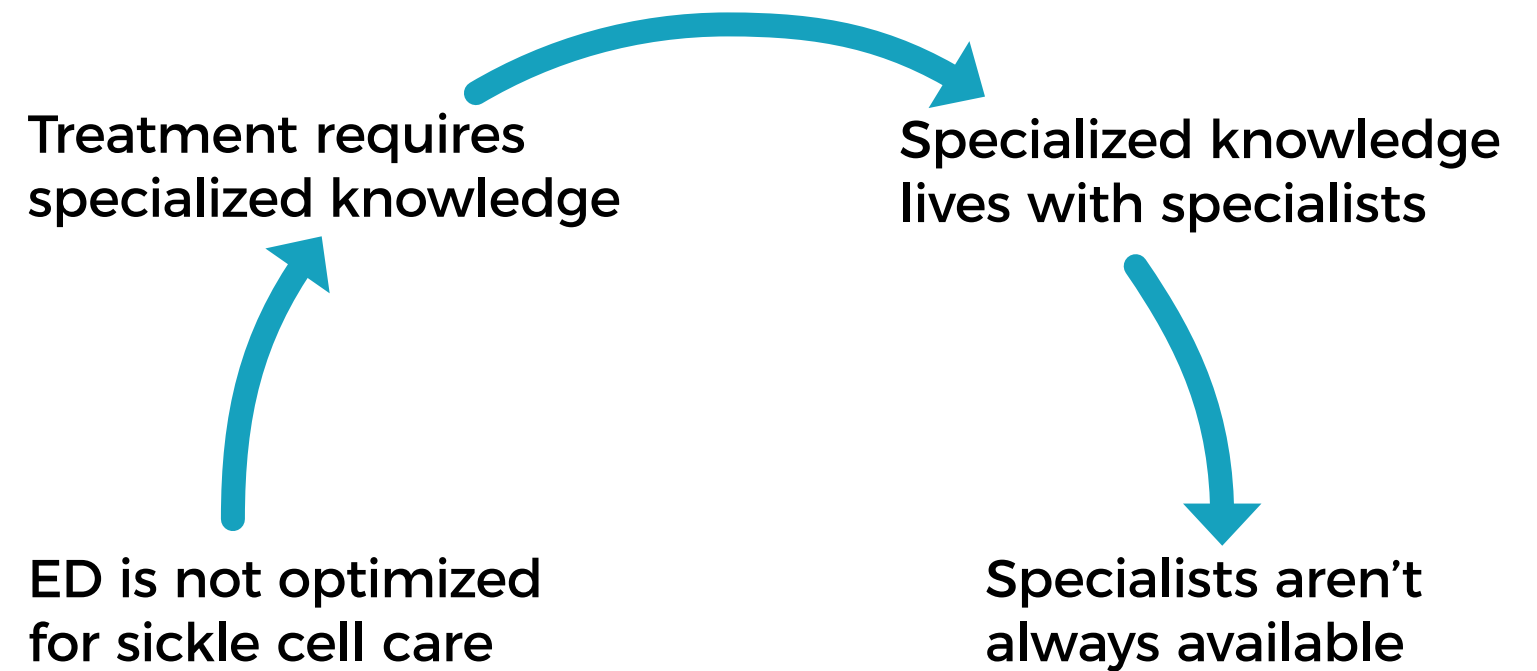
Requires highly individualized treatment



Patient-system mismatch

“I tell him it is not Monday through Friday. You can’t really get sick right now.”

