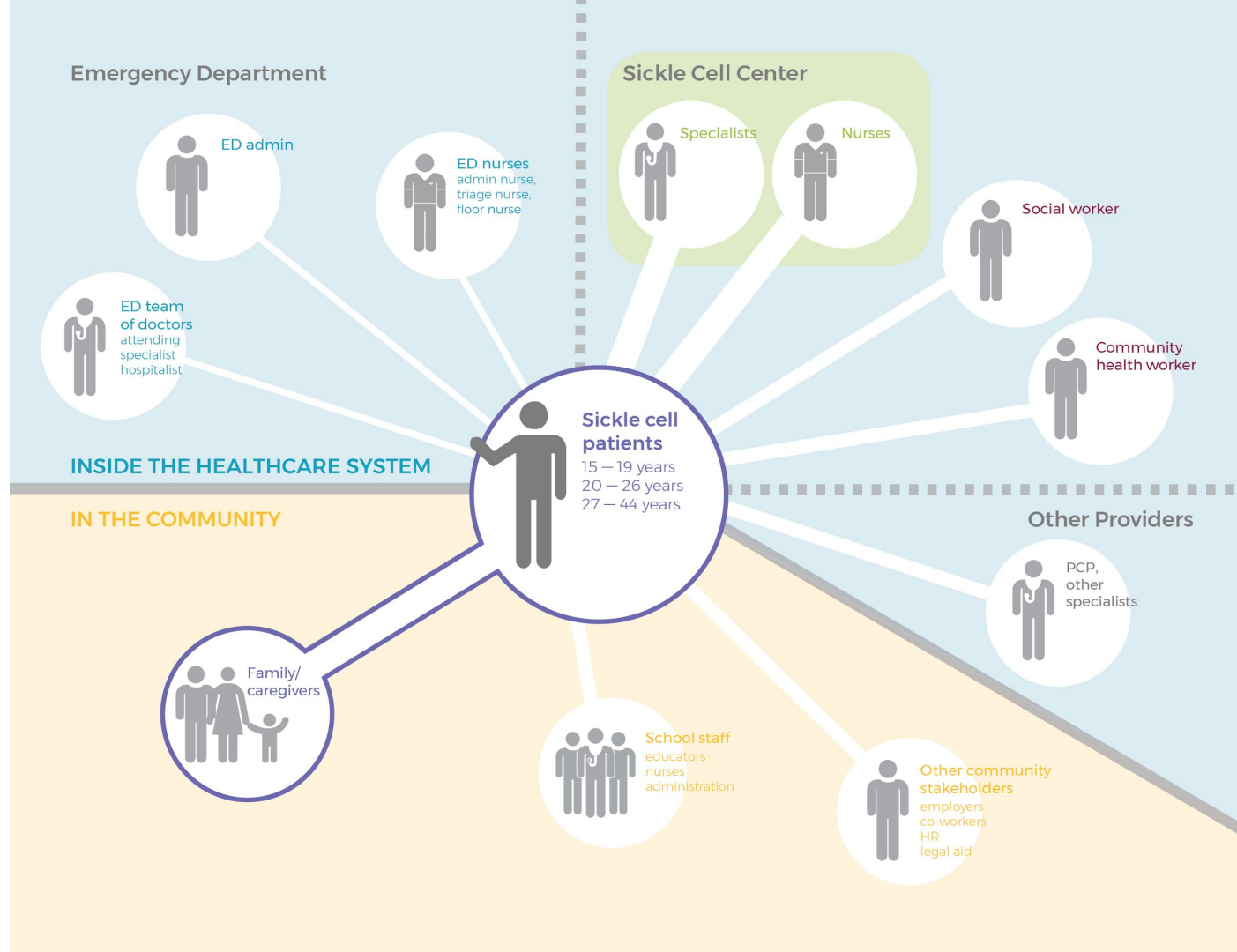


# Drivers of sickle cell care in the ED



# ISAAC

## Phase 1



# ISAAC

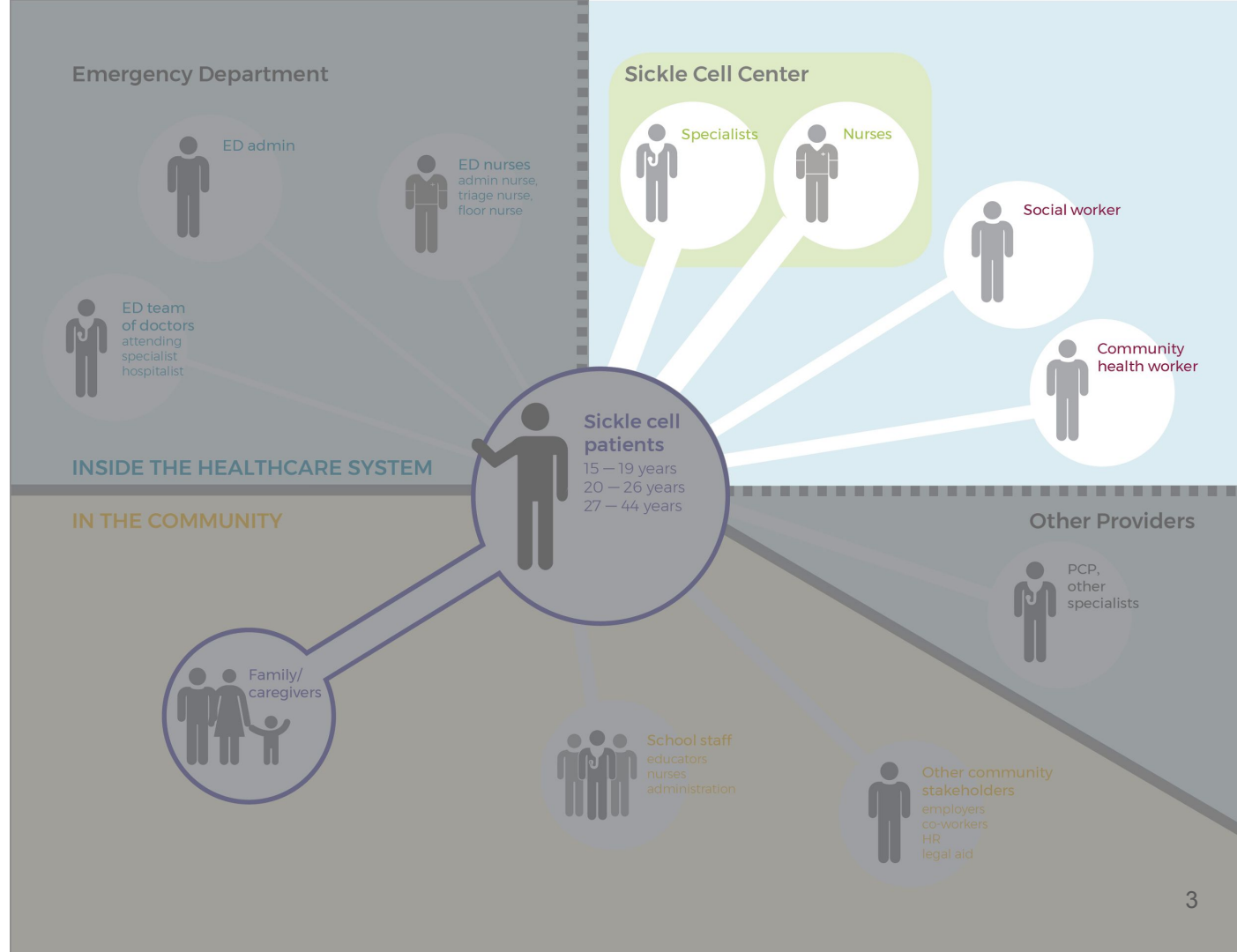
## Phase 1

### INTERVIEWS

- 3 Social workers
- 4 CHWs
- 3 Clinic nurses
- 1 ED Provider

### DIRECT OBSERVATIONS

- 2 UIC ED
- 1 Sickle cell inpatient
- 1 Acute care clinic
- 1 Patient support group



