

The background is a dark charcoal grey. It is filled with various colorful, hand-drawn style lines and shapes. On the left side, there are several overlapping geometric shapes: a large blue circle containing a red square with two horizontal pink lines, a blue square with three horizontal pink lines, and a yellow square with two horizontal pink lines. There are also various wavy, curved, and straight lines in colors like light blue, orange, yellow, pink, and red scattered across the page. Some lines form loops or spirals. The overall aesthetic is modern and abstract.

Unmasking Brain Injury Project

# THE STORY OF ACQUIRED BRAIN INJURY

Beth Callahan | HFF

# MEET THE TEAM

This project would not be possible without several collaborators, researchers, community partners, brain injury support groups, and survivors willing to share their stories.



**Olivia Vruwink**

**S. Kay Gregory**

**Katy H. O'Brien**

**Amy Kemp**

**Martin Foil and the Foil  
Family**

**Erica Rawls**

**Hinds' Feet Farm**

**Chelsea Willis**

**CogCom Rehab Lab at  
UGA**



# LEARNING OBJECTIVES

01

Apply the use of art-based narrative approaches to explore the experiences of individuals with acquired brain injury.

02

Describe how narratives can be used to relay information about holistic wellness from a person-centered approach.

03

Use holistic approaches, such as Six Dimensions of Wellness, to support people with acquired brain injury with coping and self-reflection.

# ACQUIRED BRAIN INJURY

What is it? How does it occur? What happens after an acquired brain injury (ABI)?

## Traumatic

Alterations in brain function, or other brain pathology, caused by an external force

## Non-traumatic

Damage to the brain by internal forces (lack of oxygen, exposure to toxins, pressure)



Cognitive

Communication



Social-  
Emotional

Physical

# BRAIN INJURY IS AN INVISIBLE INJURY

How do we support people with ABI to tell their stories and get support for their recovery and lives after ABI?

## Storytelling

Storytelling is a way of **processing** difficult experiences, **(re)connecting** with peers, families, or communities, and increasing **person-centered communication** in healthcare settings

## Art

Art offers a modality to **relay** abstract concepts and emotions **outside of words and beyond the linguistic abilities** of a person, **externalize the internal world**, and support **coping and processing** of emotional experiences related to ABI.





# UNMASKING BRAIN INJURY PROJECT

Mission: support people with ABI to create masks and write short narratives so they can share their stories and reflect on their experiences

# ORIGIN OF UNMASKING BRAIN INJURY PROJECT

## Hinds' Feet Farm

A residential and day program for people with brain injury to receive support, services, and community.

## Unmasking Brain Injury in Soldiers

Inspired by a National Geographic Article on soldiers making masks upon returning home from war (Alexander, 2015).