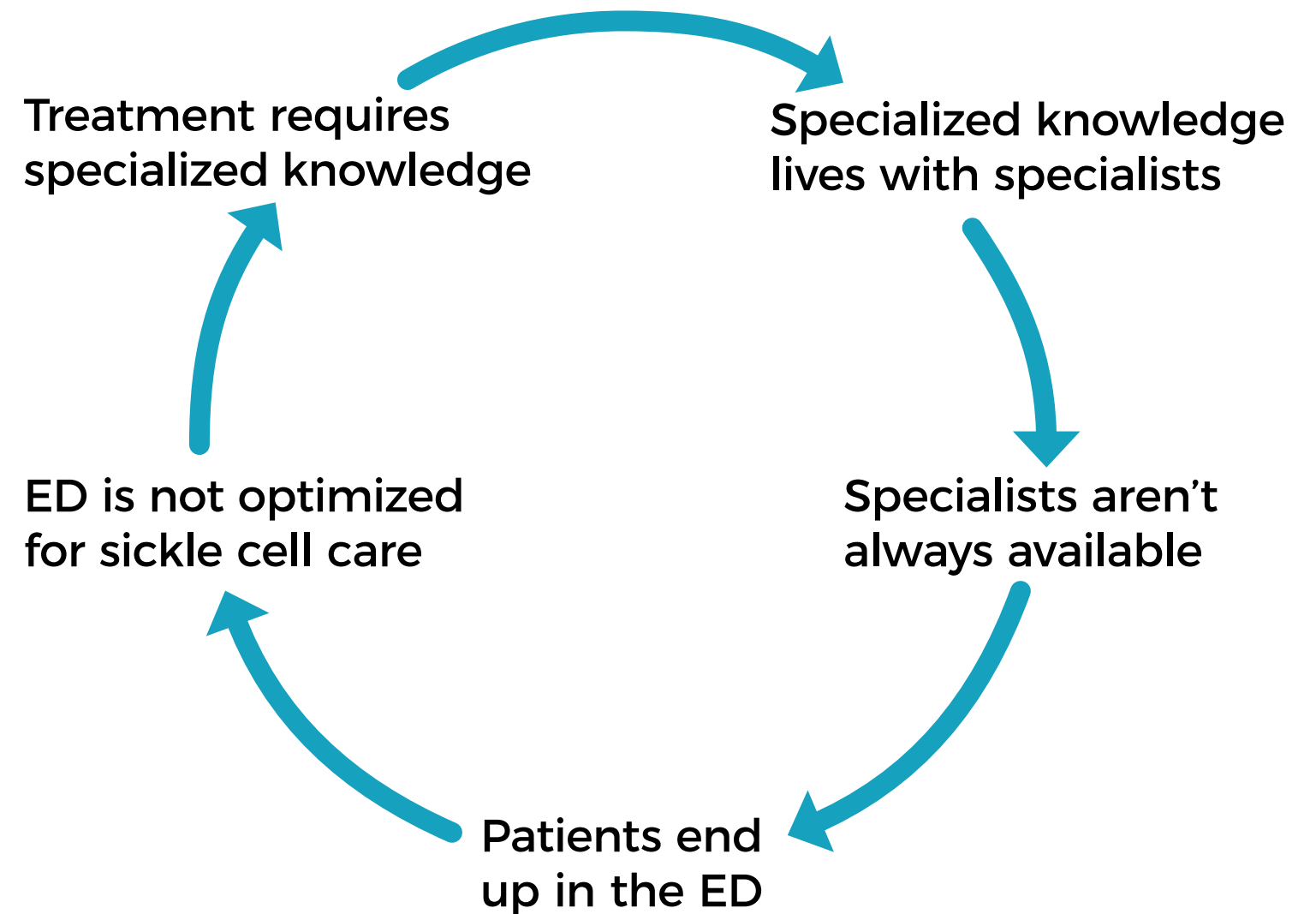
Support group mother



Patient-system mismatch

Pain crisis is potentially
life threatening

ED open 24/7



The complex patient
in a **complex system**

Emergency Department

Acute Care Clinic

Sickle Cell Center

Complex patient
in a complicated
care delivery system

INSIDE THE HEALTHCARE SYSTEM

IN THE COMMUNITY

Other Providers

ED team
of doctors
attending
specialist
hospitalist

ED admin

ED nurses
admin nurse,
triage nurse,
floor nurse

Specialists

Nurse

Social worker

Community
health worker

Family/
caregiver

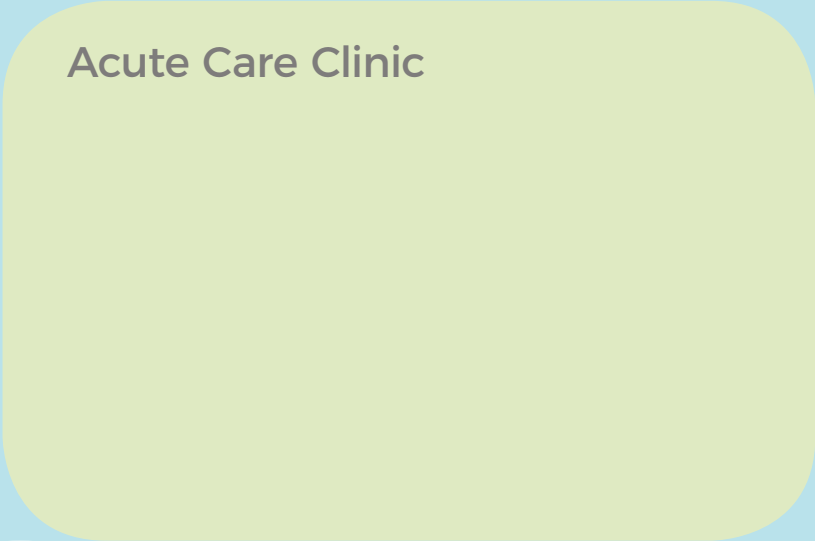
Work HR,
employers,
co-workers

School staff
educators
nurses
administration

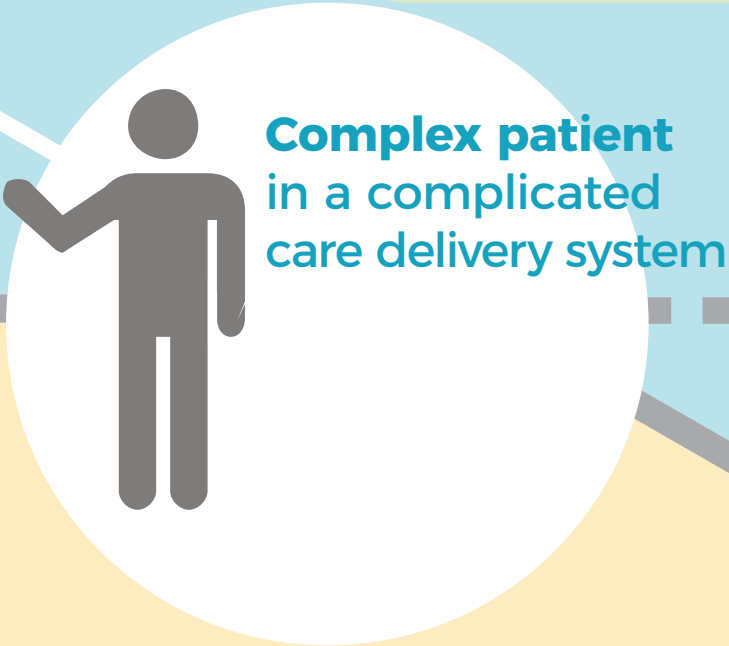
Legal aid

PCP,
other
specialists

Emergency Department



Sickle Cell Center



INSIDE THE HEALTHCARE SYSTEM

IN THE COMMUNITY



Other Providers

Being caught off guard

“The very idea that a sickle cell patient — who knows our system and belongs to a physician here — comes into our emergency department completely unannounced is shameful.”

