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# **ACCESSIBILITY IN CLINICAL ENVIRONMENTS (ACE): UNDERSTANDING THE EXPERIENCES OF PATIENTS WITH MOBILITY DISABILITIES ACCESSING HEALTH CARE SERVICES AT PENN MEDICINE**

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# BACKGROUND

- Prevalence of Mobility Disabilities

- Philadelphia county had the highest number of mobility disability of all counties in Pennsylvania:

**39%**

**~62%** under the age of 65

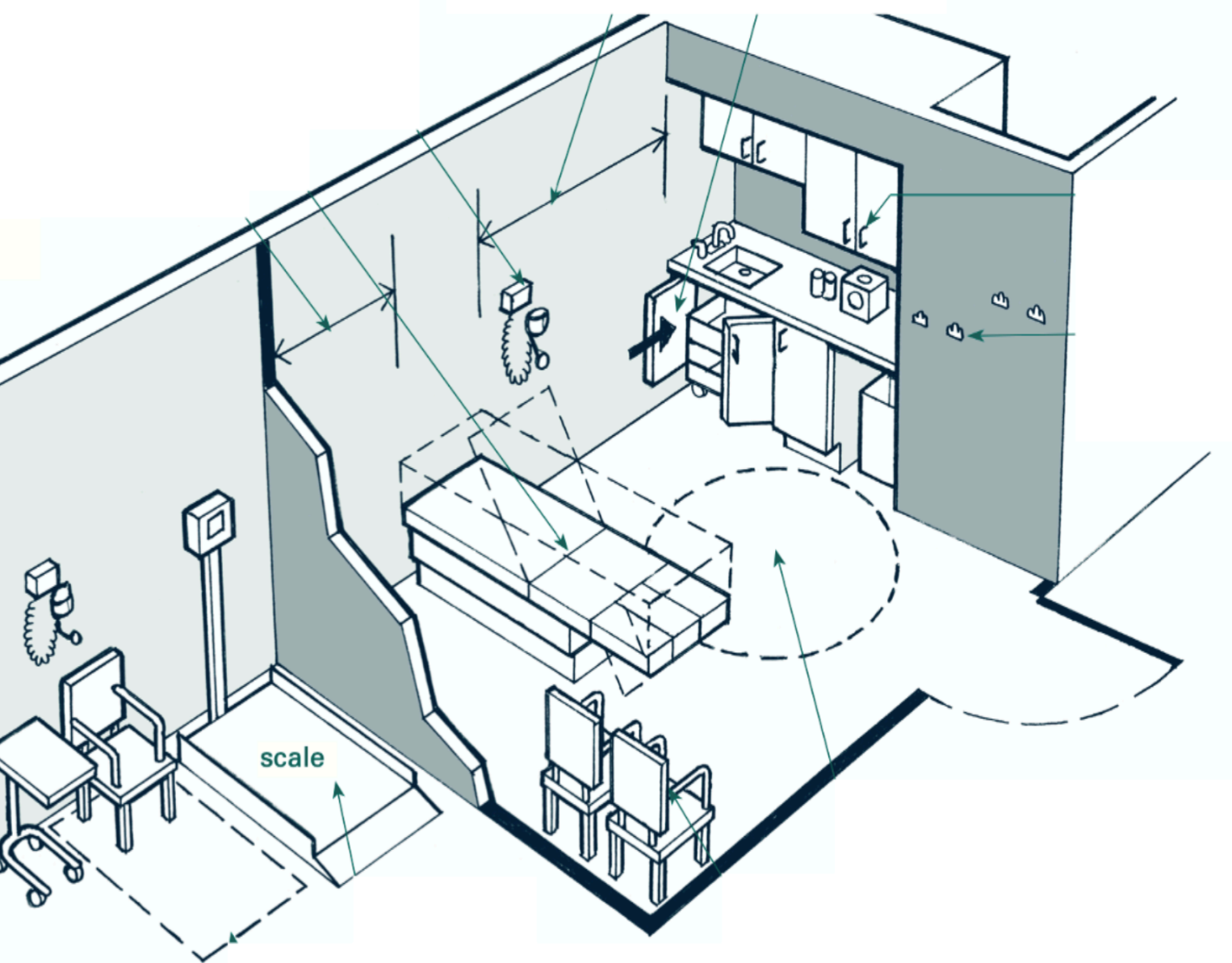
- Key Findings from Previous Literature

- Past literature highlights the need for better accommodations in large healthcare systems. (Pharr, 2020)
- A qualitative inquiry revealed barriers in both structural–environmental aspects (like facility accessibility) and process aspects (like provider-patient communication) (Pharr, 2020)