# MAKING A MASK

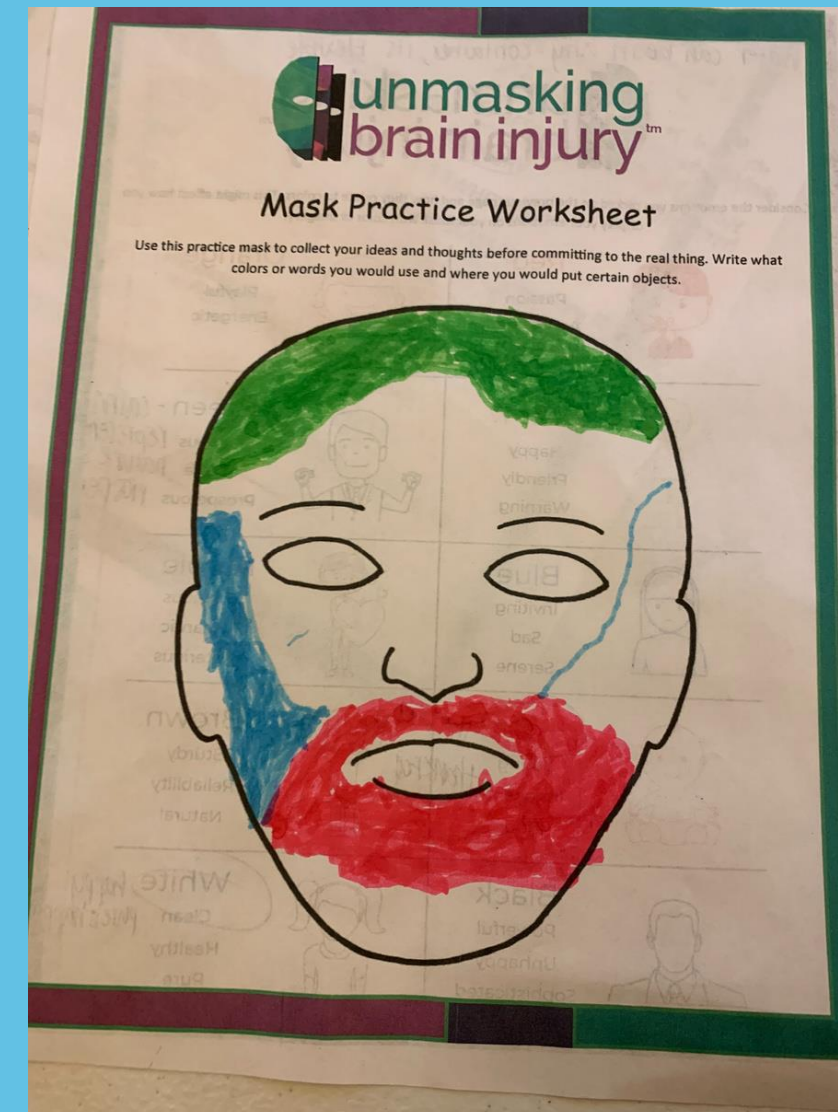
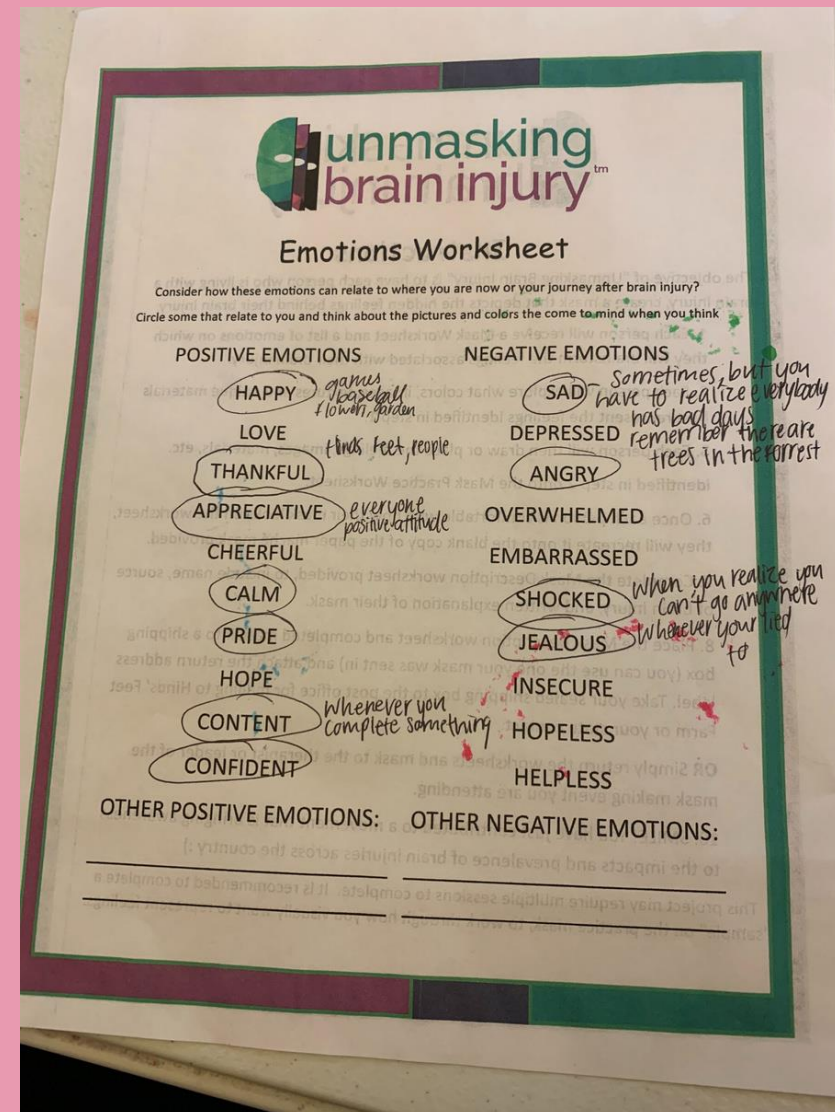
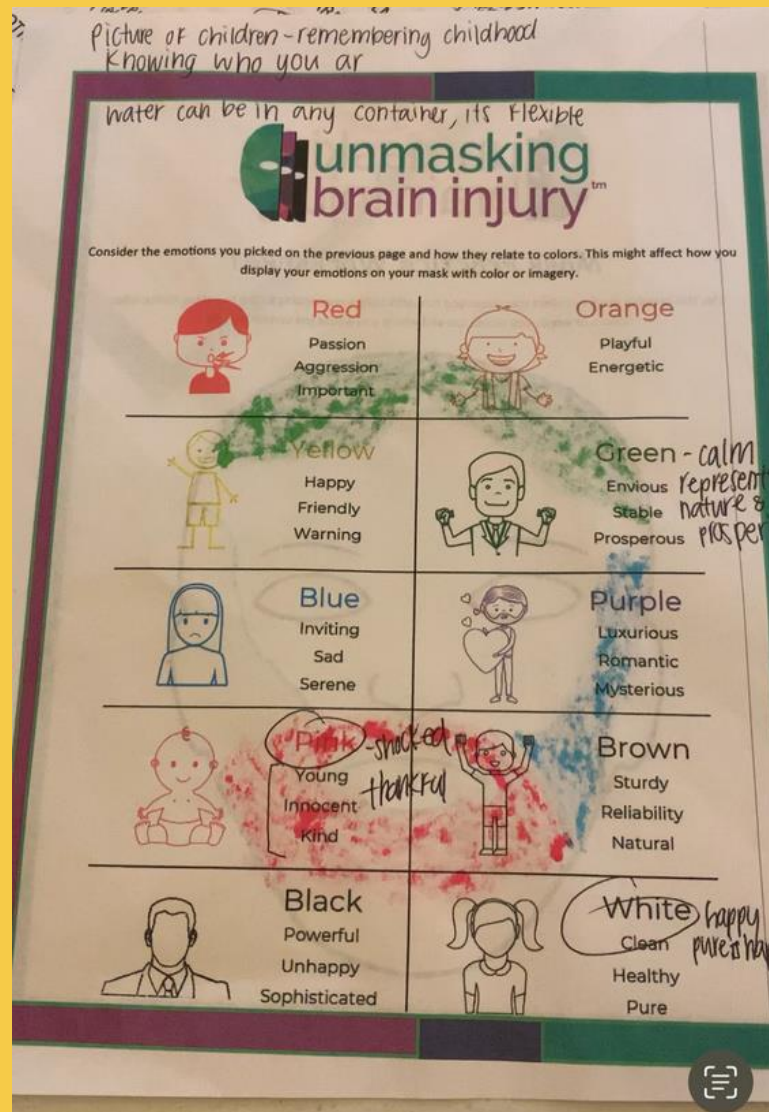
The process here is abbreviated from the formal UBI curriculum used in all UBI events or personal submissions.

