



**CASE STUDY:
MAKING THE
INVISIBLE
VISIBLE**



*Using public engagement art pieces to
increase feelings of visibility
surrounding chronic pain*

Allie Maher, IDS3 Parsons



**CHOOSING
A COMMUNITY:
THOSE
SUFFERING
FROM
CHRONIC
PAIN**

The community I chose to work with is those afflicted from silent chronic pain.

I connected with this community because for the last year and a half, I myself have have suffered from chronic foot pain due to an unresolved injury and consequential sciatica, which causes me immense discomfort and disruption in my everyday life.

Growing up as well, my mother dealt with a lot of chronic pain and illness, and I witnessed in real time the way it inhibited her career and parenting bandwidths. The more people you speak with, the more common you realize this problem is; and it is: according to the CDC, about 1 in 5 American adults experience chronic pain. It is, in many cases as well, an invisible disability.



**PROCESS
AND
DEVELOPMENT**

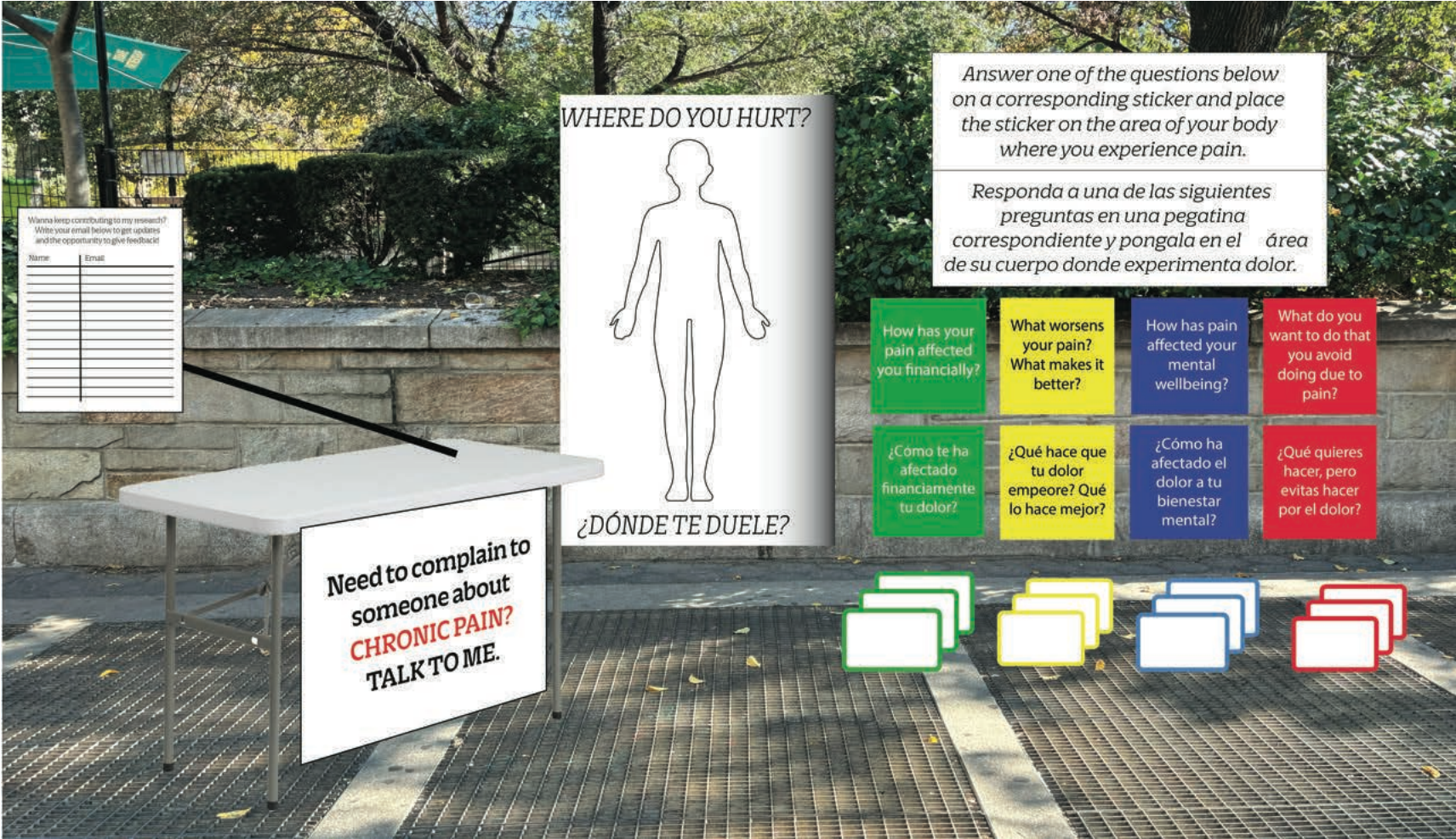
LISTENING TOOL: BRAINSTORMING

FOR ME, IT WAS IMPORTANT THAT THE LISTENING TOOL...

- Interacted with the general public, in order to expand the sample size to include a variety of age groups, socioeconomic positions, and careers.
- Engaged directly with the community and opened up conversation among participants and with myself.
- Honestly explained the goal of the project to the community.
- Was physically accessible or adaptable, such as by including chairs at a potential physical set up.
- Was considerate of location, by taking into account the likelihood of a person with chronic pain being at the location in which the listening tool would be set up.
- Respected the **Accountability Guidelines** written by my **Accountability Group**, which are as follows:

- maintain mutual respect between oneself and participants
 - be open-minded and humble
 - prioritize others' perspectives
- see oneself as not a teacher, but a student (let the selected community educate YOU)
- center experience around targeted community
 - facilitate safe environment
- offer transparency and honesty about project with participants

LISTENING TOOL: **MOCK-UP**



Hip pain from walking.
Stretching helps also aspirin

IT'S OVERWHELMING TO THINK OF PAIN AS A NEVER ENDING PRESENCE IN MY LIFE.

Better with non-western alternative medicine & walking my dog. Keeps me young.

It made my head & heart hurt so bad. making things difficult.

WORSEN - STAYING STILL
BETTER - STRETCHING

Makes me more introverted + isolated + independent

RUN!!

I CAN'T PARTICIPATE IN SOCIAL WAYS LIKE I USED TO: SUCH AS RUNNING, DANCING, WALKING, CONCERTS, ETC IT MAKES ME LONELY.

LT: OUTCOME

Although I expected more interaction with the questions "What makes your pain better or worse?" and "What do you wish you could do that your pain prevents you from doing?", the most interaction was with the question "How has pain affected your mental wellbeing?". People commonly expressed feelings of loneliness, isolation, anxiety, and hopelessness. Many people seemed mistrustful of any potential solutions or those peddling them -- such as myself. I found that to establish trust, it would likely require much more time and input with individuals. Some people sat down with me and talked, but strangely wouldn't add a sticker. I realized these individuals just wanted to feel heard in a way that felt human. Several individuals mentioned that they felt alternatives to current medical systems, Western pharmaceutical treatments, and societal infrastructures would offer better solutions to their pain.