ED Administrator

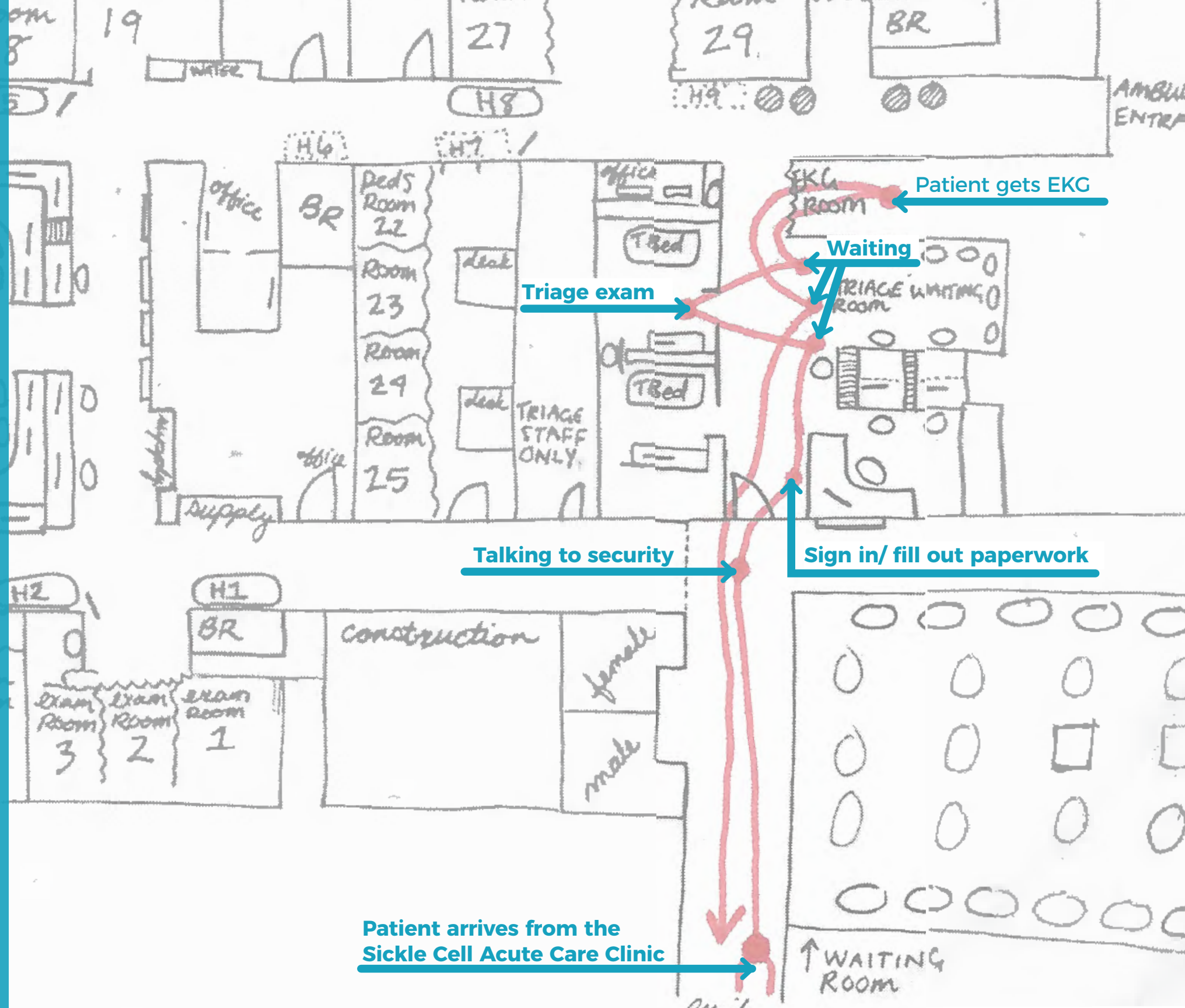


ED Observation

Fragmented patient experience

Lack of information flow between departments

Patient bears the burden for information transfer



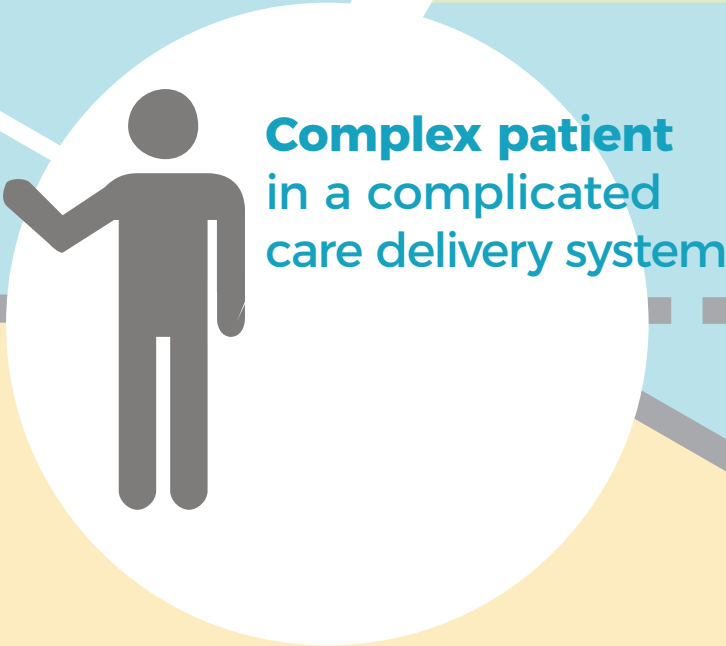
Emergency Department



Acute Care Clinic



Sickle Cell Center



INSIDE THE HEALTHCARE SYSTEM

IN THE COMMUNITY

Other Providers

Workarounds to fill the gaps

Communicates critical patient information using unique EMR workarounds.

In an effort to provide appropriate care, individuals are filling communication gaps in the system.



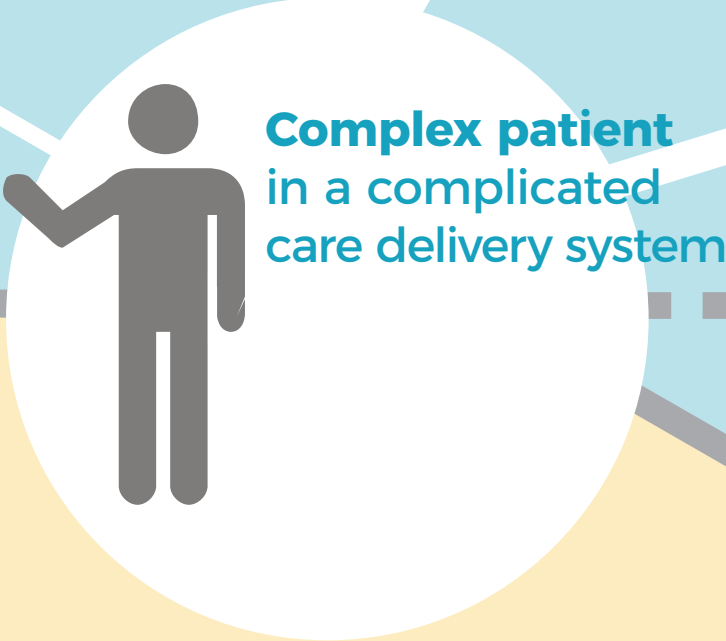
Emergency Department



Acute Care Clinic



Sickle Cell Center



INSIDE THE HEALTHCARE SYSTEM

IN THE COMMUNITY

Other Providers

The weight of the disease

“A lot of patients and family members feel a big burden, a big weight on them. Many of them don't like to admit that when the patient comes to their demise, it's a relief. And many family members are embarrassed to admit that.”



Fighting on multiple fronts

“And then we have the 30 day readmission rule, which is a big thing because you know...we have done a petition to try to get sickle cell exempt from that 30 day readmission.”



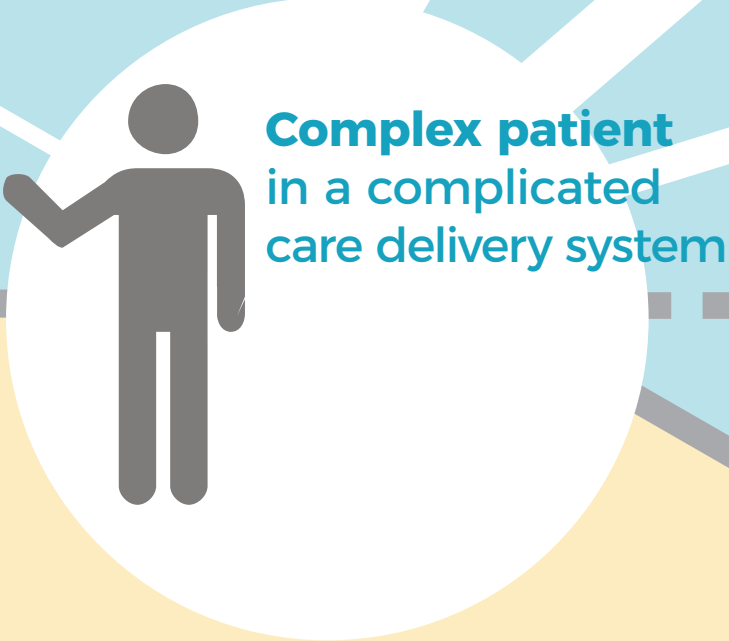
Emergency Department



Acute Care Clinic



Sickle Cell Center



INSIDE THE HEALTHCARE SYSTEM

IN THE COMMUNITY

Other Providers

Connecting the dots

“It made me look back and say he was sent home with a lot of pain medicine.

And that regimen worked here in the hospital.

Why didn't that regimen work at home?”