Identify Emotions or Salient Experiences

Match to colors/objects

Practice

Make!



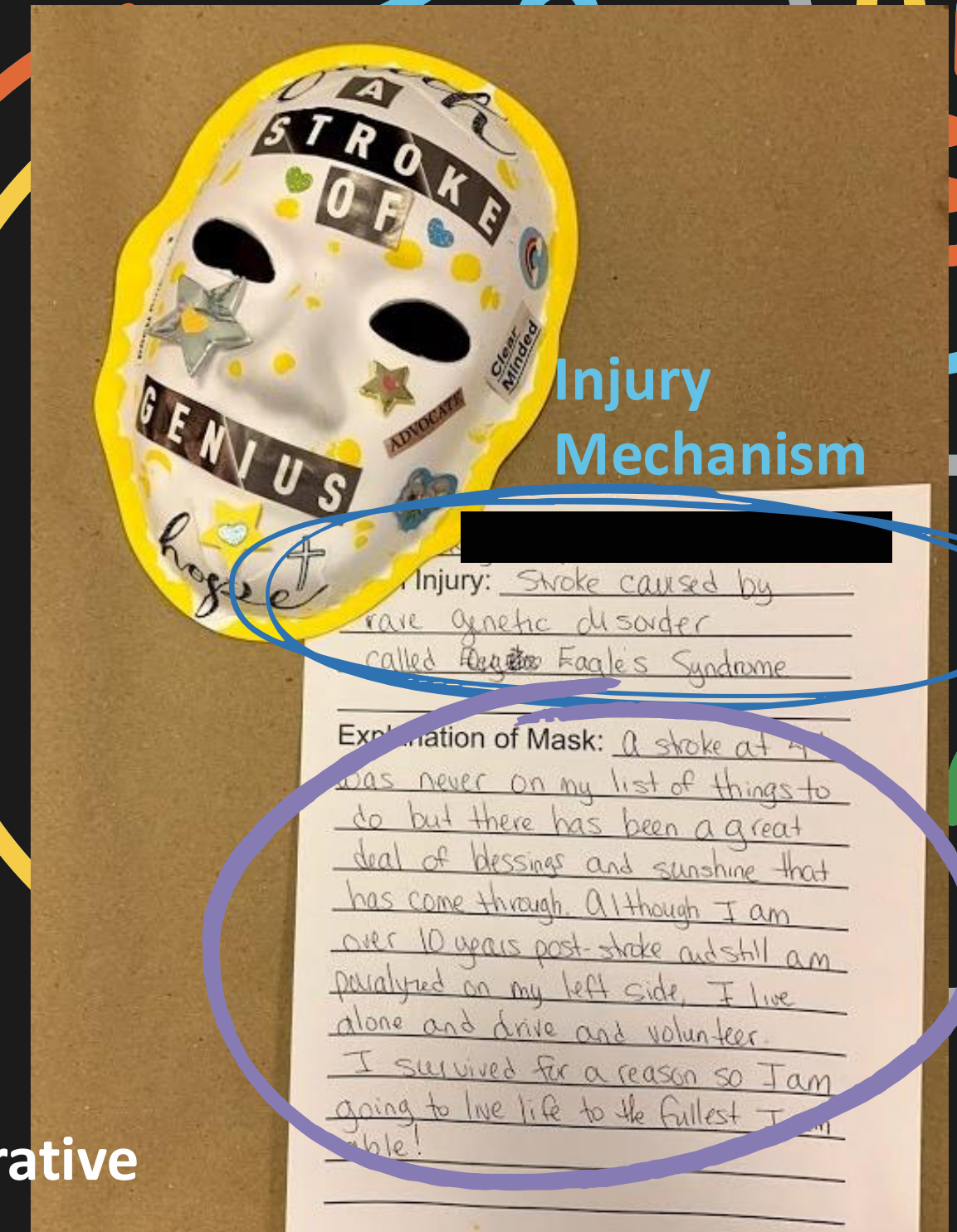
# RESEARCH QUESTIONS

There are over 5000 masks on the UBI Website!! People with ABI want to tell their stories, and I want to see what they have to say to impact what we (as healthcare professionals) can do about it!

**What emotions and experiences are people with ABI displaying in their masks and narratives?**

**What kind of experiences are in the narratives?**

**What emotional valence do people with ABI use when telling their stories?**



# MASKS INCLUDED

## 1582 masks available on UBI website

All masks available as of 1/1/2024 were included.

## 545 masks removed

105 family members  
157 developmental or degenerative  
181 did not provide narrative  
102 narratives were not relevant to storytelling

# 1019 TOTAL MASKS

## Any with narrative

1001 masks from UBI website were included

## International

Masks could be from any state or country. (Canada was most common with some from UK)

## Local Masks

18 masks were included from a local UBI event

# METHODS

## Qualitative

Inductively coded from the first 150 masks to create codebook; iterative development of codebook for remainder of masks (deductive coding)

## Quantitative

Data Mining from the UBI website  
Demographics and categorize qualitative findings  
Sentiment Analysis

# ANALYSIS STEPS

## Phase 1: Document Level

Understand the full story

## Phase 2: Sentence Level

Characterize what makes up the story

## Phase 3: Aspect Level

Asked AI to evaluate each sentences; emotional description

# ANALYSIS

## Document Level

Inductive coding narratives for what emotions or experiences were being described and *why* where they being described (storytelling intention)

## Sentence Level

Within the stories, what Dimensions of Wellness were present.