- Structural–Environmental Barriers

- Process Barriers

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# PRIMARY OBJECTIVE OF STUDY

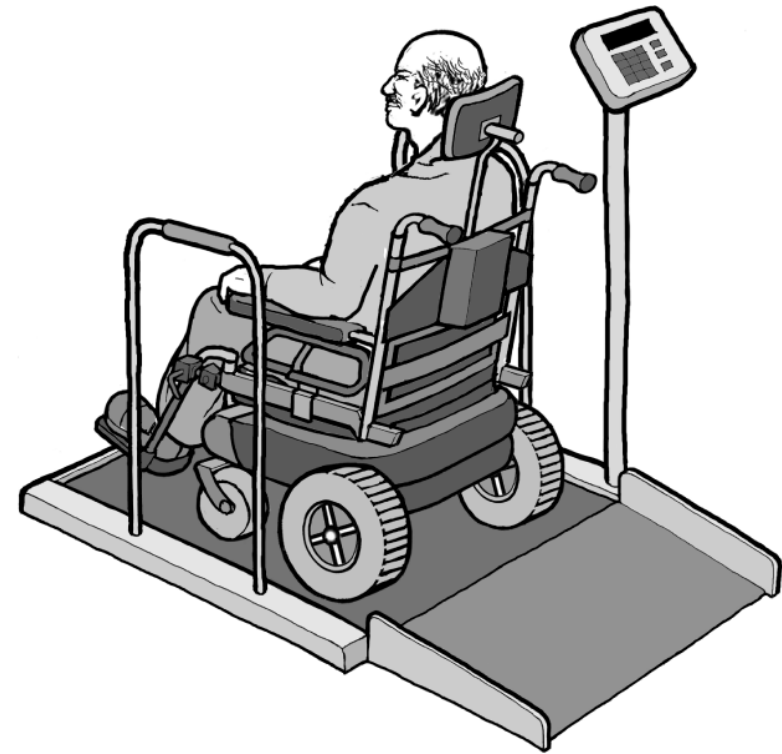
To examine the lived experiences of patients with disabilities in healthcare spaces using a qualitative research methodology called 'go along' observations (also known as 'walking' interviews).

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# SIGNIFICANCE

**“Go-Along” Observations:** “Allows researchers to observe participants’ spatial behaviors, access and interpret their perceptions and experiences about the surrounding environment” (Cao et al., 2019).

**Structural Impairments That Limit Access to Health Care for Patients With Disabilities:** “Less than 10% of physicians provided both basic accommodations for patients with significant vision limitations” (Iezzoni et al., 2022).



*Wheelchair Accessible Scale*

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# PROCESS MAP



**01**

Undergo Training on:

- *Qualitative Research / Semi Structured Interview / Go Along Method*
- *Empathetic inquiry style of interviewing*
- *Data Entry on NVIVO*
- *Reviewed Available Literature on 'go-along' interviews and disability health equity*



**02**

- Develop & Edit an Interview Guide & Observation Template
- Practice Walking Thru PCAM/Neurology Clinic



**03**

- Chart Review and Patient Recruitment via EPIC



**04**

- Schedule and Conduct Patient Pre/Post Appt. Interviews and Appointment Observation