# ISAAC

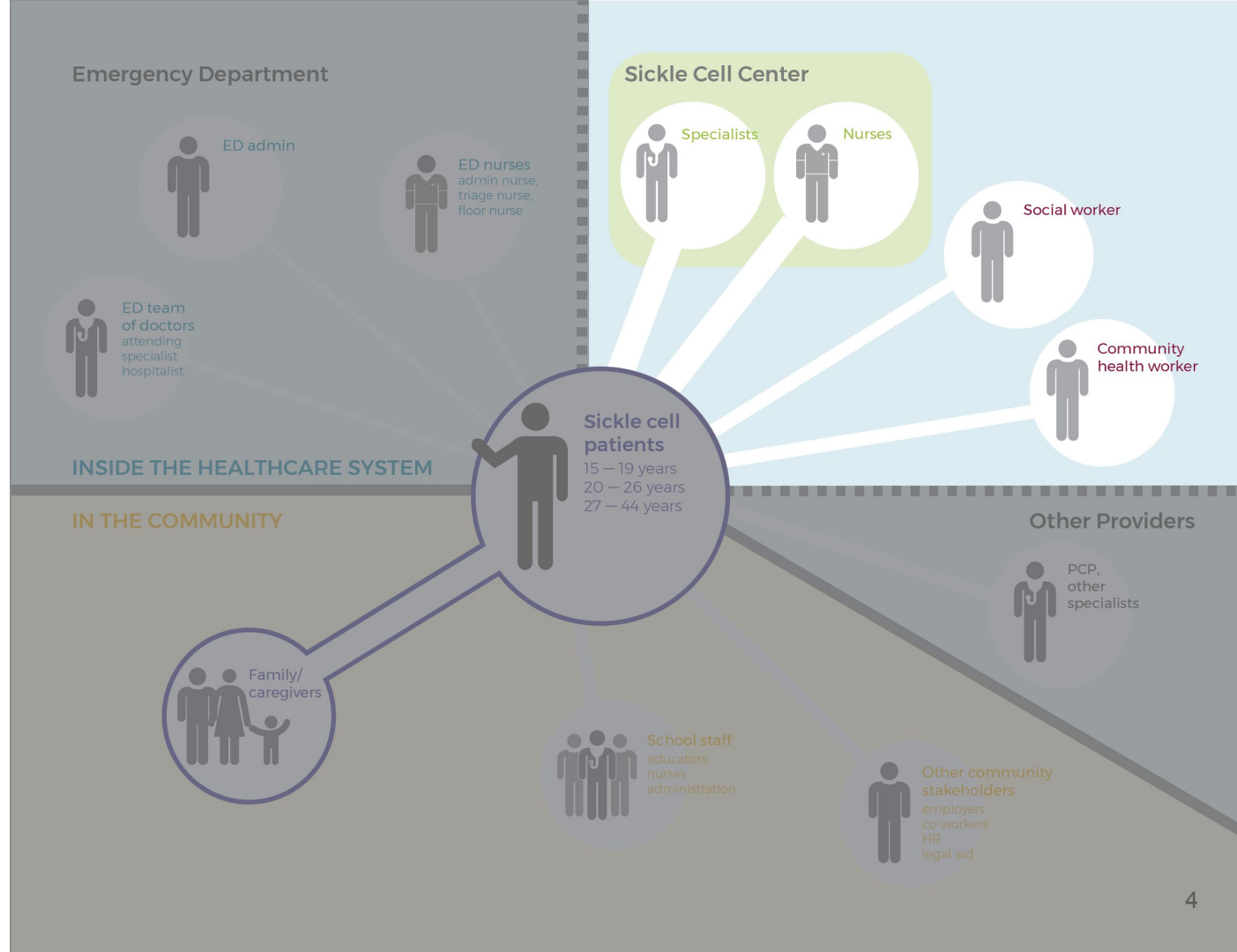
## Phase 1

### We learned...

SCD competes for patients' attention with other real world needs and goals.

Sickle cell patients with lower self-efficacy tend to be high utilizers.

Mutual distrust leads to adversarial interactions within the healthcare system.