## Aspect Level

For each Dimension of Wellness, was the artist talking positively or negatively, mixed or neutral about it?

## Sentiment Analysis:

Sentiment Analysis extracts and analyzes people's opinions, sentiments, attitudes, and perceptions towards different entities such as topics, products, or services. We used MAXQDA to complete the AI SA. All statements were scored 1 (positive), 0 (neutral), and -1 (negative). All neutral statements were evaluated and assigned a 0.5 if the statement had both positive and negative aspects.

# QUALITY

It was very important to our team to ensure that these data were represented and disseminated, matching as closely as possible to the artists' experiences. We took several steps to ensure this.

## Codebook Development

The main authors, all female, licensed speech-language pathology researchers developed the codebook from the data

## Inter-rater reliability

After the first 150 data points, three trained research assistants coded the data. 10% was dual-coded and 97.6% agreement was researched.

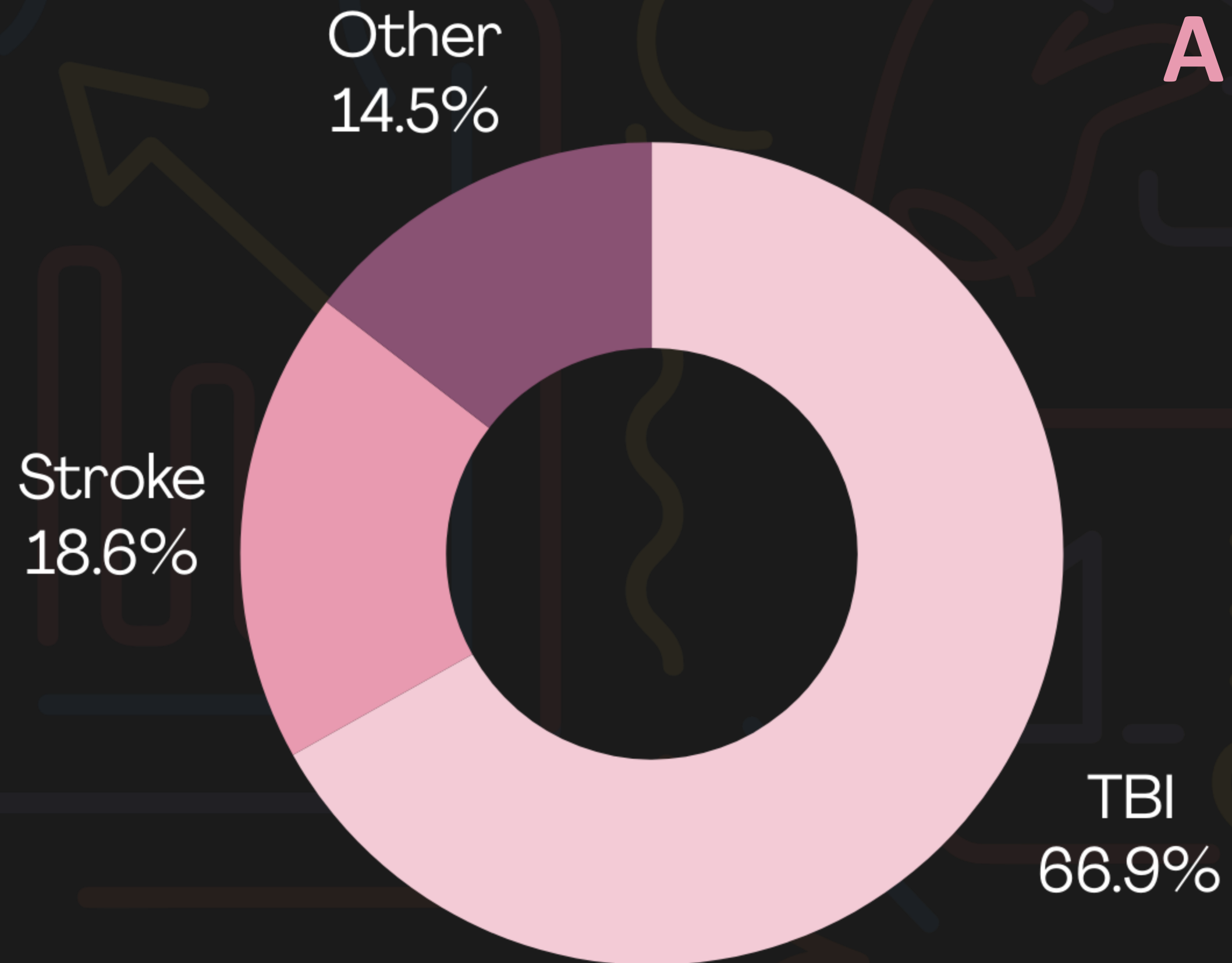
## Reflexive Discussions

For every 300 masks, the authors and coders met to discuss any new codes that arose and reach consensus on final themes/subthemes.

## Member Checking

A group of 20-30 brain injury survivors and HFF leaders, some of the original UBI artists, participated in a feedback on analysis session to give feedback and support in understanding the data.