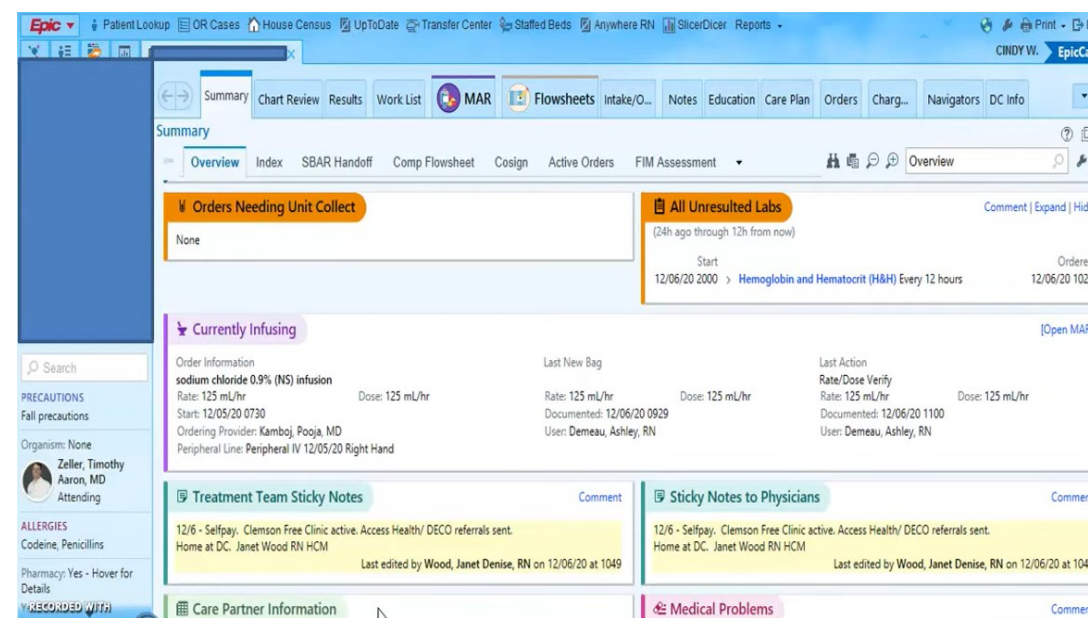
**05**

- Cleaning Transcripts
  - Inputting/Typing Up Data
    - Begin Data Analysis/Coding of Interviews
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# METHOD: CHART REVIEW AND PATIENT RECRUITMENT

- EPIC = Penn's Electronic Medical Records System
- Screened for Patients coming in for a 30 Minute Returning Patient Visit at the Multiple Sclerosis Clinic within the Neurology South Pavilion of PCAM
- Checked Charts for
  1. Abnormal Gait
  2. Use of Assistive Mobility Device
- Recruitment Timeline: July 26th – August 7th
- Kept Track of all Potential Participants on a Spread Sheet



Source: <https://www.emrsystems.net/epic-ehr-software/> (Not Real Patient Info)

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# METHOD: RECRUITMENT SCRIPT LANGUAGE & PROTOCOL

- Call Patients Over the Phone and Follow Script (~3-5 Minutes)
  - Script Includes...
    - An Overview of Study and Participant's Responsibilities if they Accept
    - IRB Consent Questions/Instructions
      - Ex.) "Your decision to participate is completely voluntary and you may choose not to participate in this study at any point"
  - 3 Eligibility Criteria Questions (need to say yes to all three to participate)
    1. Can you confirm that you have an upcoming appointment on \_\_\_\_\_ at \_\_\_\_\_?
    2. Do you still plan on attending this appointment?
    3. Do you have any mobility difficulties and/or currently use a mobility assistive device like a wheelchair/walker or cane?
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# METHOD: PRE-INTERVIEW PROTOCOL

- Transition from Phone to Zoom Audio to Record Interview (can also schedule pre interview for another day)
  - Estimated Length of Pre-Interview = ~ 10-15 minutes
  - Pre Interview Script Divided into 3 Main Categories of Questions
    1. Making an Appointment
    2. Transportation to Your Appointment
    3. Anticipated Barriers Once Reaching Your Appointment
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# PATIENT OBSERVATION



*#1: Perelman Lobby & Navigation to Final Clinic*

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# PATIENT OBSERVATION



*#2: Elevators*



*#3: Navigation to/From Clinic*



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# PATIENT OBSERVATION



*#4/8 Check In/Check Out Process*



*#5 Waiting Room*

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# PATIENT OBSERVATION



*#6: Vitals*



*#7: Exam Room*

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# METHOD: OBSERVATION TEMPLATE

*Covers Nine Locations:* (1) Perelman Lobby, (2) Elevators, (3) Navigation to Clinic, (4) Check In Process, (5) Waiting Room, (6) Vitals, (7) Exam Room, (8) Check Out Process, (9) Navigation to Final Destination