Result Type
Result Date
Result Status
Result Entered
Performed By
Verified By

Patient Education Content
Auth(Verified) & Reviewed
Patient Education Content
Auth(Verified) & Reviewed
Patient Education Content
Auth(Verified) & Reviewed

January 28, 2017 4:23 PM
January 28, 2017 4:23 PM
January 28, 2017 4:23 PM

* Final Report *

Immunizations
No Immunizations Documented This Visit

Laboratory or Other Results This Visit (last charted value for your 02/20/2017 visit)
No Laboratory or Other Results This Visit

Home Medication List:

albuterol CFC free 90 mcg/inh inhalation aerosol
Inhale 2 puff by mouth every 4 hours as needed for wheezing

Dilaudid 4 mg oral tablet
Take 4 mg by mouth every 4 hours as needed for pain

docusate sodium 100 mg oral capsule
Take 100 mg by mouth every day as needed for constipation

folic acid 1 mg oral tablet
Take 1 mg by mouth every day

Special Instructions: Please take 1 daily only and as directed

hydroxyurea 500 mg oral capsule
Take 1,500 mg by mouth every day

methadone 10 mg oral tablet
Take 20 mg by mouth every 12 hours

Special Instructions: Take 2 tablets by mouth every 12 hours. FOR ANALGESIA

medication to treat your pain. This medication is mostly used for a short time. If that happens, you may need to go to the hospital. If that happens, you may need to go to the hospital. If that happens, you may need to go to the hospital.

Background: Morphine, codeine, and other opioid medications are used to treat pain. But these medications can make you too sleepy. If that happens, you may need to go to the hospital. If that happens, you may need to go to the hospital. If that happens, you may need to go to the hospital.

What you should do to keep you safe? Your health care team checks for early signs of opioid side effects. This ensures the medication is safe. Your health care team checks for early signs of opioid side effects. This ensures the medication is safe. Your health care team checks for early signs of opioid side effects. This ensures the medication is safe.



Emergency Department



Acute Care Clinic



Specialists



Nurse

Sickle Cell Center



Social worker



Community health worker

INSIDE THE HEALTHCARE SYSTEM

IN THE COMMUNITY



Complex patient
in a complicated
care delivery system

Other Providers

Cross-pollinators

“I think I learn more from other patients... Because they say, ‘Oh, I haven’t been in a pain crisis forever,’ and I’m like, ‘What is unique about your experience?’”



Stakeholder goals



Complex patient

Stay out of the ED



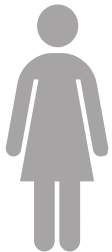
ED admin

Treat the patient
effectively & efficiently



Specialists

Keep their **patients**
healthy and **receiving**
proper care



Nurse

Provide patients with
the **care and education**
that they need



Social worker

Connect patients
to resources to help
them succeed



Community health worker

Support patient in
complying with care

We are all aligned around the same high-level goal:
keep sickle cell patients healthy.

Design understands needs across levels

Content level

Best-practice guidelines
Clear messaging + actions
Reading level + language fit
Visual hierarchy + structure