# ARTISTS



# TBI INJURY MECHANISM

Multiple mechanisms

1.3%

Recreational/sports injury

4.4%

Struck by/against something

7.6%

Not reported

8.1%

Physical abuse

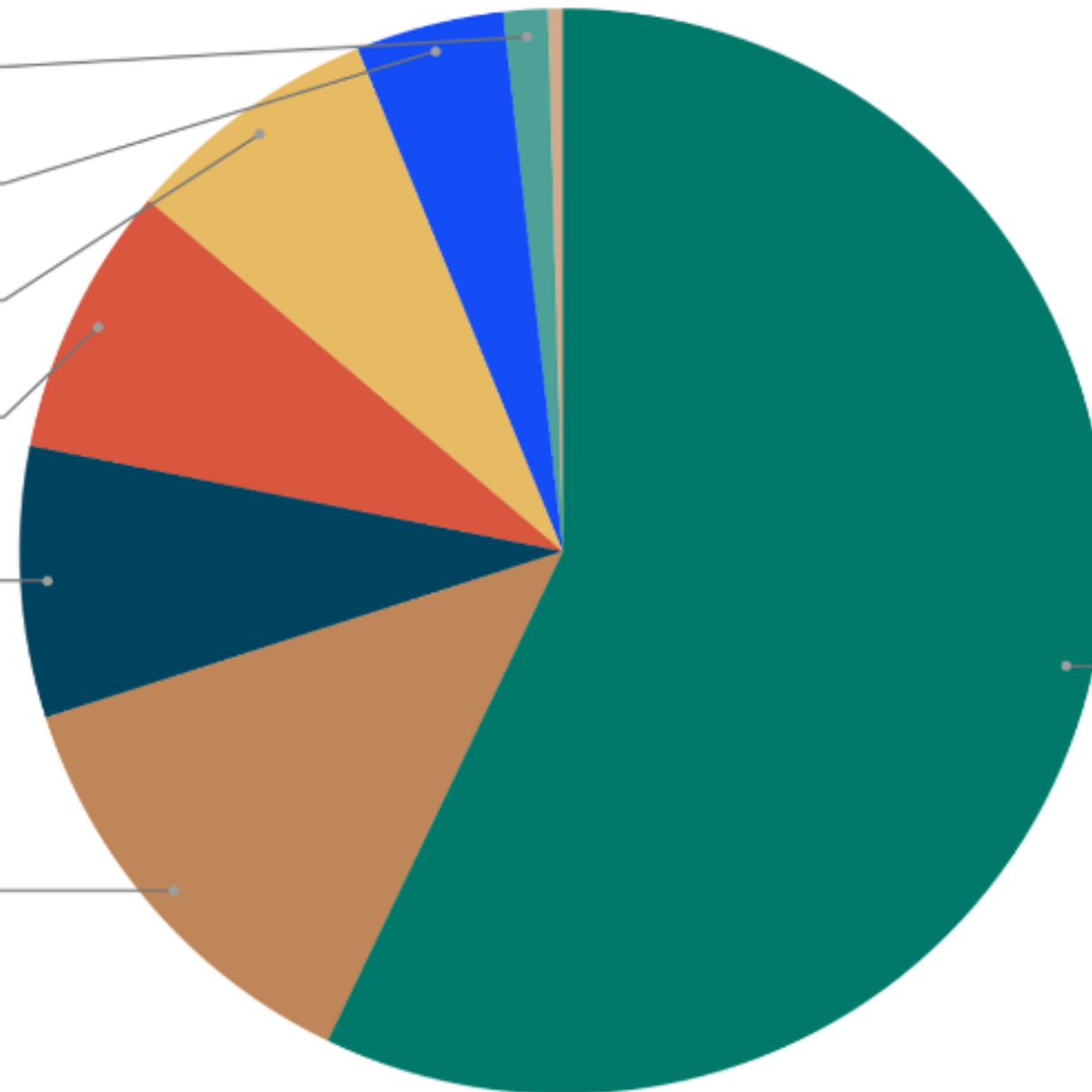
8.1%

Fall

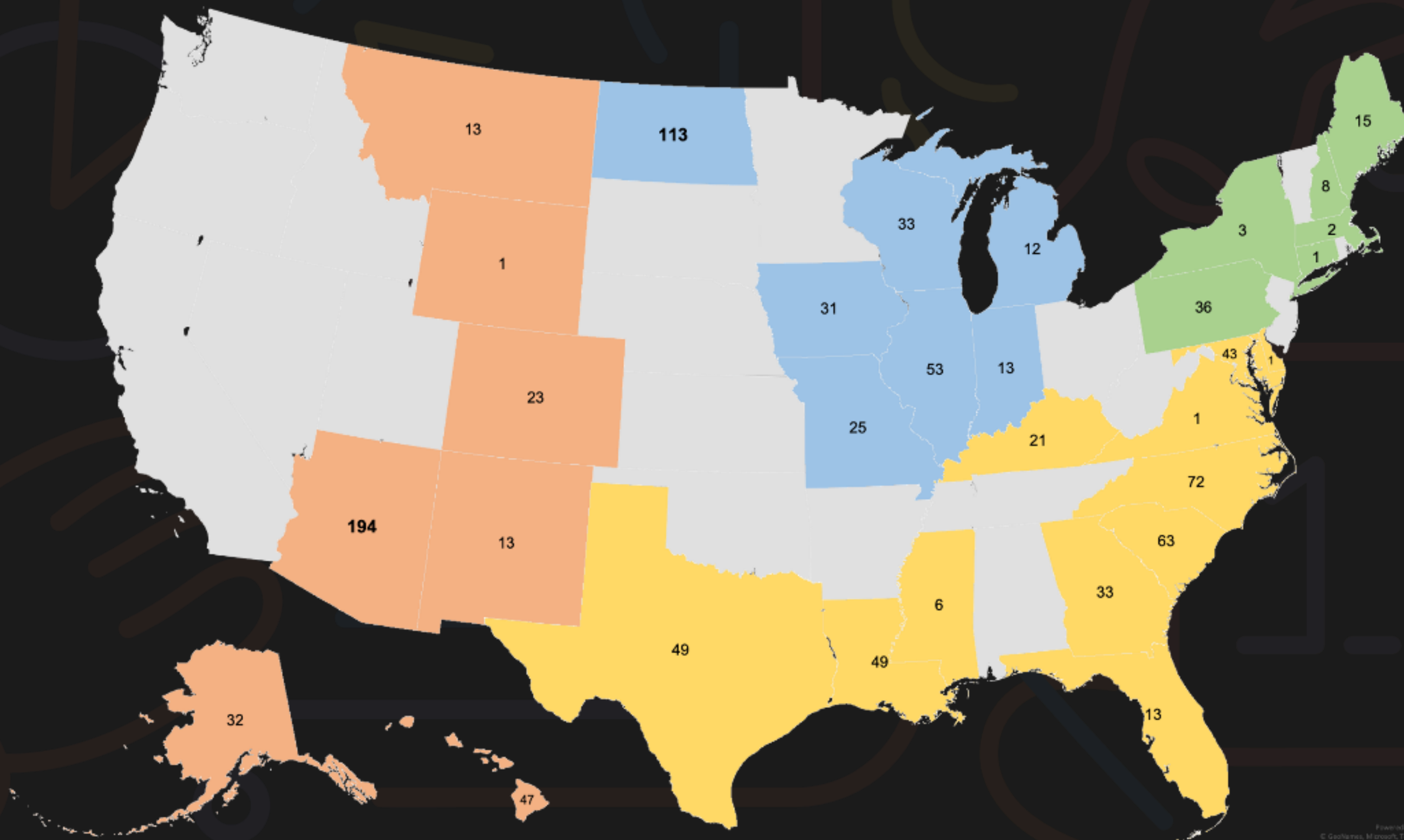
12.9%

Car accident

57.1%



# GEOGRAPHIC LOCATION



Northeast: 6.4%

Midwest: 27.5%

South: 34.4%

West: 31.7%

The background is a dark navy blue. It is decorated with various colorful, hand-drawn style lines and shapes. On the left side, there are several loops and swirls in blue, orange, and yellow. A large yellow circle is positioned in the upper left quadrant, containing an orange figure-eight shape. To the right of this circle is a blue square with a light blue outline and a blue squiggle inside. Further right, there is a yellow zigzag line and a purple circle. At the bottom left, there are more blue and orange loops. A green zigzag line is at the bottom center. In the bottom right, there is a faint, dark brown rounded rectangle containing horizontal lines and a large number '1'.

## RESULTS

Based on the three phases: document,  
sentence, and sentiment