# ISAAC

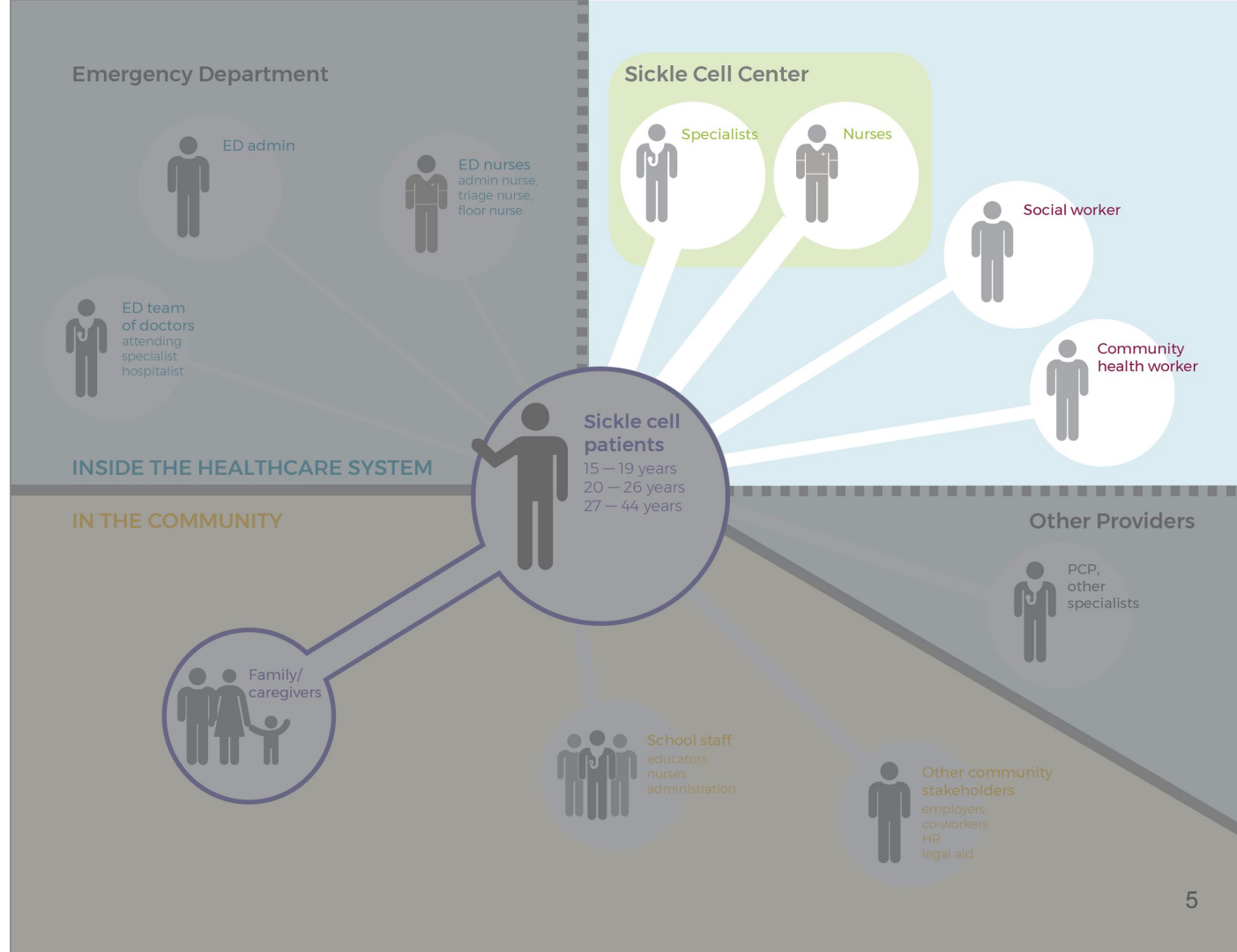
## Phase 1

### Themes:

Navigating the healthcare system is the patient's burden.

Continuity of care is critical to a patient's success.

While SCD can lead to isolation, a strong community can alleviate these experiences.



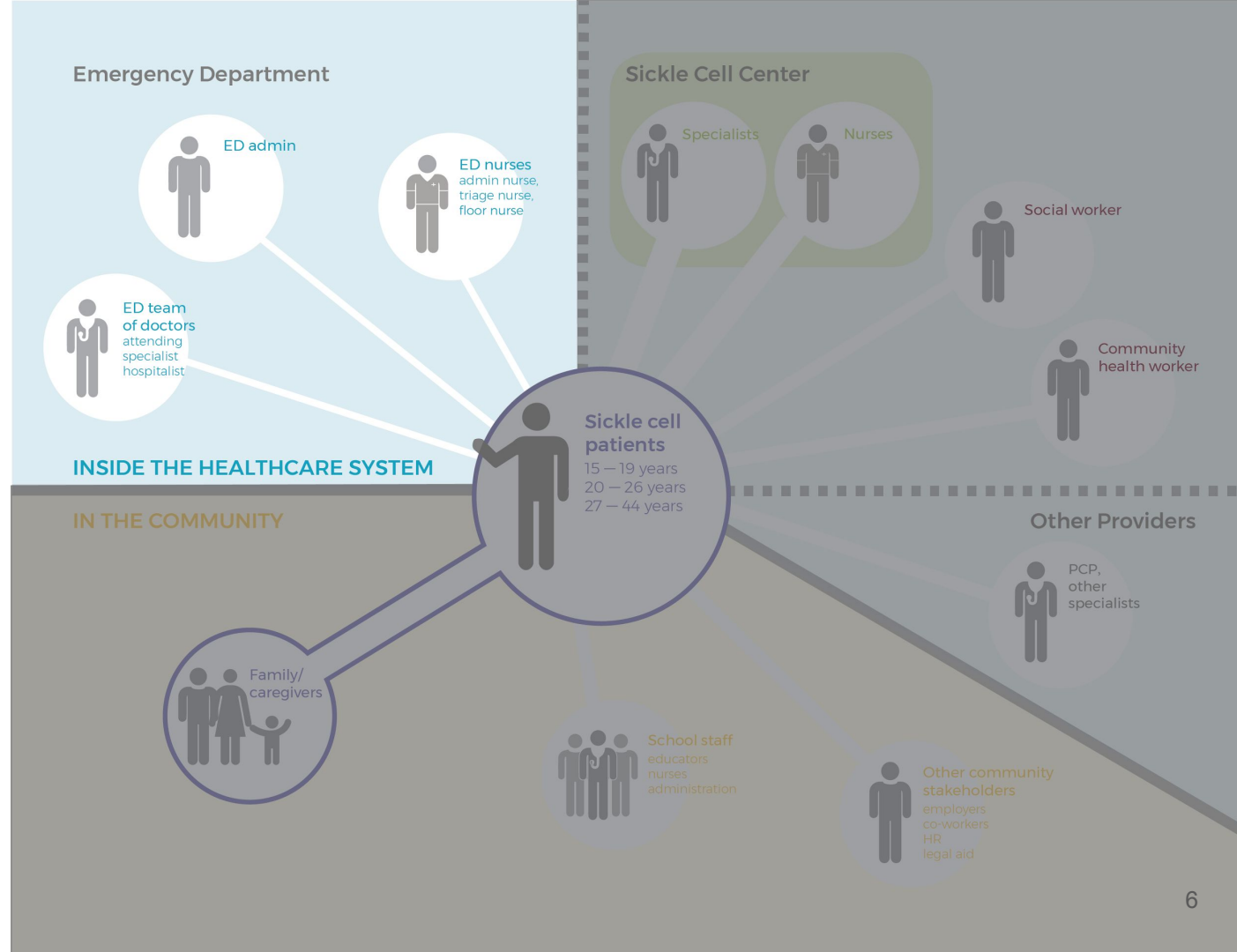
# ISAAC

## Phase 2

5 UIC ED provider interviews to date.

Goal: 8 doctors & 8 nurses per site at 2 sites.

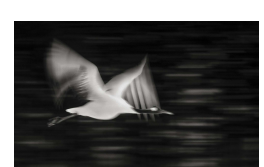
Findings to date are provisional.



What is it like to provide care for SCD patients in the ED?