User needs level

Role + responsibilities
Knowledge needs
Relevance + value

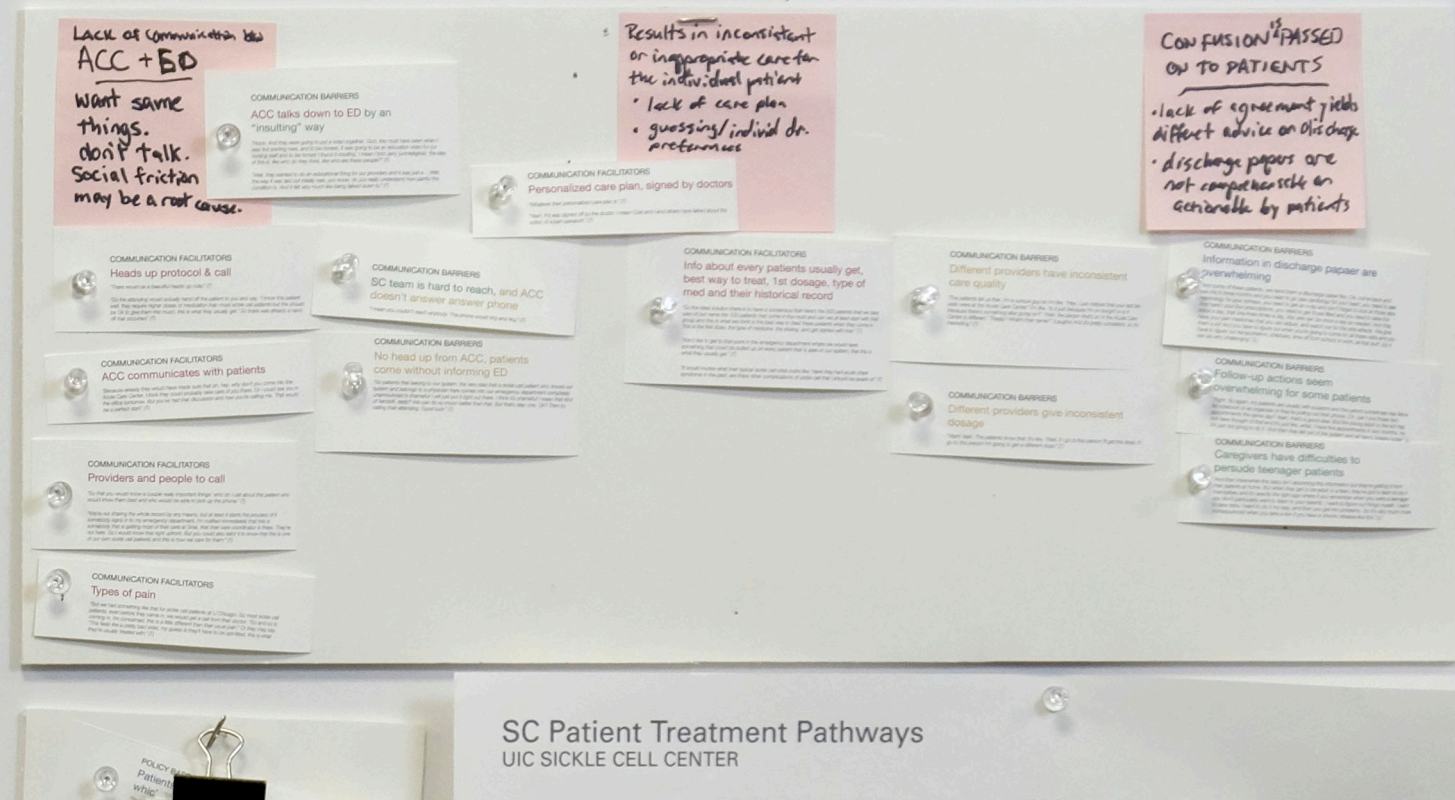