FEELING
HOPELESS

IDEATION FOR DELIVERABLES AFTER RECEIVING FEEDBACK ON LISTENING TOOL

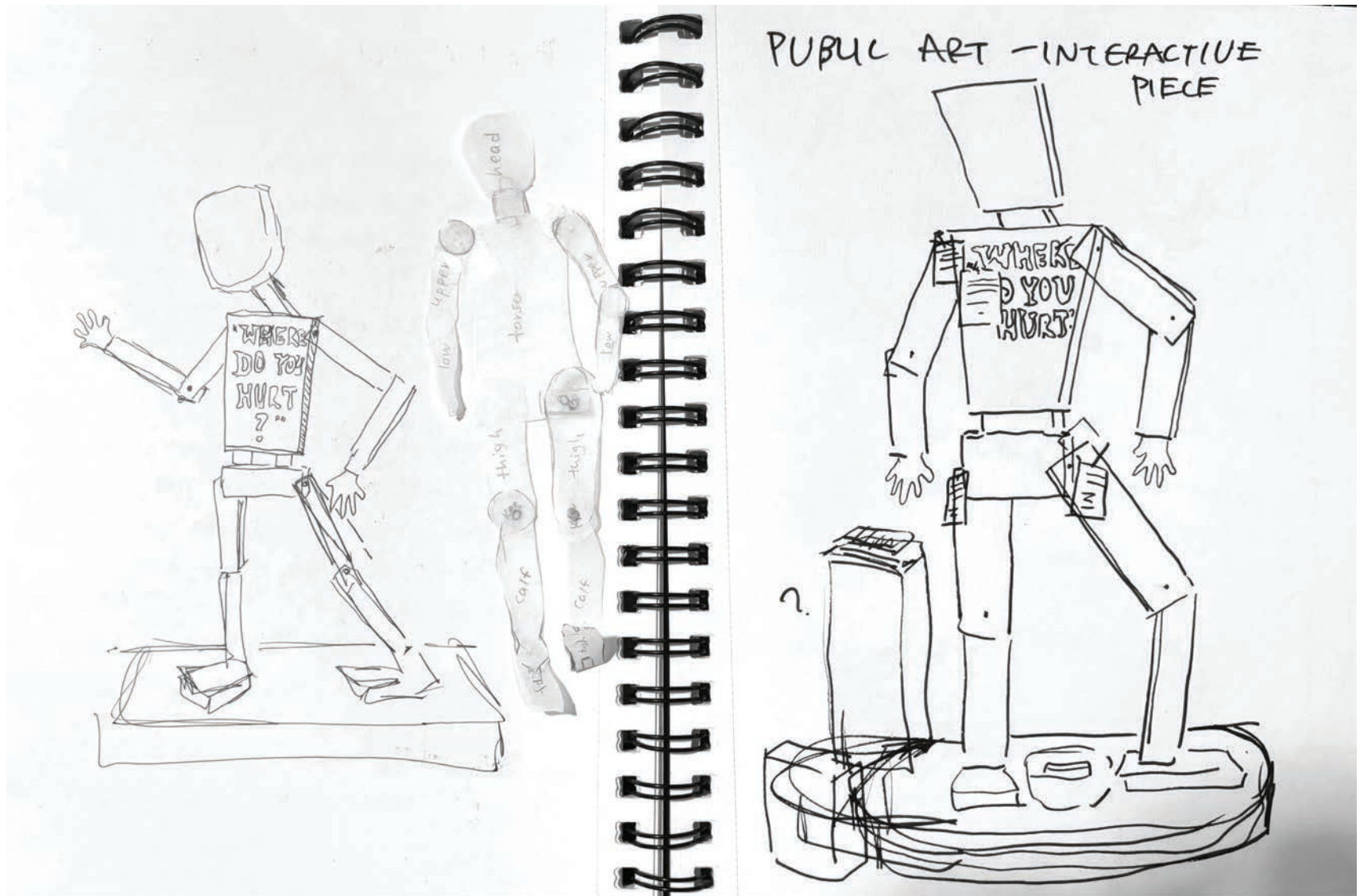
INITIAL IDEAS:

- **A Book on Self-Advocacy Within/Navigating the Medical System:** The hopelessness and bitterness expressed by my community during the Listening Tool informed me of a larger problem, inferable as frequently feeling unheard or unable to access solutions. Their mistrust of me implied a mistrust of anybody promising solutions, most likely connected to failures and frustrations within the medical world, which often leaves people with unsatisfactory treatment, with demographics such as Black women or non-English speakers suffering the brunt of this issue. Since my community revolves around a medical problem, I felt this could be a useful tool for advocating for oneself to get appropriate treatments or answers about their pain.