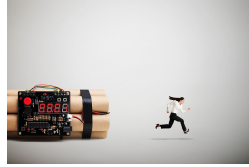
# Feelings about treating sickle cell patients in the ED

## Projectives exercise



# Feelings about treating sickle cell patients in the ED

## Projectives exercise



# Feelings about treating sickle cell patients in the ED

## ED Provider



“ You’re **draining too much emotional energy** from me. ”



“ It’s **sweet, this is easy**. I do the same things. There’s no real thinking about it. ”



“ It’s the **walking a tightrope** of someone who’s manipulative, actually. ”

# Feelings about treating sickle cell patients in the ED

## ED Provider



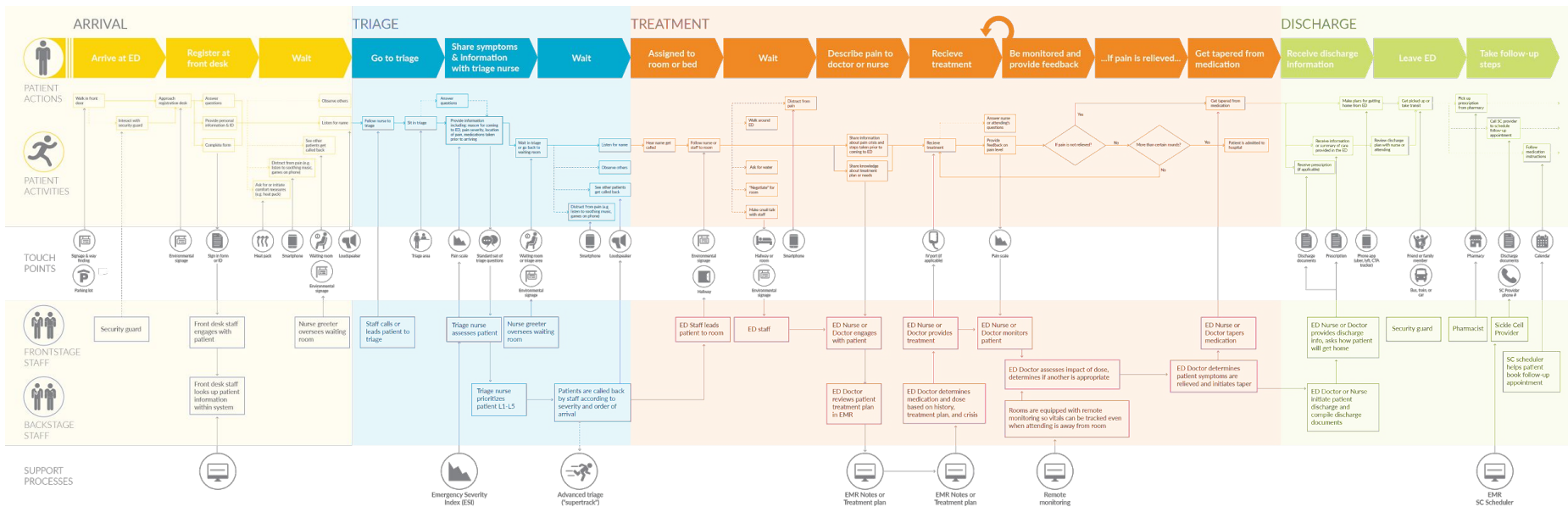
“This is definitely for feeling a part of the system that **I’m not really in control of.**”



“We’re potentially causing these people to be **addicted** to the same substance that heroin abusers are on the street for.”



# ED SERVICE BLUEPRINT



Opportunities



# PRE-ARRIVAL

## Getting to the ED earlier

“If you wait too long or if you undertreat [the pain], then there’s this cascade of events that is amplified. Ideally you have earlier treatment, and the duration of treatment is less because you’ve treated it earlier.”