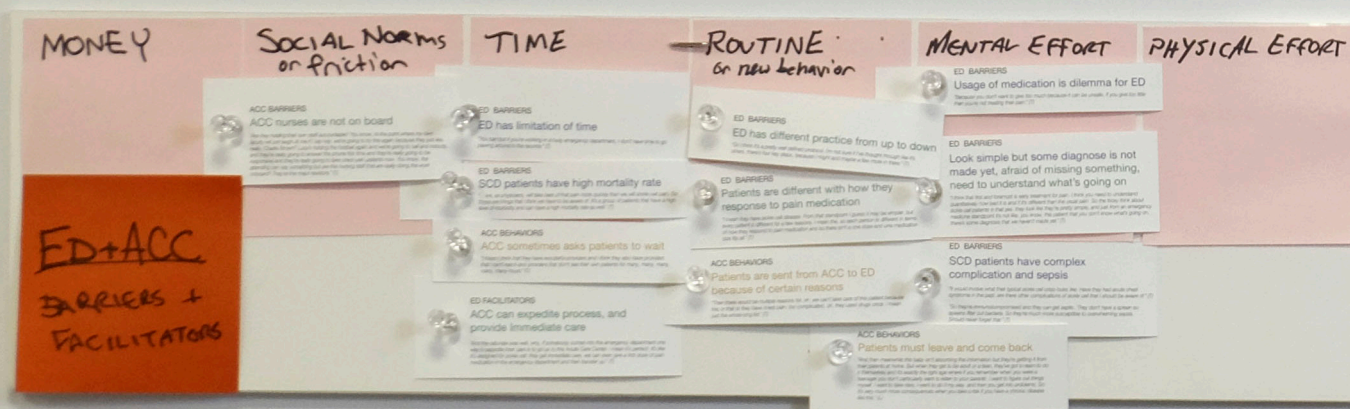
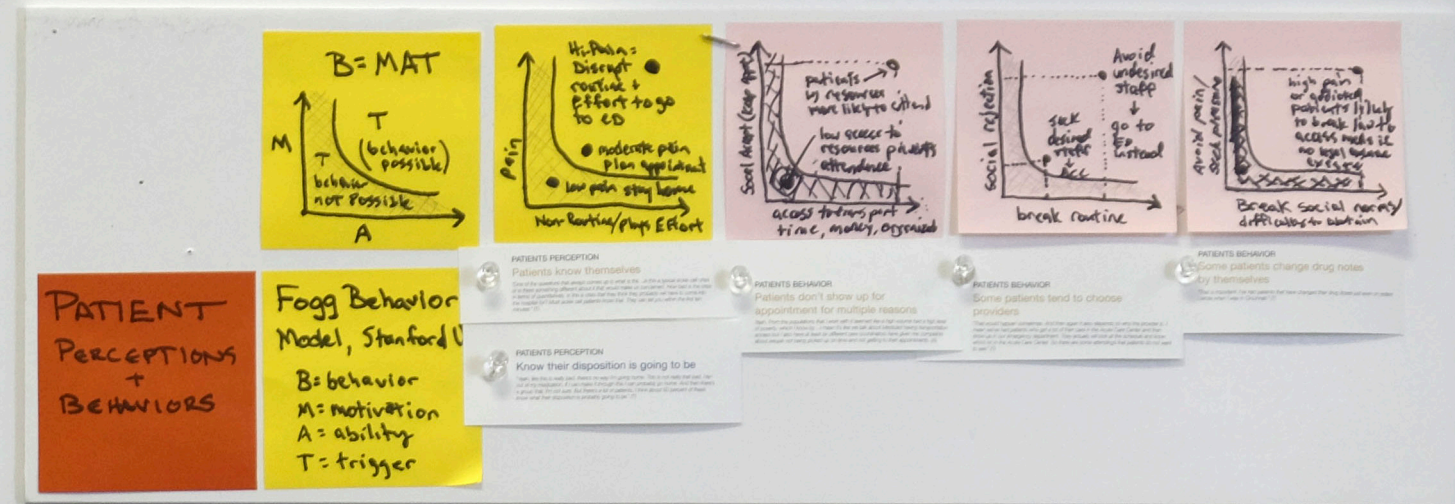
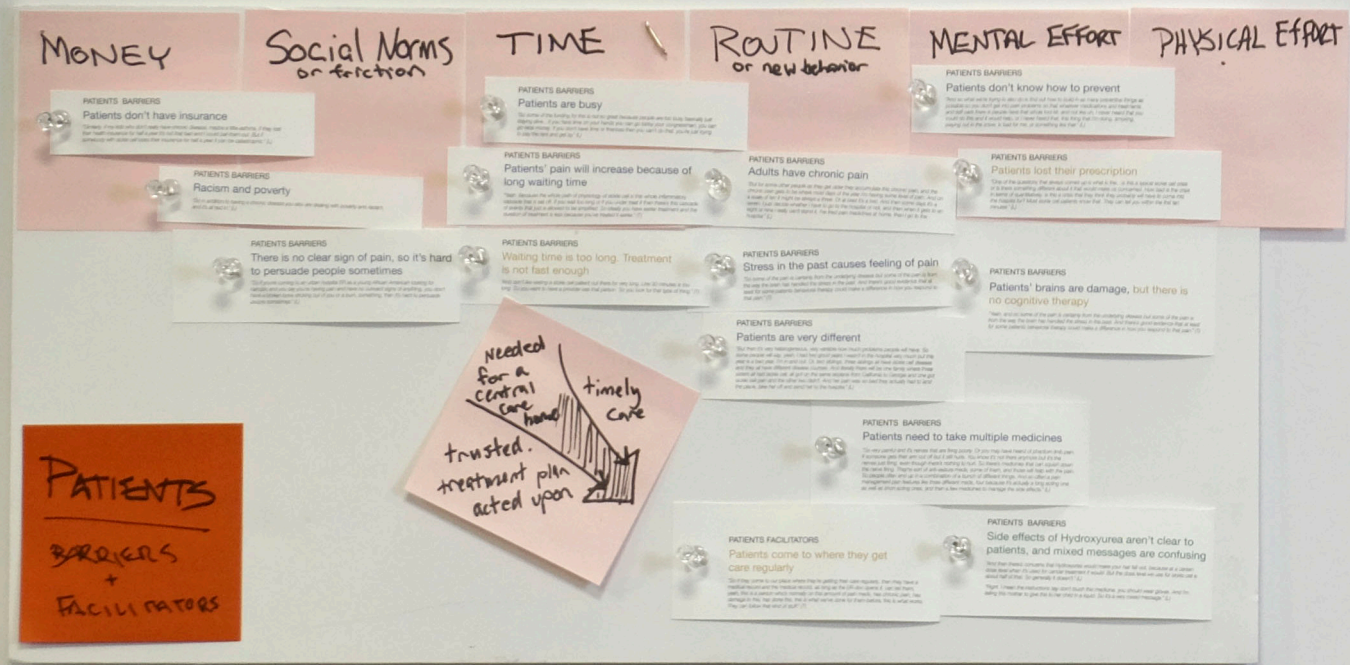