Perelman Lobby OR Perelman 2 <sup>nd</sup> Floor Lobby*			
Players	Background	Activity	Interpersonal Communication
<input type="checkbox"/> Patient <input type="checkbox"/> Social Support/Escort (Family, Caregiver, Friends) Note how the accompanier is related to participant. <input type="checkbox"/> Physician <input type="checkbox"/> Nurse/MA/NA <input type="checkbox"/> Front Desk Personnel <input type="checkbox"/> Help Desk Personnel <input type="checkbox"/> Patients  Document if participant already has a mobility device. [Y/N] If yes, type [if not sure, ask participant]: <input type="checkbox"/> Own wheelchair: manual/power(electric) <input type="checkbox"/> Hospital wheelchair: with/without handle brake <input type="checkbox"/> Scooter <input type="checkbox"/> Walker: type (no wheels/2/3/4 wheels) <input type="checkbox"/> Crutches <input type="checkbox"/> Cane: type (C-cane/tripod/quad/forearm)	Document the atmosphere (i.e. lighting, noise, ambiance, noise).  Note how they entered the location (doors used).  Note ease of communication.  Note the visibility and availability of RedCoat staff and signage.	<input type="checkbox"/> Was staff assistance already present at start of observation [Y/N] <input type="checkbox"/> If no, is assistance asked for/offered? Y/N <input type="checkbox"/> If yes, who initiates it: Participant/accompanier/staff  Note what the assistance is for.  Wait times for RedCoat assistance: 1= 0-5 min, 2= 6-10 min, 3= 11-15 min, 4= 16-20 min  If assistance for wheelchair, note wait times for wheelchair: 1= 0-5 min, 2= 6-10 min, 3= 11-15 min, 4= 16-20 min	Describe the presence and nature of all types of verbal, nonverbal, and physical communications between actors.  Note who the players communicate with (i.e. the participant, accompanier).  Note who the players make eye-contact with (i.e. the participant, caregiver, no eye-contact).

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# METHOD: POST-INTERVIEW SCRIPT/PROTOCOL

- Find a Time to Conduct Post Interview after Completing Observations/Day of Patient's Appointment
  - Estimated Length of Post-Interview = ~ 15-30 minutes
  - Post Interview Script Divided into 8 Main Categories (1 Standard Question/2-3 Patient Specific Questions Per Category)
    1. Perelman Lobby
    2. Elevators from Lobby
    3. Navigation to Clinic
    4. Check In Process/Waiting Room
    5. Vitals
    6. Exam Room
    7. Checkout Process
    8. General Wrap Up Questions
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CAN YOU SHARE YOUR **EXPERIENCES**  
DURING \_\_\_\_\_ AND IF THERE  
WERE ANY **DIFFICULTIES OR**  
**OBSTACLES** THAT YOU PARTICULARLY  
FACED OR THINGS THAT COULD BE  
MADE **EASIER**.

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# METHOD: MANUAL DATA CODEBOOK

1. Initial Transcript Sampling
2. Open Coding with Color Highlights
3. Iterative Refinement of Themes
4. Double Coding for Reliability
5. Application to Remaining Transcripts

What does it take participants to get to their appointment?  
Psychosocial barriers/facilitators

Effects of built environment  
Any challenges after their appointment

0:09:24  
I: Okay. That's good.

0:09:26  
P: Sounds good.

0:09:28  
I: And then just a couple more questions. Have you ever used the wheelchairs at Perelman?

P: Once.

0:09:36  
I: Okay.

0:09:37  
I: Do you know where they're usually stored or who to ask if you need them?

0:09:45  
P: The wheelchairs are right out front.

0:09:47  
I: Okay.

0:09:48  
P: I mean, they're right outside the revolving door and you just can go get one. Sometimes those people, red cap, whatever they're called, will ask you, because they want to know where their wheelchairs are going. When you tell them, it's okay. But most of the time, they don't ask me anything. I've been going there for so long.