ED Provider



# PRE-ARRIVAL

## Balancing obligations & crisis care

no transportation

couldn't miss daughter's graduation

can not maintain job

couldn't get  
medications

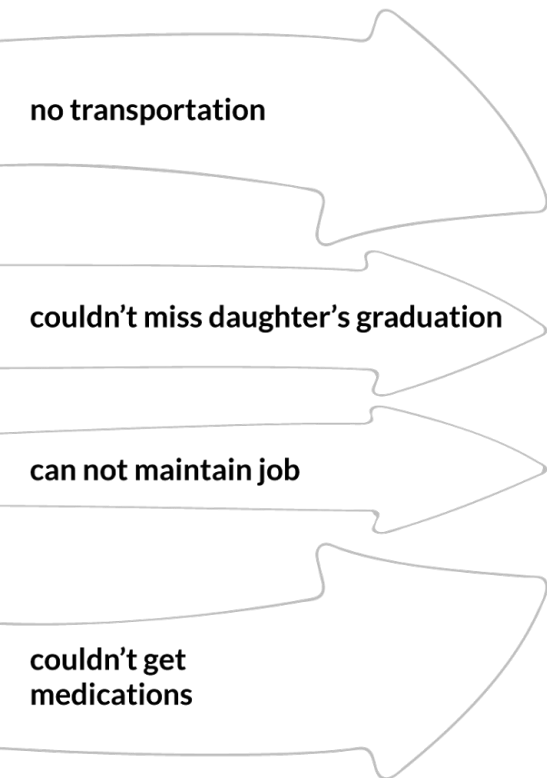


### everyday life

get to appointments  
go to work  
go to school  
be with family

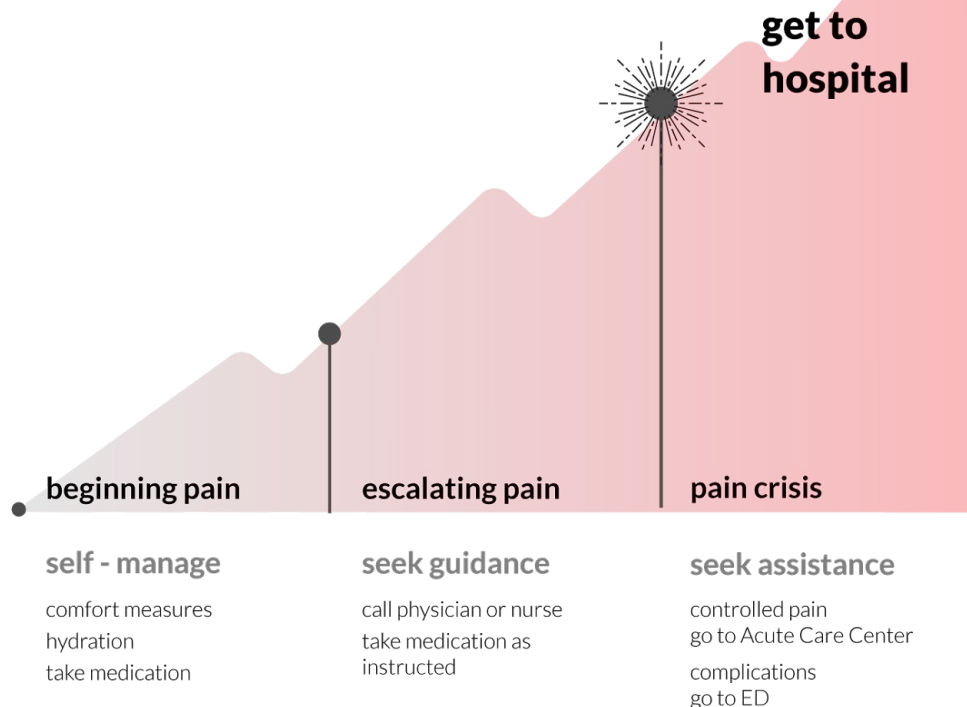
# PRE-ARRIVAL

## Balancing obligations & crisis care



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# PRE-ARRIVAL

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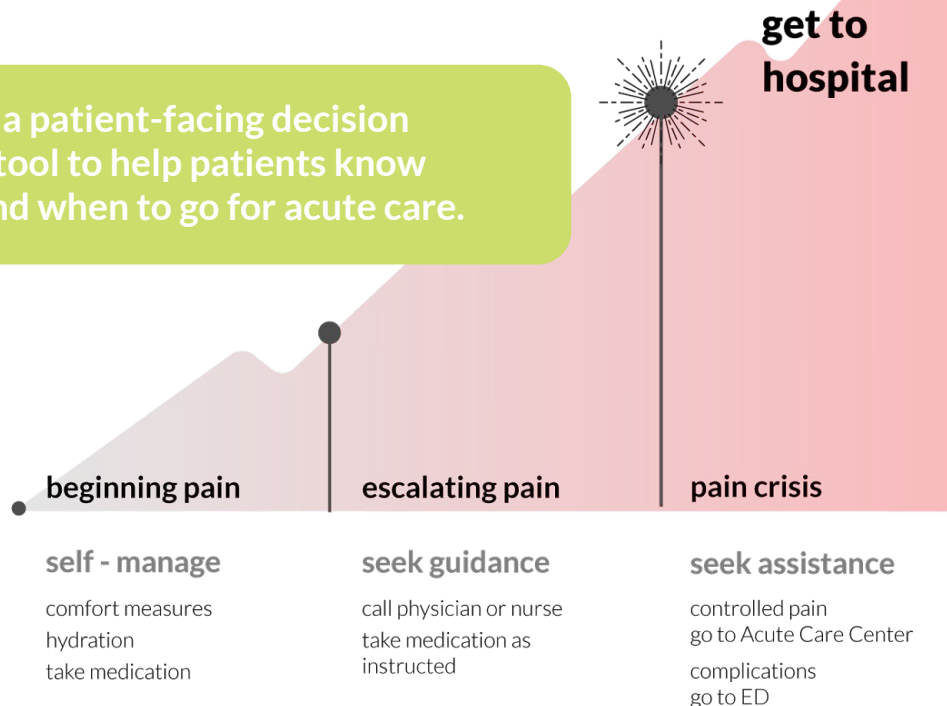


Develop a patient-facing decision support tool to help patients know where and when to go for acute care.

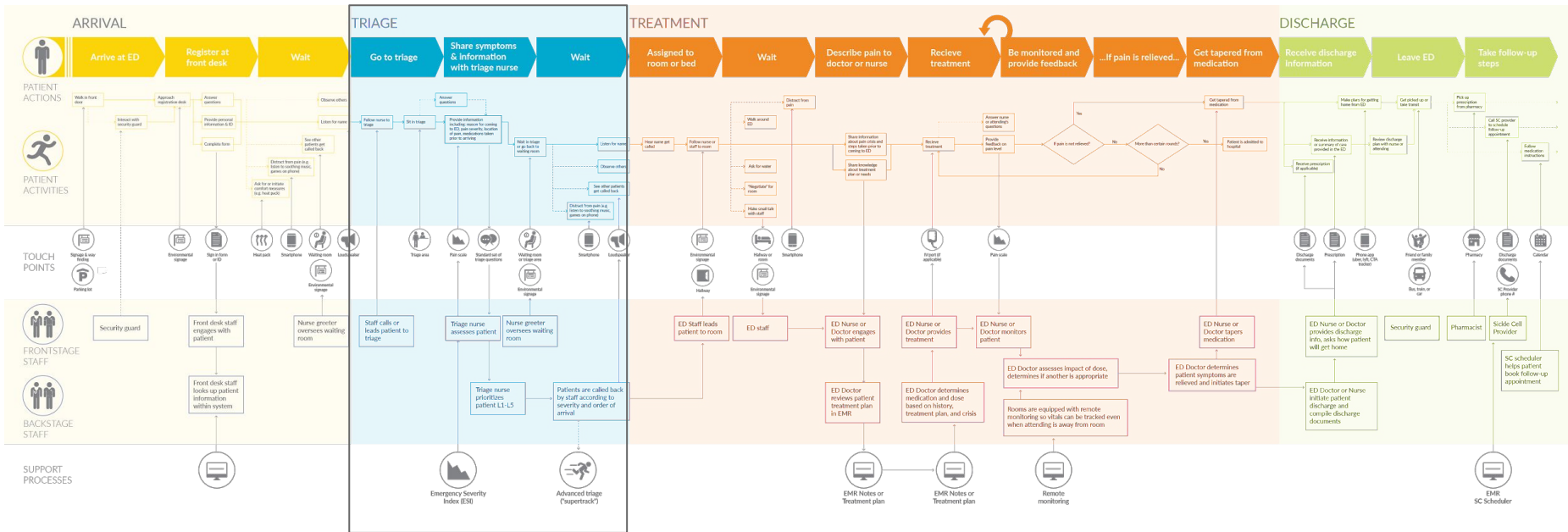


### everyday life

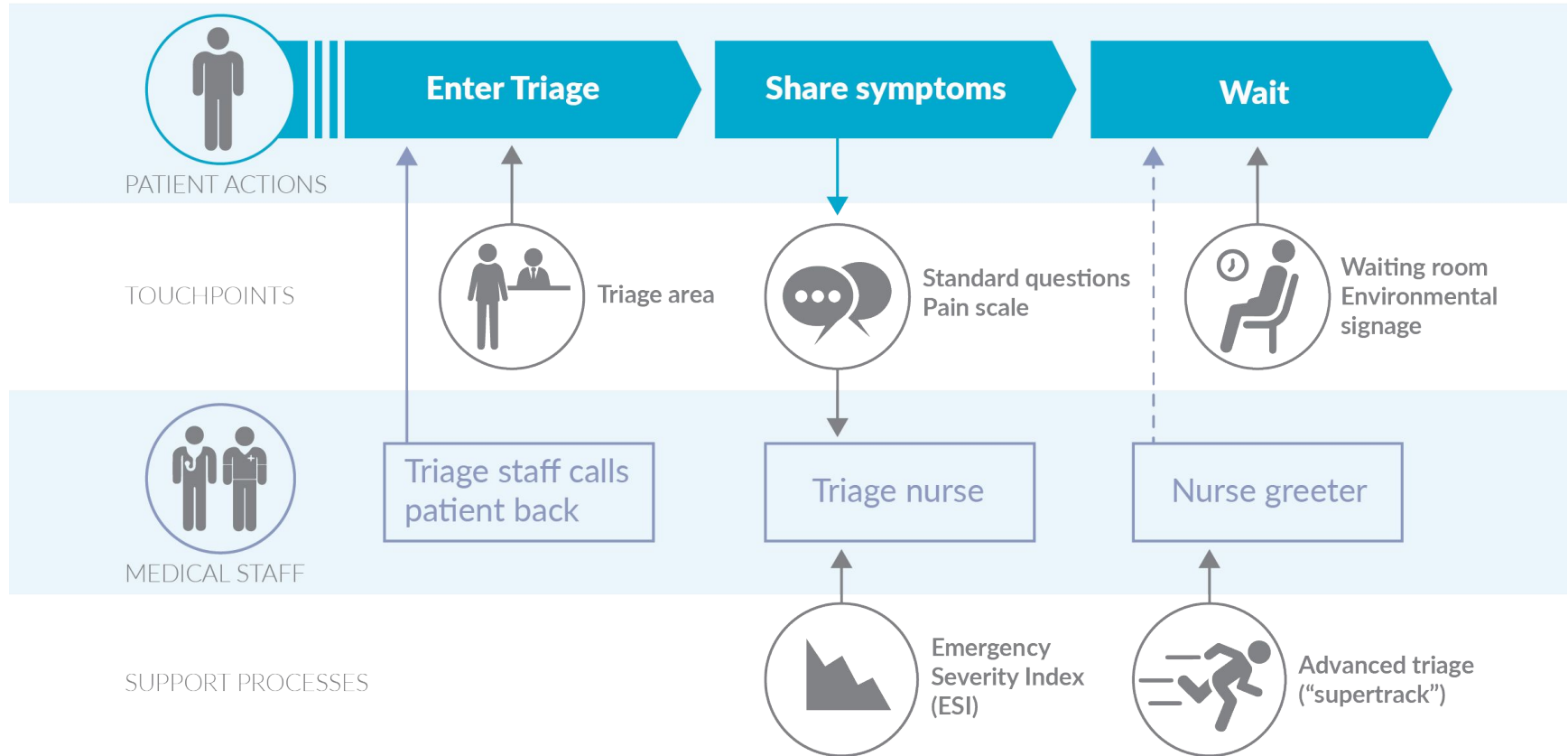
get to appointments  
go to work  
go to school  
be with family