Contextual level

Supports key interactions
Fits workflows
Prompts key conversation +
reduces practice variation



Design identifies barriers and facilitators...



...and the relationships between them

POLICY BARRIERS

Restricted medications limit treatment options

"I think they also have their ED guidelines that they have to follow, and it's just certain medication that they cannot go over certain doses. And this physician did tell me that once. I didn't believe him. Then I talked to another ER physician that didn't work here but was elsewhere and she told me yes. I said then those guidelines need to be changed for sickle cell. So maybe this will happen."

Social Worker

ED BEHAVIORS

Use caution when administering high doses of medication

"They have a pretty good idea. If it sounds like a really high dose I'll divide it up first and we'll see how they respond. And they need to be on a monitor."

Medical Doctor

COMMUNICATION BARRIERS

SC team and ED have difficulty connecting with one another about patients

"I mean you couldn't reach anybody. The phone would ring and ring."

Medical Doctor

ED BEHAVIORS

Staff ask patients their dosage

"I will do my best to go back to the last few visits. But I mean there's a standard dosing, and you can ask the patient. You know, what medication do you usually get when you come in for a crisis."

Medical Doctor

COMMUNICATION BARRIERS

Patients don't always know how to communicate what they need

"Then when they say no, it's time to get off of it, then there's that clash. Even, now some of our support group meetings, we have had topics in terms of getting your needs met, what's the appropriate way of communicating, how to communicate to get your needs met."