# DOCUMENT

**What emotions and experiences are people with ABI displaying in their masks and narratives?**



## **Emotional Pain and Loss (71.9%)**

Loss of self, identity, feeling stuck or trapped, invisibility of injury. Masks contained dark colors, frowns, and crossed-out or removed features.



## **Multiplicity (45.5%)**

The juxtaposition of their sense of self and emotions. Masks were often divided into sections with contrasting elements. Often this looked like a “before” and “after”



## **Positivity, Purpose, and Faith (21.6%)**

Encouraging or positive messages, identification of meaningful participation including people, places, rehabilitation, or spirituality that improved their outlook and outcomes from ABI. Often represented with words or symbols of strength or faith and bright colors or textured elements.

# DOCUMENT

What emotions and experiences are people with ABI displaying in their masks and narratives?

Inward Reflection  
43%

“Although having to learn life’s new ‘norm’ has been a long road of challenges, i would still choose this norm over my pre-accident norm. My TBI doesn’t define me, but instead I define the presence and role my TBI has within my life.”

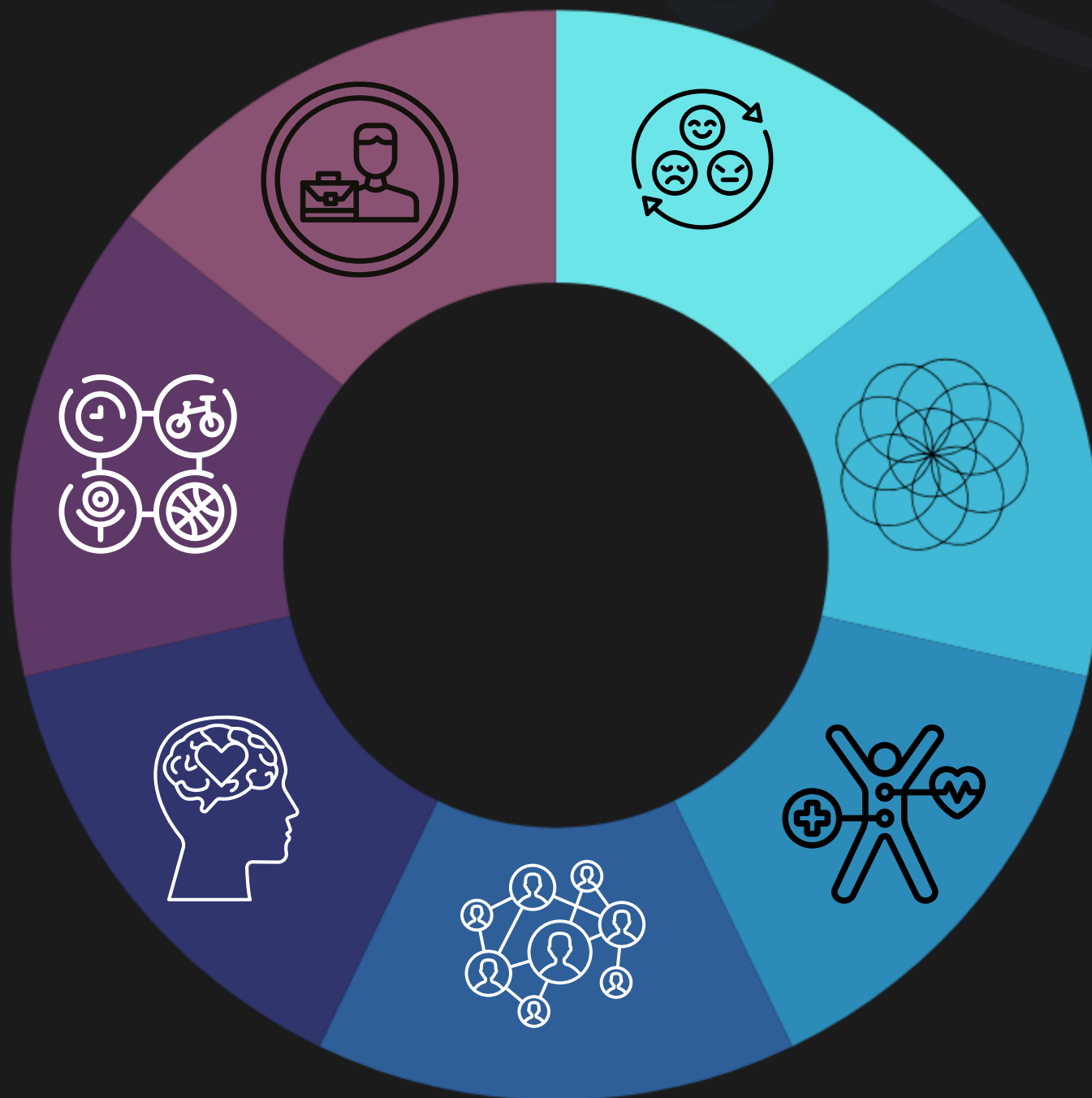
“Even though all this is going on, I look like any other teenager. Looking normal and happy is not the same as feeling normal and happy.”