# ED SERVICE BLUEPRINT



# TRIAGE



# TRIAGE

## SC Patient Prioritization in ED

“More sickle cell patients **probably** ought to be categorized as 2 rather than 3.”

ED Provider



ACC

Optimized for SC Treatment

“ When you’re in the ER, you’re behind babies with pennies in their ear.

But in Acute Care you come up and **within 30 minutes** you’ve got an IV in you and you’re getting medicine. ”

Social Worker





ACC:ED

Providing care for sickle cell patients

ACC



ED

ACC:ED

Providing care for sickle cell patients

ACC



ED

ED to ACC

## **BARRIERS TO TRANSFER**

Demand during ACC's off-hours

“The dream of the former director was for us to have a **24-hour acute care center** so that patients wouldn't have to go to the emergency room. ”

Social Worker

ED to ACC

## BARRIERS TO TRANSFER

Demand during ACC's off-hours

### Unclear on ACC function

“It’s a little unclear when they should go to the ACC versus my department. **I’m not sure what the roles are.**”

ED Provider

“As an ED provider, I know what my emergency department can provide. **I don’t know what the ACC can provide.**”

ED Provider

ED to ACC

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ED Provider

“As an ED provider, I know what my emergency department can provide. **I don’t know what the ACC can provide.**”

ED Provider



Develop a shared understanding of each department’s role and when to move patients between them.

ED to ACC

## BARRIERS TO TRANSFER

Demand during ACC's off-hours

Unclear on ACC function

**Unclear ACC patient profile**

“Is there a guideline telling us **what they [ACC] want and how much space they have available?** ”

ED Provider

“[Patients] can go downstairs to the ER and know that they're going to see me regardless and **get pain medicine either way.** ”

ED Provider

ED to ACC

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“[Patients] can go downstairs to the ER and know that they're going to see me regardless and **get pain medicine either way.** ”

ED Provider



Have ACC and ED agree on what defines an ACC-appropriate patient.

ED to ACC

## **BARRIERS TO TRANSFER**

Demand during ACC's off-hours

Unclear on ACC function

Unclear ACC patient profile

**No communication plan**

**“ I need a phone number. ”**

ED Provider

**“ I mean you couldn't reach anybody. The phone would ring and ring. ”**

ED Provider



ED to ACC

## BARRIERS TO TRANSFER

Demand during ACC's off-hours

Unclear on ACC function

Unclear ACC patient profile

**No communication plan**

**“I need a phone number.”**

ED Provider

**“I mean you couldn't reach anybody. The phone would ring and ring.”**

ED Provider



Establish a communication channel  
between ED & ACC.