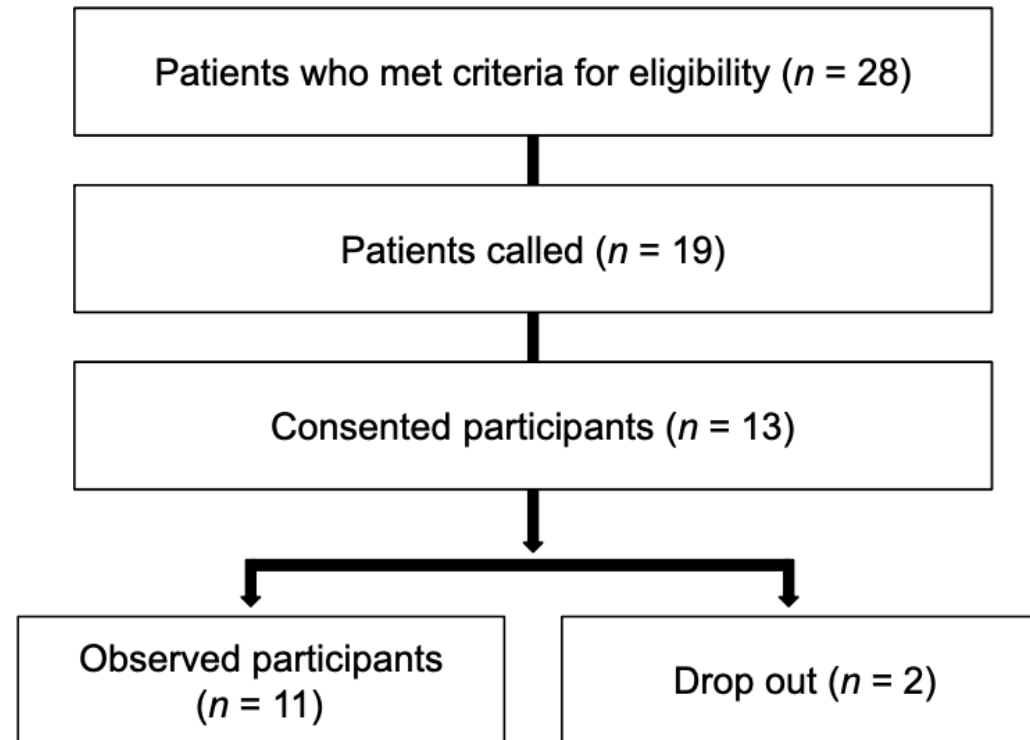
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# CONSORT DIAGRAM