- **A Workshop:** After presenting on my listening tool, classmates suggested I look into designing a workshop for members of my chosen community as a method of building feelings of connection and combatting the frequently-expressed loneliness that comes with their chronic pain. I considered including meditation elements to address the apparent disconnection between mind and body. However, I found this could be difficult for the reasons expressed in the following section.

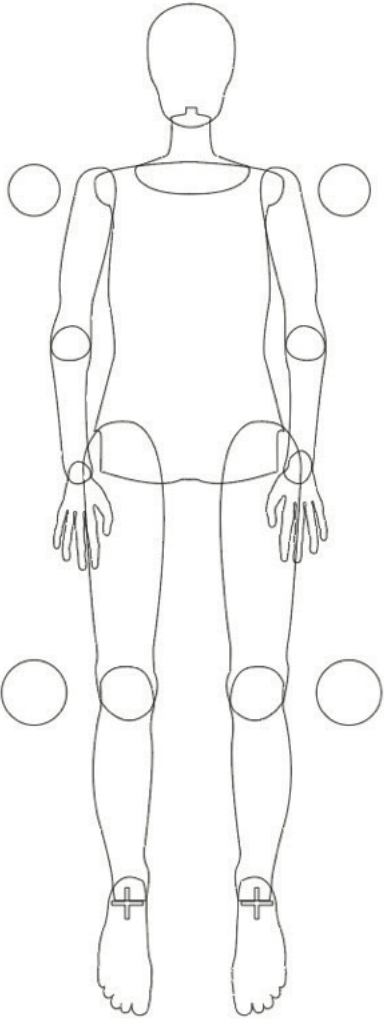
SOME OBSTACLES:

Seeing as my community centers around a medical problem, I felt a certain heightened responsibility to navigate it safely and correctly. One issue that arose is the mere range of issues encompassed under the umbrella of chronic pain. There is no one-size-fits-all solution, and it felt dishonest to oversimplify it into a single workshop. For example, several members of my community expressed that sitting for long periods of time caused flare-ups in pain, which made me consider alternate ways to meditate other than seated -- such as with careful yoga or stretching. However, after speaking to a professor who specializes in disability studies, I felt that to lead a group in such activities would be irresponsible given that I am not a medical professional and each body would need individualized treatment. I felt that a workshop would not end up meeting my community's needs while upholding my accountability guidelines sufficiently.




PRELIMINARY SKETCHING AND PLANNING: After deciding against a workshop or solo booklet, I ultimately decided to advance the concepts explored within my listening tool for the final, focusing on public engagement with an interactive sculpture and raising visibility of the epidemic of physical pain in order to help my selected community feel more seen. The materiality was to be clear acrylic (1/4"-1/2" thick), drawn within Illustrator and cut out with the laser lab machines, as a way of referencing the oft invisibility of chronic pain.

accompanying booklet



<p>GIVING THE BODY COMPASSION HEALING MIND-BODY CONNECTION</p>	
<p>AS YOU READ THIS... ♡ YOUR LUNGS BREATHE, YOUR HEART BEATS, & SYNAPSES FIRE IN YOUR BRAIN.</p> <p>WHAT OTHER UNNOTICED PROCESSES GO ON IN YOUR BODY DAY IN & DAY OUT? MEDITATE ON THESE, & LIST THEM HERE:</p> <hr/> <hr/>	<p>ex) Body: I'm sorry ♡ for smoking while we were sick and then blaming you & getting pissed you weren't better "fast enough".</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>