ED to ACC

## **BARRIERS TO TRANSFER**

Demand during ACC's off-hours

Unclear on ACC function

Unclear ACC patient profile

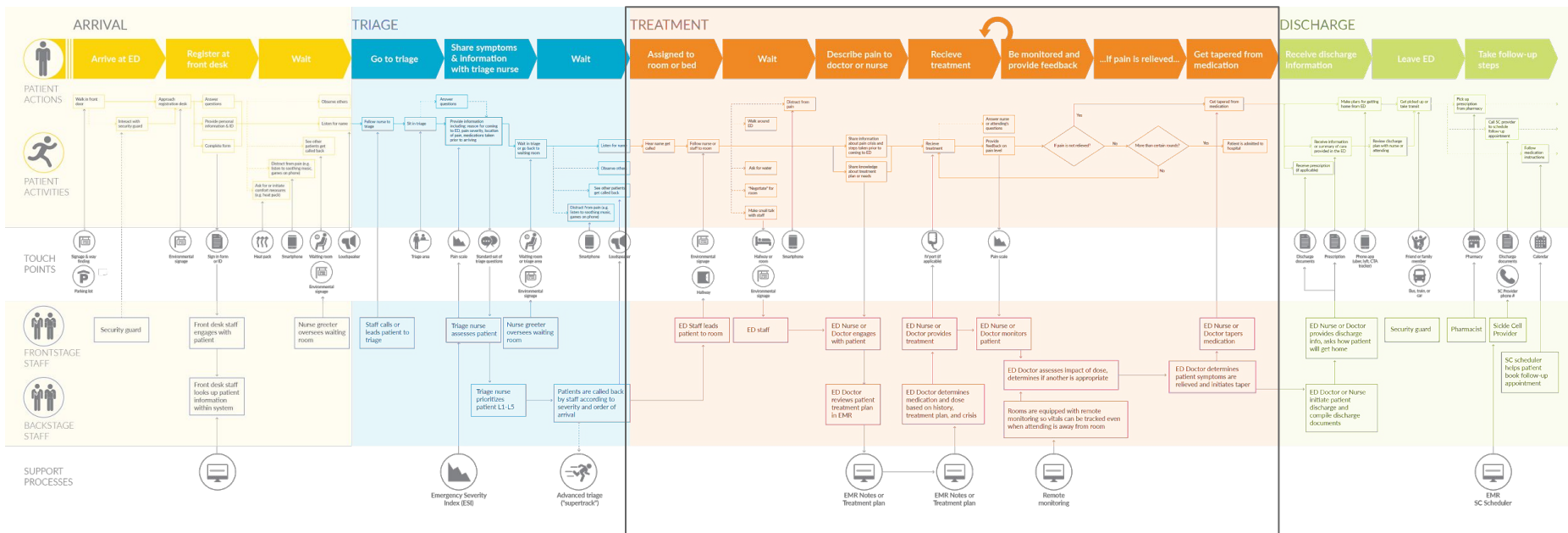
No communication plan

**Past experience with ACC**

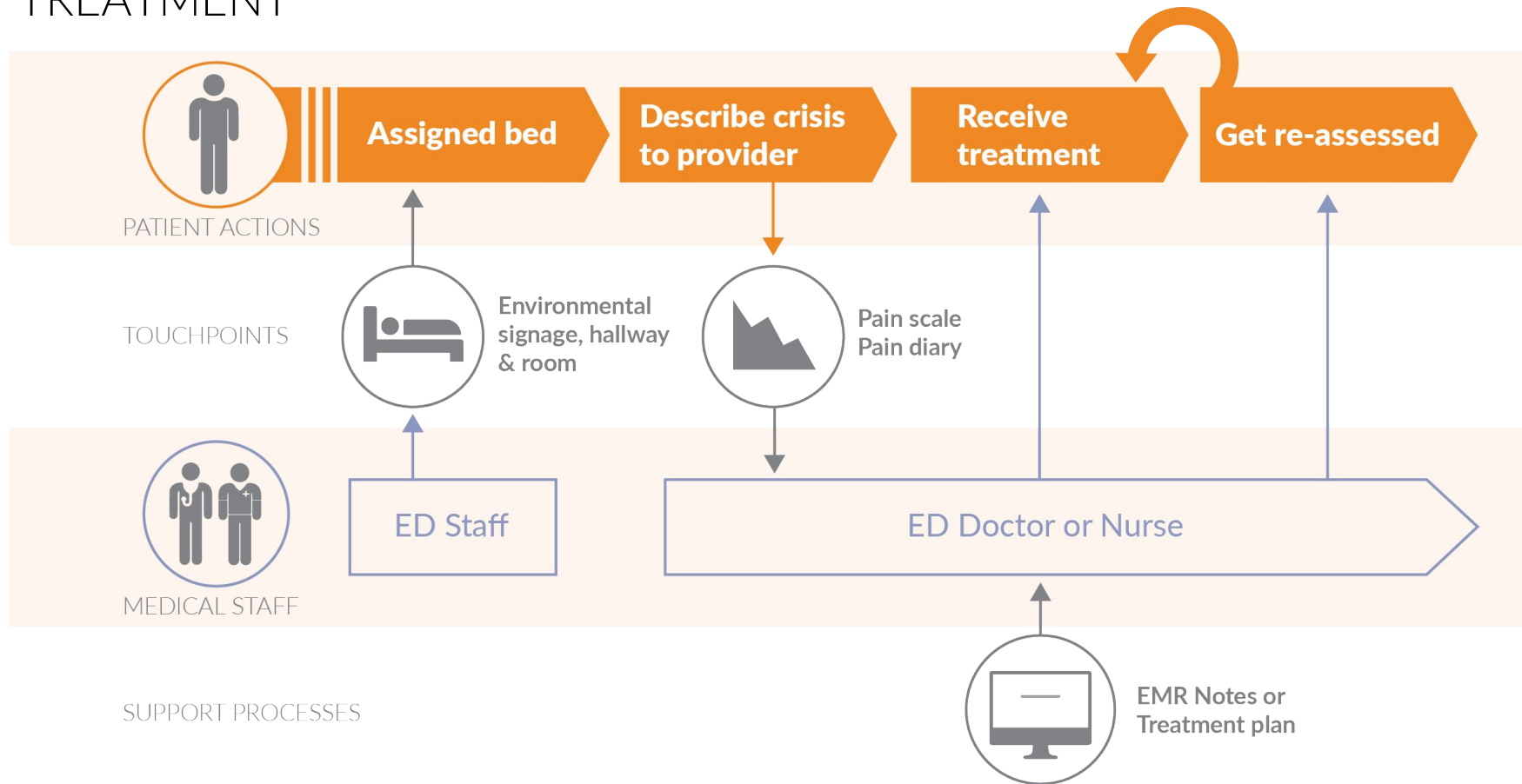
**“So then I sort of gave up.”**

ED Provider

# ED SERVICE BLUEPRINT



# TREATMENT



Drivers of ED Provider

## **TREATMENT PRACTICES**

Every ED provider brings their education, experiences, and philosophies to the bedside when treating SC patients.

Drivers of ED Provider  
**TREATMENT PRACTICES**

## Informal ED protocol for SCD

“You draw a certain set of labs and you **give pain medicine.** ”

ED Provider

“The protocol is a **socialized** change. ”

ED Provider

“There’s not much I can do so **I end up compartmentalizing them.** This is what I do for the sickle cell patients, this is what I do for the drunks, and they’re kind of in the same population. They are quick and easy.

ED Provider

Drivers of ED Provider  
**TREATMENT PRACTICES**

Informal ED protocol for SCD

**Specialist's treatment notes**

“ I go out of my way to make myself familiar with their **treatment plans**. ”

ED Provider

“ **I don't have time** to go pawing around in the records. ”

ED Provider

“ I've been **begging for these notes** for the adults for a long time. We don't have that in place. ”

ED Provider

Drivers of ED Provider  
**TREATMENT PRACTICES**

Informal ED protocol for SCD

Specialist's treatment notes

**Institution's approach**

“This hospital socializes the doctors to try to give higher doses because we have such a large sickle cell population.

**A lot of other places will not give anything close to what we give. ”**

ED Provider



Drivers of ED Provider  
**TREATMENT PRACTICES**

Informal ED protocol for SCD

Specialist's treatment notes

Institution's approach

**Individual philosophy on opioids**

“I have a line that says **this is where I stop**, and that has to do with my own comfort level. ”


ED Provider

“I am, in comparison to my colleagues, probably much **more comfortable using higher doses of narcotics** than they are. ”

ED Provider

## Mindsets and actions

of ED providers



I think we get comfortable pretty quickly using probably higher doses than you might use in typical practice.

“I’m using doses high enough that if any of us were to receive them, we would need some intervention to keep us breathing.”



We are out of good options. There’s things I can fix and things I can’t fix.

“ you’re going to get what you’re going to get because you have this awful disease”



This hospital socializes doctors to go ahead and give more and more

“there is a maximum dose I will give...”

Drivers of ED Provider  
**TREATMENT PRACTICES**

Informal ED protocol for SCD

Specialist's treatment notes

Institution's approach

Individual philosophy on opioids

**Education & prior experience**

“ If you go to Ohio, they use Oxycontin extensively. **It's the culture of how that area is.**

If you come here, if you go to most of the community hospitals around here, almost no one will write Oxycontin for you. ”

ED Provider

Drivers of ED Provider  
**TREATMENT PRACTICES**

Informal ED protocol for SCD

Specialist's treatment notes

Institution's approach

Individual philosophy on opioids

Education & prior experience

**Experiences with SCD patients**

“Are they really in pain or are they having an emotional crisis **so they're just here to get high?** ”

ED Provider

“This is not a pain crisis, you're in opiate withdrawal, which I understand is miserable.