Social Worker

ED BEHAVIOR

ED ask patients about their pain plan dosages, then don't administer them

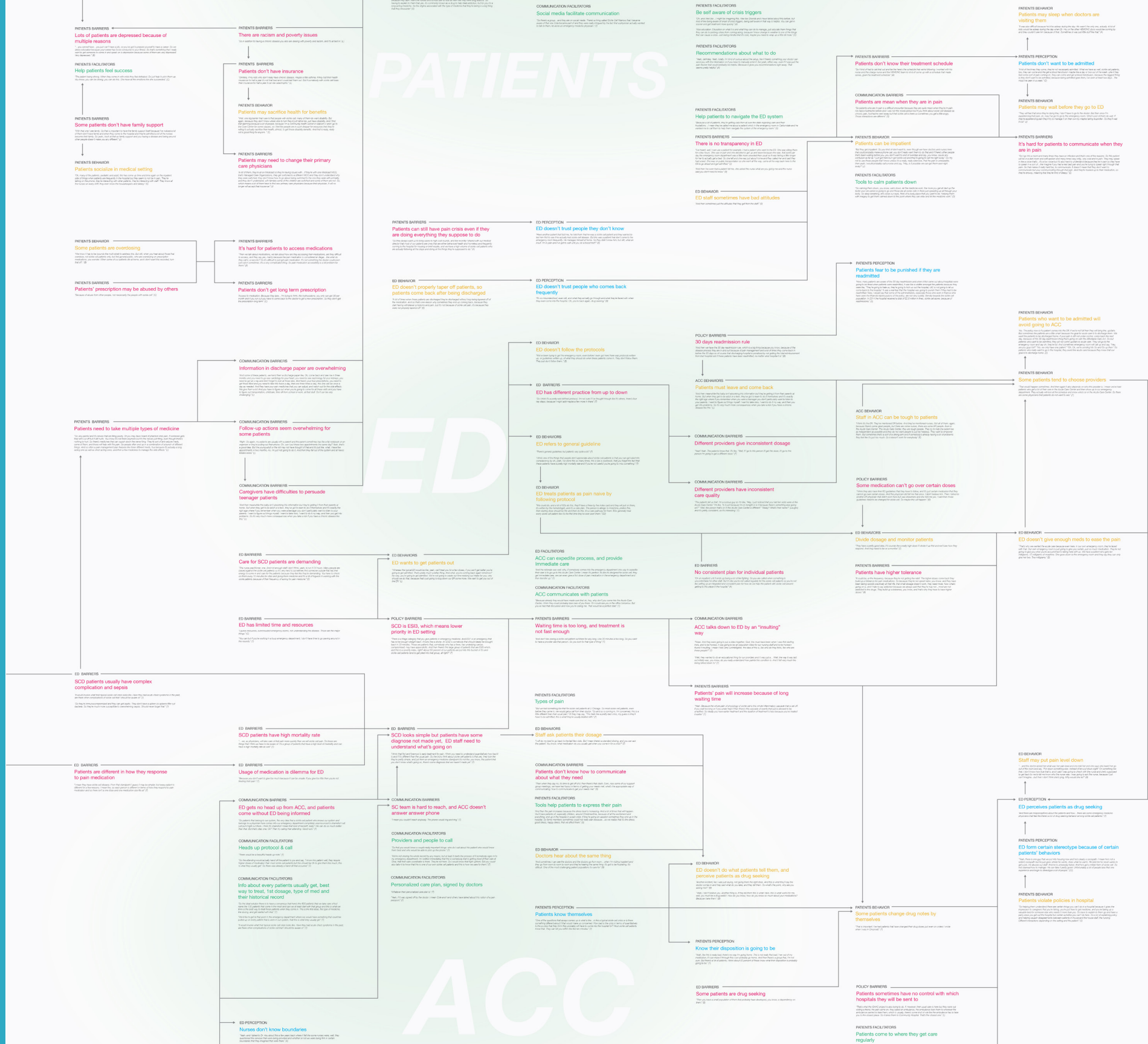
"Another incident, like I was just saying, not giving them the right dose. And this is what they'll say the doc and they said what do you take, and they tell me. So what's the point, why are you asking me?"

Social Worker

"Yeah, I don't believe you. Another thing is, if they tell them this is what I take, this is what works for me, well, you must be a drug addict. How do you know, how do you know so much about your medications? Because I take them."

Social Worker

thinking



Design criteria

Care plan created and maintained by provider

Facilitates secure transfer of information

Facilitates communication of individualized care plan

Supports monitoring health patterns and pain tracking

Relevant information and action steps for self-management



What's next?

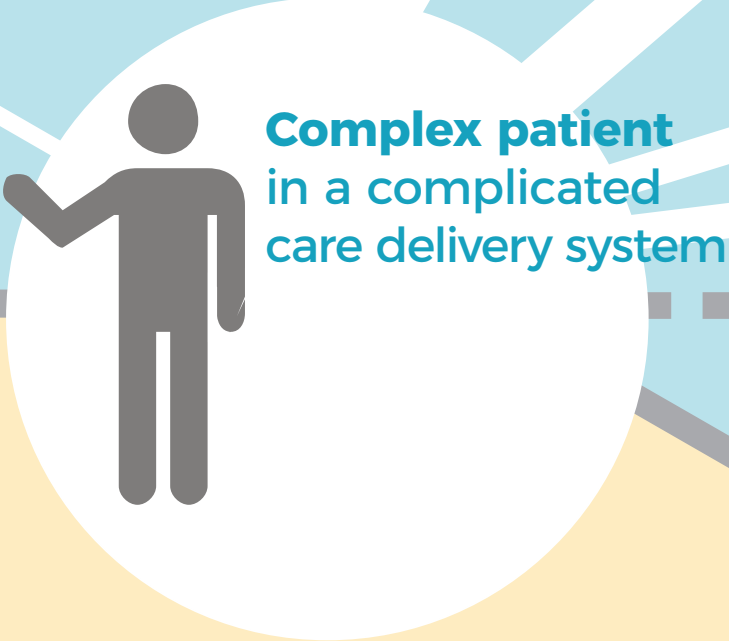
Emergency Department



Acute Care Clinic



Sickle Cell Center



INSIDE THE HEALTHCARE SYSTEM

IN THE COMMUNITY

Other Providers

Emergency Department

Acute Care Clinic

Sickle Cell Center

Complex patient
in a complicated
care delivery system

INSIDE THE HEALTHCARE SYSTEM

IN THE COMMUNITY

Other Providers

ED team
of doctors
attending
specialist
hospitalist

ED admin

ED nurses
admin nurse,
triage nurse,
floor nurse

Specialists

Nurse

Social worker

Community
health worker

Family/
caregiver

Work HR,
employers,
co-workers

School staff
educators
nurses
administration

Legal aid

PCP,
other
specialists