Outward Sharing  
57%

# SENTENCE

What kind of experiences are in the narratives?

## DIMENSIONS OF WELLNESS



### Emotional:

Feelings, emotions, perspectives, identity, mental health

### Spiritual:

Faith, luck, spiritual

### Physical:

Gross or fine motor movement, coordination, balance, function

### Social:

Social roles, community, family, friends

### Cognitive:

Memory, attention, language, planning, humor, personality

### Recreational:

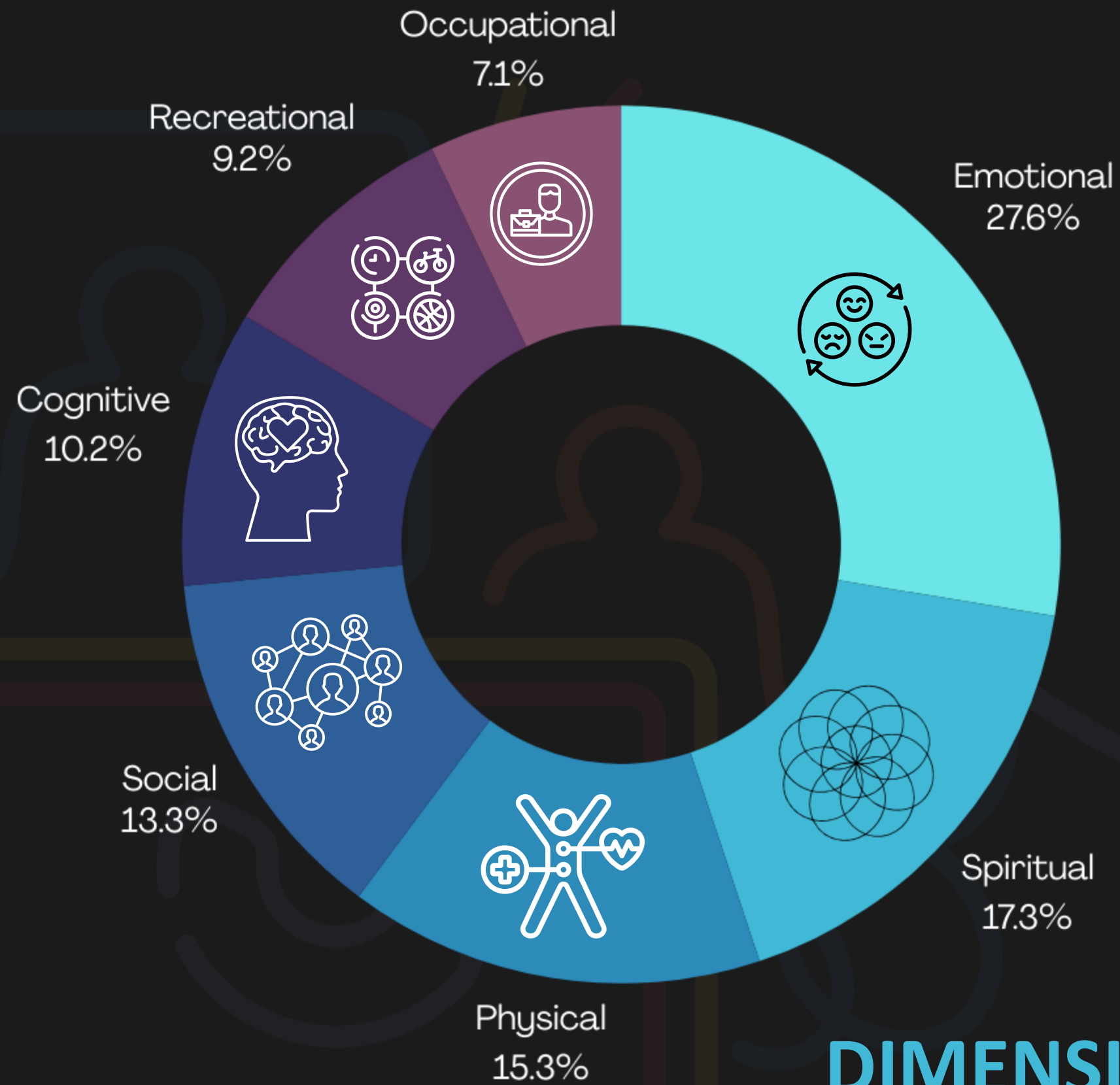
Activities of interest, hobbies, passions