But now **I think you're misinterpreting what is a pain crisis.** ”

ED Provider

Drivers of ED Provider  
**TREATMENT PRACTICES**

Informal ED protocol for SCD

Specialist's treatment notes

Institution's approach

Individual philosophy on opioids

Education & prior experience

Experiences with SCD patients

**Job satisfaction**

**“I don't get the greatest satisfaction  
from treating them** because it is sort of a  
**frustrating condition. ”**

ED Provider

# PROVIDING CARE TO SICKLE CELL PATIENTS IN THE ED

## Summary

1. Providing care in the ED is **emotionally taxing** for some providers.
2. **Patients are coming to the ED too late.** There is an opportunity to create a decision support tool to help patients make decisions about where and when to seek care.
3. When patients arrive in the ED, they are waiting too long. A **stronger working relationship between the ACC and the ED** can help expedite time to treatment for patients.
4. Treatment practices, specifically pertaining to opioids, **vary greatly across provider and institution.**

# APPENDIX

# Opportunities

Pre-arrival



Develop a patient-facing decision support tool to help patients know where and when to go for acute care.

ED to ACC



Develop a shared understanding of each department's role and when to move patients between them.

ED to ACC



Have ACC and ED agree on what defines an ACC-appropriate patient.

ED to ACC



Establish a communication channel between ED & ACC.



# Feelings about treating sickle cell patients in the ED

## ED Provider



“Sickle cell patients **with chest pain are particularly worrisome.** ”



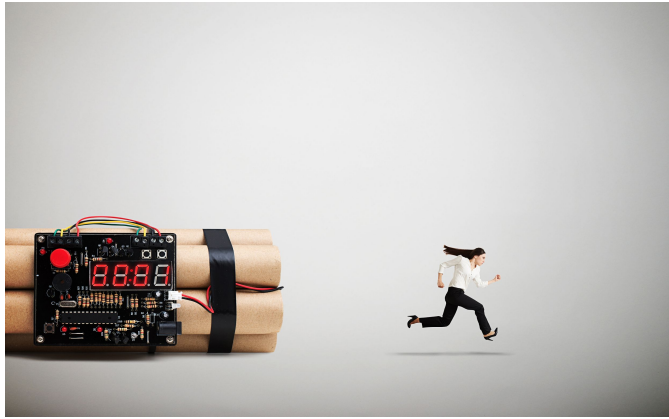
“This is a group of **patients that have a community** outside of the hospital. ”



“I care about them and **I want to make their pain better** and we’re going to try to take good care of them. ”

# Feelings about treating sickle cell patients in the ED

## ED Provider



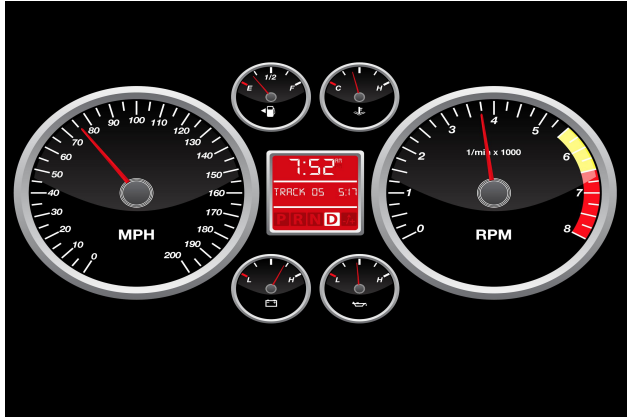
“The problem is when **they get sick they get sick very quickly.**”



“It’s kind of a **heartbreaking disease...**It can be satisfying when you **make people feel comfortable.**”

# Feelings about treating sickle cell patients in the ED

## ED Provider

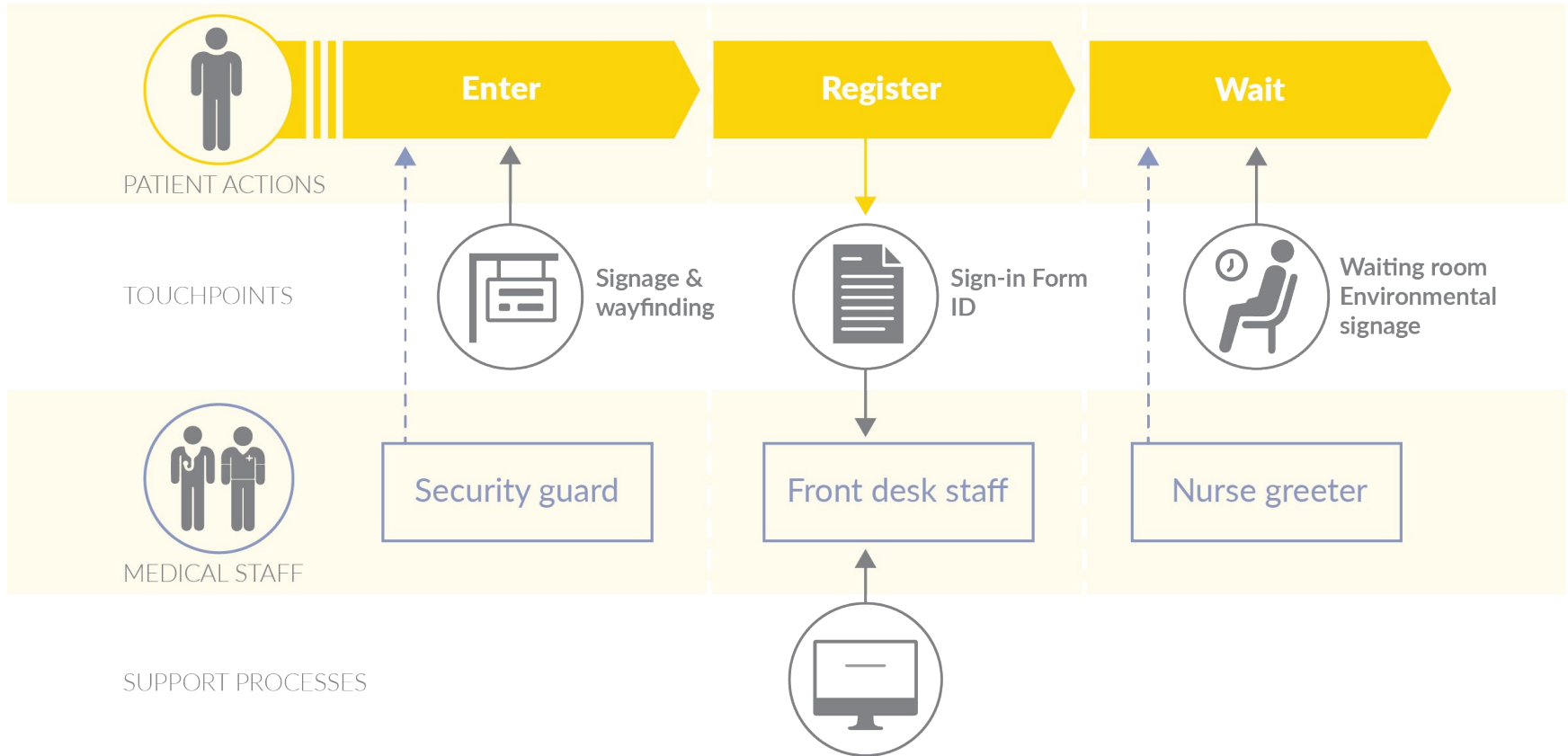


“I know what **labs I need**, I know how to **start your treatment.**”



“I think, unfortunately, the natural tendency is for there to be **less empathy in the world** for these patients.”

# ARRIVAL



# DISCHARGE