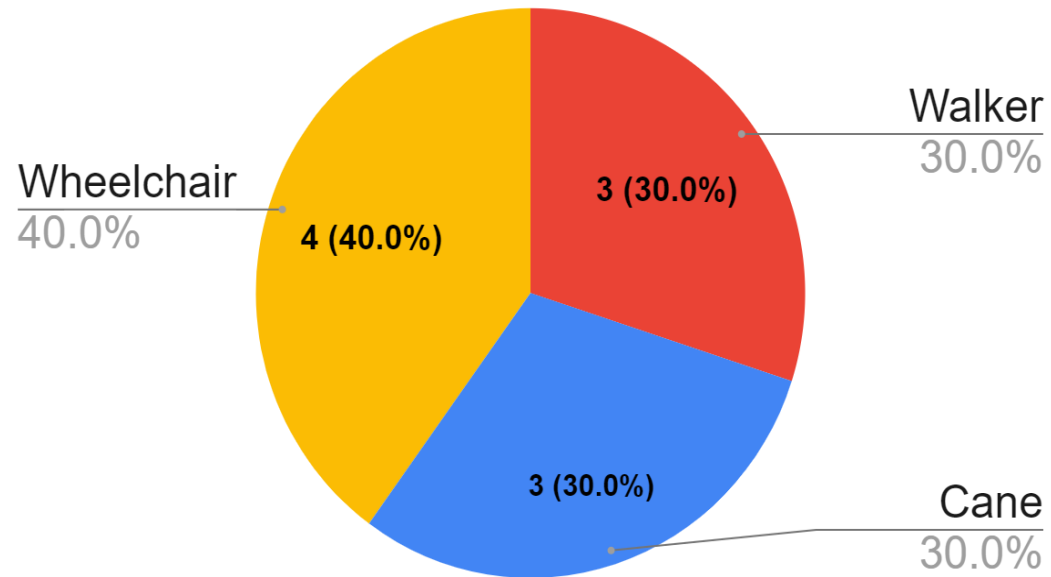
Enrollment



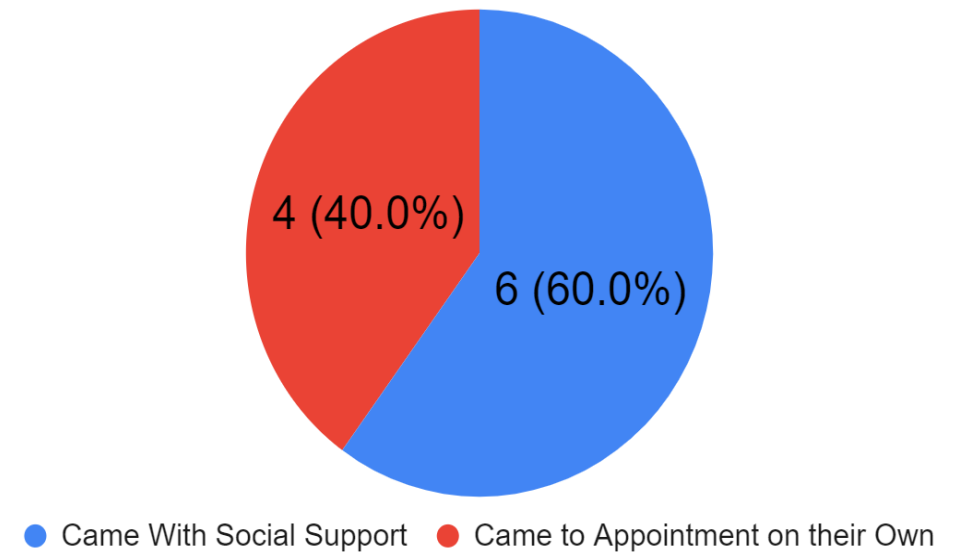
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# RECRUITMENT OUTCOME

Mobility Assistive Device Used By Participants Observed



Need for Social Support Present at Appointment from Participant's Observed



## EMERGING THEMES: ACCESSING APPOINTMENT



This theme refers to any logistical issues or administrative burdens that impede or facilitate a patient's physical transportation to the Perelman Center.

- Participants note mobility issues causing stress and difficulty in preparing for transportation to the appointment.
- The valet is "congested" and busy, but the parking garage is crowded, and oftentimes all of the handicap parking spaces are taken.

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# PRELIMINARY FINDINGS: ACCESSING APPOINTMENT

## Logistical Constraints

- “I had the wheelchair and I had what they call the rollator. I have all that, but the walker seems a little easier for me... Some of that stuff don't fit in the transportation vehicles, so, the walker.” —Participant 01
- “It takes me that long to set up the ride cause I need 72 hours to schedule the ride” —Participant 01

