

# Needfinding

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# Domain

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- People with unique medical histories that differ from their immediate community
- Why?
  - What goes on behind the scenes in the medical lives of seemingly normal people?
  - How do these “hidden” disabilities affect the way people interact with strangers and their community?



# Participants

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- Female, high school sophomore
- Currently lives with juvenile epilepsy
- Personal connection to a team member



- Female, 3rd year psychology student
- Lives with anxiety, panic attacks, overthinking
- Personal connection to team member
- lives in a very different community



- Male, college athlete
- Had brain tumor
- Currently lives with deafness in one ear
- Personal connection to a team member
- Extreme user due to multiple unique health challenges and is receiving ongoing treatment



- Male, college athletic coach
- Has family members with healthcare challenges
- Works daily with athletes who have physical limitations
- Met at Jimmy V's (campus cafe)
- Non-user, has no direct medical challenges

# Interview Logistics

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Participant 1 was interviewed in person (Maya interviewer, Jonathan transcriber).

Participant 2 was interviewed in person (Maya interviewer/transcriber) on UC Berkeley campus.

Participant 3 was interviewed via Zoom (Gaya interviewer, Maya transcriber).

Participant 4 was interviewed in person (Jonathan interviewer, Janelle transcriber) at a Stanford Cafe.

Apparatuses used included laptops and iPad to take notes and transcribe interviews.

# Questions Asked

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How do people compensate for having a disability/strategies used for accommodating them?

Tell me about a time you experienced issues with accessing healthcare?

Was there ever a time where you found healthcare support in your community?

Was there a time when your community was lacking in healthcare?

Have you ever felt isolated by your medical history? And/Or what has helped you overcome that?

Do you feel adequately supported for your health, mental and physical? Why?

Was there any challenge in your life that a disability or health issue has impacted?

What unique challenges or experiences have your health issues brought into your life?

What tactics have you used to accommodate people with different medical backgrounds than you?



# Key Quotes

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“Community is way more important than medical care” - Participant 1

“[you] have to try and understand what people are going through, but not let it affect you” - Participant 3

“a lot of people in [my] current community don’t know [I] had a brain tumor” - Participant 2

“Gone through the hardest of the hard” - Participant 2

“Google can help or make things worse. What really helps [with stress and anxiety] is talking to others and seeking community” - Participant 4

# Surprises?

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- Majority of participants seemed to suggest of their own volition finding community as method for dealing with isolation and healthcare challenges
- Can also be extremely stressful for non-users to perceive the healthcare challenges that users deal with
- Human body, mind, spirit is extremely resilient
- Some people that one might think are obligated to help individuals with healthcare concerns (i.e. parents) may actually obstruct access to healthcare
- Sometimes change of environment is significant help for increasing healthcare access

# Analysis – Empathy Map for Participant 1

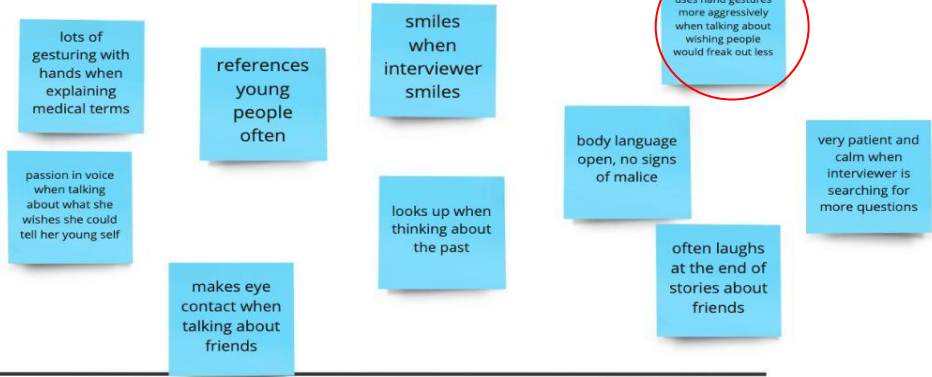


# Participant 1

## Say



## Does



## Think



## Feel



# Analysis - Key Insights

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- Fear of stigma and how people will react greatly affects openness
- Young people and children seem less likely to report symptoms
- More people suffer than meets the eye
- Community can be helpful for recovery, but often it is hard to reach

# Analysis - Empathy Map for Participant 4

# Participant 4

## Say

Having an uncommon ailment or limitation can be isolating as there is no one to talk to who has gone through the same thing

Communication is important when working with individuals who have physical limitations

Can connect to community by knowing people in person who have shared experiences and talking about those

Athletes can overcome hometown healthcare access issues by coming to college and getting a scholarship, as colleges generally have doctors and specialists students can access

Google can help or also make anxiety worse

Has relative whose job forces her to deal with inconsistent healthcare coverage and cost

Seeking community is the best way to cope with anxiety and stress caused by healthcare challenges

Stress and anxiety is caused when a family member or a loved one has undiagnosed or unknown issues

Has worked with athletes from underserved communities who have had difficulty in the past getting adequate healthcare access

It's important to find ways to work around things that exacerbate preexisting conditions

## Does

Looks upwards when thinking about personal experiences or family member experiences

Smiles frequently

Raises eyebrows a lot when emphasizing points

Uses hands when expressing personal opinions

Uses a wide stance with feet placed apart

Puts greater intonation on certain words and phrases for emphasis

Moves head frequently when emphasizing words

When hands are not in motion, has hands clasped at waist

Maintains pleasant expression and tone of voice

Shifts forwards and backwards when struggling to think of ways to articulate things

## Think

As a coach, not much he can do other than empathize, sympathize, and communicate

Unsure of his authority when it comes to healthcare accessibility since he personally has not been affected by any challenges accessing adequate healthcare

Finding community is important when dealing with anxiety and stress regarding healthcare

Certain jobs can limit access to healthcare

Taking care of a family is difficult

Getting to a different area can help change access to healthcare

Shared experiences are comforting

Talking to others is helpful to alleviate concerns

Less affluent communities will always have less adequate healthcare access

Need to help people who have physical limitations and difficulties, not ignore them

## Feel

Guilt for not having personally experienced healthcare limitations

Stressed from having to take care of people

Like he wants and needs to help athletes that have physical challenges

Sympathy for those dealing with ailments

A sense of responsibility to bridge the gap with people that have extra healthcare needs

Relieved from finding a sense of community

Helpless sometimes when dealing with healthcare unknowns

Stress and anxiety when thinking about family's healthcare issues

Worsened stress and anxiety sometimes when Googling to find more info

Lessened stress and anxiety when finding out someone else has shared experience

# Analysis - Key Insights

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- Health and opinions of loved ones impacts own mental health
- Location impacts access to health care
- Community can be impactful in recovery
- Fact discovery does not always quell anxiety

# Summary

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## Key Learnings:

- *Finding community* is both a key coping mechanism and method of achieving greater access to healthcare
- While workarounds can help make the best of a situation, *real help is needed*
- There is a wide variety of access to healthcare consistency and cost
- *Younger people who cannot identify what they are going through struggle with identifying with a group after diagnosis*

## What's Next?

- *How do we establish a form of community to bring together individuals with unique health concerns?*
- How do we connect these communities to healthcare specialists so they can have adequate healthcare access? *Or, how might we notify their personal communities of their situation to make living more comfortable?*
- How do we make sure this form of community is accessible to all *in the first place?*

**Thank You**