### Occupational:

Work, school, productivity activities (e.g., volunteering)

# SENTENCE

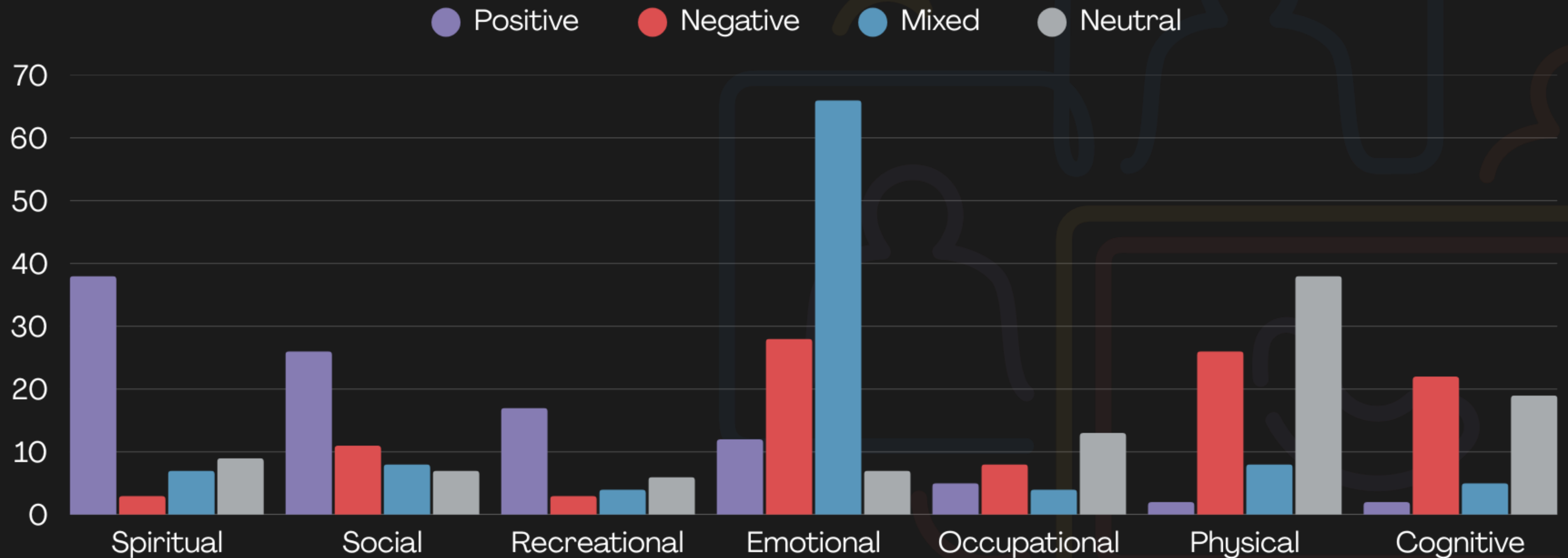
What kind of experiences are in the narratives?



**DIMENSIONS OF WELLNESS**

# ASPECT

What emotional valence do people with ABI use when telling their stories?



# ASPECT

What emotional valence do people with ABI use when telling their stories?



“A big part of my identity was lost when I lost my memory (emotional/cognitive) and I am still struggling with feeling like a STRANGER TO MYSELF, that is represented by the puzzle pieces (emotional)...I try to put on a brave face but I am really sad and depressed, that is the frown(emotional)...”



“My mask shows two sides to my injury. Before my stroke, I was a very eccentric and outgoing person. The flowers with the pearls represent this beauty. The black and white represents the darkness that feel over me after my stroke and depicts how I no longer feel like myself...”  
(emotional/cognitive)

# ASPECT

What emotional valence do people with ABI use when telling their stories?



“The prominent question mark represents my inability to formulate coherent thoughts and sentences (cognitive). My information recall and processing deficiencies create barriers to connecting with people (cognitive/social). I placed the question mark over my eyes and mouth because it is an invisible barrier between myself and others(social)...I feel lucky to be alive and that I survived the accident...(Faith)”



“My mask is like a remembrance (emotion) It reminds me of baseball (a sport I love) and that maybe I will get to return to playing the sport one day. (Recreational)”



# CONCLUSIONS

What should you take away from this talk with?



# ART IS A TOOL

## Patient-Centered Care

Identifying meaningful goals and priorities, improving accessibility, and promoting agency and voice in care after ABI

## Processing and Coping

Visible and Tractable areas of health; may be a way to show change over time

## Engagement with Others and Self

Public advocacy on what changes after ABI, what recovery looks like, and what might help some with recovery

## Self-Reflection

Identifying what change for the person, reflection on their own recovery, and what made a difference in their own life



## LIMITATIONS

These **data could not be verified**, so specific injury characteristics are unknown. Demographic data was **also not available**. Finally, those who created masks and were included in the analysis needed to have **access** to an Unmasking event and **needed to elect to create a mask**. Not all masks that were made were **uploaded on the website** and able to be analyzed..

# FUTURE DIRECTIONS UNMASKING BRAIN INJURY PROJECT

## Reflection of Time Since Injury

Over time, what changes? How can art show these changes at the person-centered level by addressing what matters to people with ABI and their families

## Written vs. Spoken Narratives

When asked to tell a story of ABI, does presenting to an audience change what is discussed?



Happy to take questions!

**THANK YOU  
FOR LISTENING!**

Scan to read the research papers!