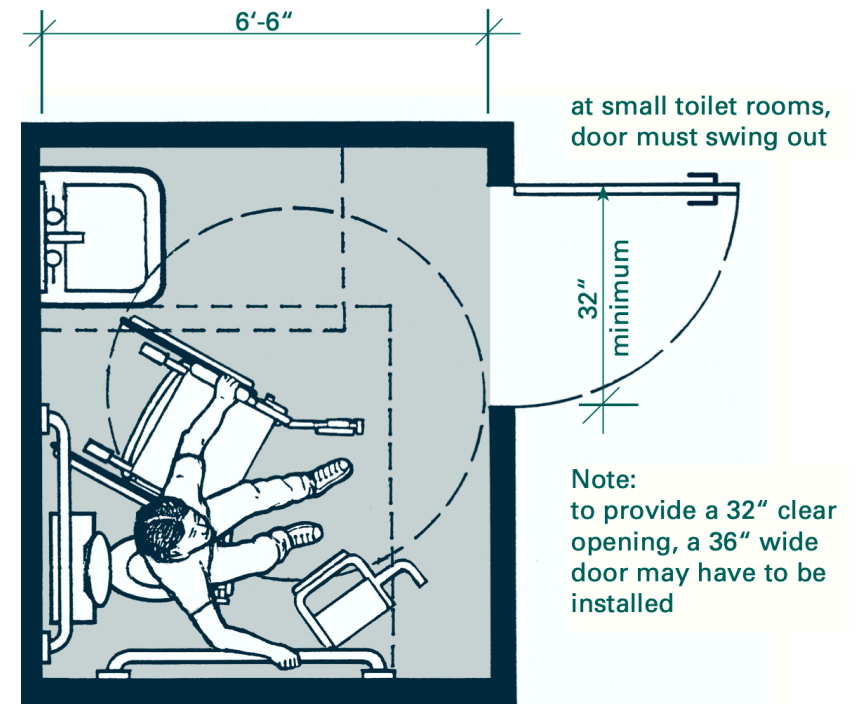
## Stressors

- “Lately it's been kinda stressful because I've been having more, like, problems with my mobility... My legs have been bothering me more, so, it's, kinda, like more, I guess I don't know that's harder than before. With the walker. Right. I mean, so it is kinda stressful, but I mean, I make do” —Participant 02

# EMERGING THEMES: BUILT ENVIRONMENT

This theme refers to any physical structures (e.g. signage, directions, objects) that act as barriers or supports during a patient's navigation to the Neurology clinic.

- Some participants found that the elevator stopped too briefly, closing before they were able to get on.
- A majority of participants complained about the long walk to the clinic after exiting the elevator.
- Some participants had difficulty parking their wheelchair or walker in the Neurology clinic because of a lack of floor space.



*Frank Porter Graham Child Development Institute*

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# PRELIMINARY FINDINGS: BUILT ENVIRONMENT

## Stressors

- “And the only thing that's hard for me is that revolving door. Maybe they can slow it up just a little bit. You know, **it goes around too fast.**”—Participant 01

## Insufficient Space

- “It'd be nice if [the elevators] were bigger... Especially having a walker, they take up more space. **Sometimes I have to wait for another elevator to come.**”—Participant 02
- “The problem is that a lot of times you go into a room and you're facing one way, but you wanna face the other way... **[They should] give you enough available space where you could do a complete 180° and not disturb anybody that's sitting next to you.**”—Participant 06

## Ineffective Design in Clinic

- “**I guess if they just worked up closer because they always sit back behind the monitor and everything pretty far back**”—Participant 06

## **EMERGING THEMES: INTERPERSONAL COMMUNICATION**

This theme addresses the quality and nature of interactions between patients and healthcare staff, including both barriers and facilitators in communication.

### **Barriers in Communication**

- Some participants felt that doctors and staff did not spend enough time listening to their concerns, leading to feelings of being rushed or overlooked.
- Several participants expressed discomfort and distress when sensitive topics were broached without empathy, feeling that their emotional well-being was not adequately considered during such discussions.

### **Facilitators in Communication**

- Many participants appreciated staff and doctors who took the time to explain procedures and diagnoses in layman's terms, fostering trust and understanding.
- Positive feedback was given to healthcare professionals who showed empathy, patience, and genuine concern for the patient's well-being.

### **Emotional Impact of Interactions**

- Patients who experienced positive interactions reported feeling valued, understood, and more confident in their care.

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# PRELIMINARY FINDINGS: INTERPERSONAL COMMUNICATION

## Barriers in Communication

- “I mean, I told, I think, you know, I told you that one time I was doing intake and they weren't even facing me and they're like, Do you have suicidal thoughts? I'm like, I don't know, say that again. I can't hear you. You're facing the wall. You know, it's just wrong.”

## Emotional Impact of Interactions

- “Well, even with the walker, where I had the caregiver, I fell a couple of times. So that's why I need the caregiver to go with me because you know we fall and hit next team and it ain't no joke. And nobody stops to help you. Forget about that in Philadelphia.”
- “So, when I get into the clinic, well you were there, I mean, and I was really late. And they still took me. A lot of doctors don't do that. You miss your appointment? That's it. You know, in the rules, I mean, we've been {doctor} dealing with each other for a while. So. Yes, and you were there, she got me in, got me out. And it's very nice.”

## Facilitators in Communication

- “No, no, no, my appointment was Stellar. My time with my neurologist is very, very meaningful. It's never just a routine exam. She's just always invested in me as a whole person and patient and I got the questions answered and we talked about future treatment things and it was very you know, very, very nice.”



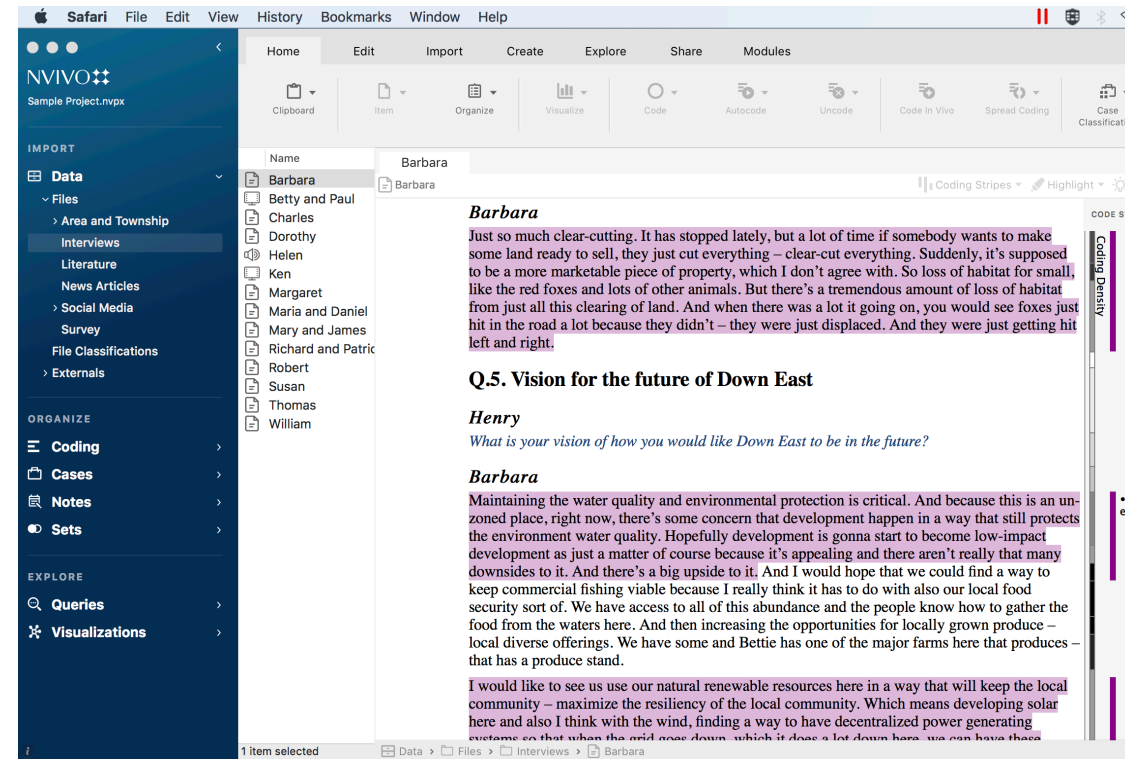
# NEXT STEPS

## Immediate:

- Use open coding to further refine codebook
- Double-code 10% of the sample to reconcile coding discrepancies improve inter-rater reliability
- Import data into NVIVO for additional subgroup coding and comparisons
- Revise emerging themes as new patterns develop
- Continue recruitment until thematic saturation

## Long Term:

- Dissemination of Findings
- Abstracts and Publications
- Operations – Present Findings to Key Internal Stakeholders



*Example of NVIVO Coding*

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# CHALLENGES ENCOUNTERED & LESSONS LEARNED

- We honed our interviewing skills and learned how to navigate a medical records platform for the first time.
  - It is important that peripheral players in a study, like the medical assistant and clinic staff, know about the study and believe it is reputable and trustworthy.
  - It is paramount that participants understand the objectives of research studies, especially when patients are members of historically vulnerable communities.
  - As researchers, we had to transition from a purely objective stance to embracing the subjective and interpretive nature of qualitative research.
  - Disability accessibility is not one size fits all: different people with different mobility devices have different needs that sometimes contradict.
  - This project allowed us to improve and see value in the ways we interact verbally/nonverbally with patients and practice active listening so that participants feel more at ease in research scenarios
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# THANK YOU

- To Our Mentors: Dr. Mihir Kakara, Dr. Jaya Aysola, & Dr. Matthew Kearney
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