<p>WHILE THERE ARE ♡ CERTAINLY TIMES WHERE EXISTING IN A BODY CAN BE SUFFOCATING + PAINFUL, THIS SAME BODY IS A VESSEL FOR YOU. WHAT ARE SOME THINGS YOUR BODY LETS YOU DO? ex) I thank my body, for letting me move my fingers and wrists to draw & write. →</p>	<p>I thank my body for.... ♡</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
<p>ALL OF US, AT ONE ♡ TIME OR ANOTHER, HAVE CRITICIZED, CURSED, OR PUNISHED OUR BODIES. DESPITE THE "INCONVENIENCES" & ANXIETIES IT CAUSES, ARE THERE TIMES IN WHICH OUR BODIES DESERVE AN APOLOGY FROM US? WE (BRAINS) ARE ON THE SAME TEAM. TAKE A MOMENT TO REFLECT ON HOW YOU COULD TREAT YOUR BODY KINDLY.</p>	<p>CHOOSE ONE OF THESE PROCESSES & VISUALIZE IT BELOW: ex) hair growing: </p> <div data-bbox="1757 1021 2005 1165" style="border: 1px solid black; height: 90px; width: 115px;"></div>

In response to my community's initial expression of defeatedness, loneliness, and isolation, I spoke to those in my life (who I know personally) afflicted with pain, who commonly shared that they felt a disconnect and anger towards their body, as well as feelings that others do not "see" or understand their suffering. Seeing as this severance between mind and body can lead to stress, which can cause inflammation and tension, I included booklets about "Giving the Body Compassion" alongside the statue as an effort towards mending this relationship or to provoke thought about its connections, as well as ease some of the "overwhelming" feelings about life-long pain.

laser layout

IMPLEMENTATION



IMPLEMENTATION

Due to construction/scheduling problems I ran into at the laser lab, my implementation portion was later than I had expected and hoped for. It landed on the last day before Thanksgiving break and on Dec 2nd and 3rd when I returned. The weather during these days was incredibly cold and windy, so I assumed it was unlikely to get much interaction out in a public place such as the park. Additionally, I was crunched for time, and concerned about how best to transfer the sculpture place to place -- carrying it too far seemed a threat to the structural integrity and I simply did not have time to reconstruct portions if that became necessary. For this reason, I put it in both the Parsons lobby and making center.

To the left is a friend of mine adding one of the first gems to the sculpture, which I had added intentionally before official implementation in order to get the ball rolling once the sculpture was left unattended in the lobby of the building. I put these gemstone stickers in a bowl at the feet of the Invisible Man next to a stack of my "Giving the Body Compassion" booklets.





I encouraged Parsons students and faculty to interact with the plexiglass sculpture by use of rhinestone stickers -- a deliberate choice to make the visuals more "fun" and thus hopefully more appealing to actually engage with. Additionally, I posed the question as a general one: "Where do you hurt?", to tie in the universality of the experience of discomfort and popularize the piece a bit more. In this way, I hoped it would attract a wider crowd and cause them to consider the implications and prevalence of chronic physical afflictions. The statue got a lot of interaction -- I was surprised by just how many more stickers it got than the original listening tool. This may have been in part because I was not standing beside it, as I did with the L.T. Many people also took the "Giving the Body Compassion" booklet, which suggested to me this was a thread maybe worth following in the future.

OUTCOME



PROJECT OUTCOMES

The intended goal of this project was to increase visibility of chronic pain in order to address my community's expression of feeling unseen, lonely, isolated, and misunderstood. I felt that the piece was interacted with to the degree I had hoped -- an element of success -- but it's hard to say how much the installment increased feelings of visibility among members of the actual community. If I had another chance to do the project again, I think I would have identified a small sample group of people I could interview at the start and finish of the project as a way of measuring effectivity. I also would like an opportunity to implement in a public area during a better time to do so, when the weather is nicer, or maybe in a location that feels more content-appropriate, such as in a hospital complex or outside a PT office. For these reasons, it's hard to determine "success"; if "success" is that there was engagement with the work (addition of stickers and removal of books) then it can be deemed successful.

Physical Deliverables:

