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statement of intent

According to several studies on pain, women, especially those with chronic pain, are misdiagnosed, mistreated, and misunderstood when trying to communicate their issues to doctors. My project explores how to deliver agency back in the hands of women as experts on their own personal medicine by equipping them with a toolkit and vocabulary to communicate their pain and by bringing both visualisation and quantification to invisible and amorphous pain.

This is an art-activist project and a real-world design intervention.

The toolkit itself will sit in pain clinics. They will allow patients and pain professionals to engage in dialogue about pain.

The engineering diagrams, the film, and other research outputs inspire activism, especially for increased medical funding. This collection can be partnered with organisations like EndoAware and the Invisible Women movement to speak to women health disparities. I can imagine it being sited at a place like the Wellcome Collection, maybe inspiring them to do an exhibition on invisible illnesses and invisible women.

fibromyalgia



energy levels

My prior project explored introversion and the energy levels expended within social relationships. I wanted to expand that into focusing on personal energy levels and how to be more aware of your own body.

I was struck by a constant muscle knot that I have in my lower back, which leads to chronic pain and fatigue. In my head, this was just something that I would mitigate with yoga, back stretches, and rest. Not something I would consider a medical condition.

After research, I came across the term myofascial trigger points, which describes sensitive areas of muscle fibers. In other words, muscle knots. If these knots persist, they may be classed as myofascial pain syndrome, MPS. This medical condition has pages dedicated to it on the NHS and the Mayo Clinic. It is real. Common.

So why did I feel like my pain was something I should diminish, that I shouldn't bring to a doctor?

Persisting MPS may be one of the causes of fibromyalgia, a long-term chronic pain condition that most healthcare practitioners still struggle to understand. To diagnose it, the doctor presses on eighteen tender points to see if the patient feels pain. This imprecise method relies on believing the patient.

Amy Berkowitz's Tender Points shares her journey with fibro. She was out of office at the same time as a coworker who broke his leg. When he came back, he had get well soon cards. When she did, she had doubt. People didn't understand. Thought she was faking it. People disbelieved her pain.

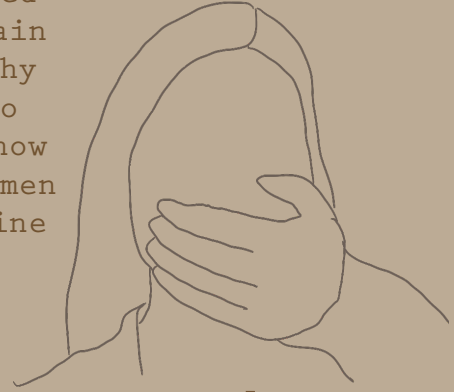
myofascial pain

invisible illnesses

personal medicine

I began to think about invisible illnesses. How pain that isn't easy to diagnose or see is often discredited. How patients often have trouble explaining their pain. How difficult it is to quantify it.

Dianne Hoffman and Anita Tarzian's scientific study *The Girl Who Cried Pain* details whether women felt pain differently than men (yes), and why social norms often cause women to downplay that gap. It highlights how the medical field disadvantages women in pain, which is echoed in Caroline Criado Perez's *Invisible Women*.



I expanded my topic to explorations of pain and how it can be made visible. I also wanted to explore how to help patients better communicate with their doctors, to allow them to be heard and believed and validated.

The questions I want to explore:

How might we get patients to regain agency and ownership of their bodies?

Doctors may be the experts in general medicine, but everyone is the expert in their own personal medicine. What works for them and their bodies.

How might medical consultations become more of an equal partnership?

Lastly, and most provocatively, is the way that we approach medicine disrespectful to patients' bodies? Are doctors less considerate of bodies than, say, BDSM professionals?

This is not to discredit healthcare professionals, whom I respect deeply and who are time and resource constrained. However, the education and training system is flawed. So are our medical systems, which prioritize speed over humanity. How might we fix this?

patient agency

The background is a solid teal color. There are four large, dark brown circles scattered across the page: one in the top right, one on the right side, one on the left side, and one in the bottom left corner.

pain

pain

pain

pain

pain

pain

Chronic pain points.
Fibromyalgia tender points.
Myofascial trigger points.



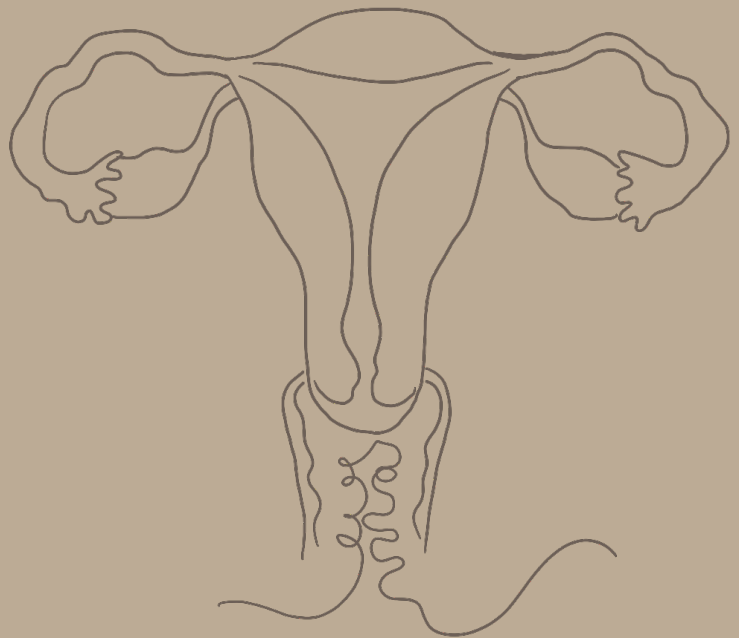
I conducted an interview with a patient with endometriosis, a condition in which tissue usually lining the uterus grows outside of it, causing chronic pain.

I created a video summarizing some of the main quotes from the interview. Many of them emphasized how her voice and her pain was not taken seriously, “by both male and female doctors.”

Juxtaposed with it at the following quotes that I pulled out from some of my reading sources.

One of my initial ideas for how to make pain visible was to visualize muscle knots using shibari, a rope bondage art. After this interview, I gained further insight for the necessity of a visual vocabulary of pain to help decrease the gap between doctors who may prefer more technical terminology and patients who are coming from more emotional and contextual interpretations of pain.

endo metriosis



The problem is
you can't put **pain on trial**.

As I read more about the history of
invisible illness, I'm surprised and amused
to diagnose myself with **hysteria**.

Female pain is
regularly discarded, discounted, and dismissed,
largely because it **does not always conform**
to the clear organic model of appendicitis or a
broken arm.

Doctors' insistence on
the mysterious, unknowable
nature of **fibromyalgia** functions as a
similarly **misogynistic** tactic,
trapping female patients in a state of **uncertainty**
where it's impossible to assert themselves or be
heard as an **authority in their own experience**.

Gentle misogyny is woven
deep into the fabric of our culture.

quotes from amy berkowitz's tender points
& david morris's the culture of pain

Yentl Syndrome. Women are more likely to be treated less aggressively in their initial encounters with the health-care system until they “**prove** they are as sick as male patients.”

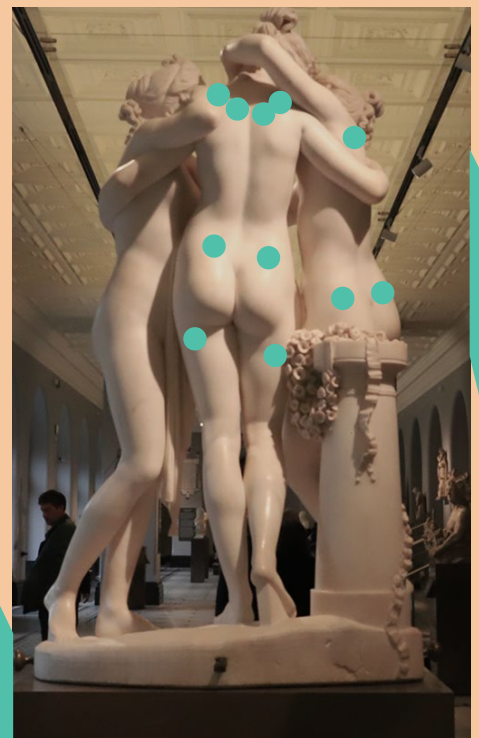
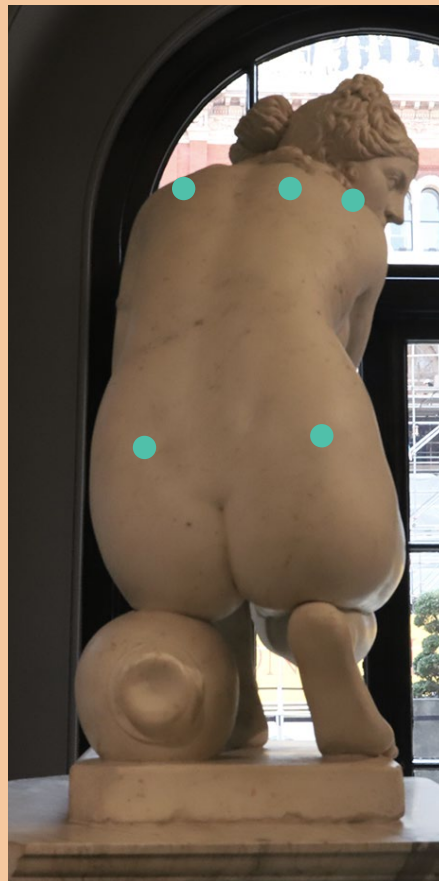
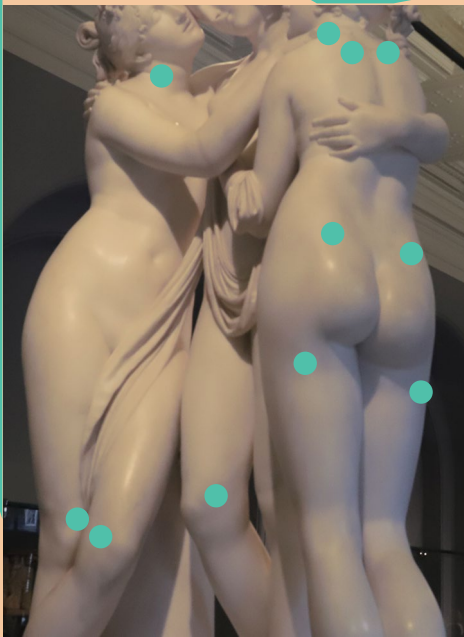
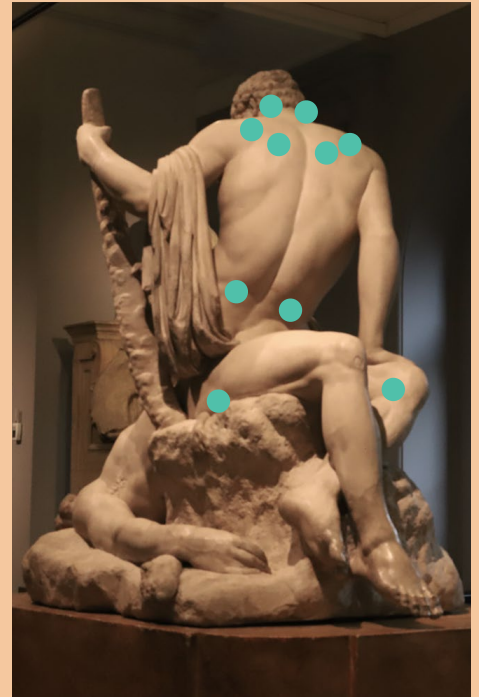
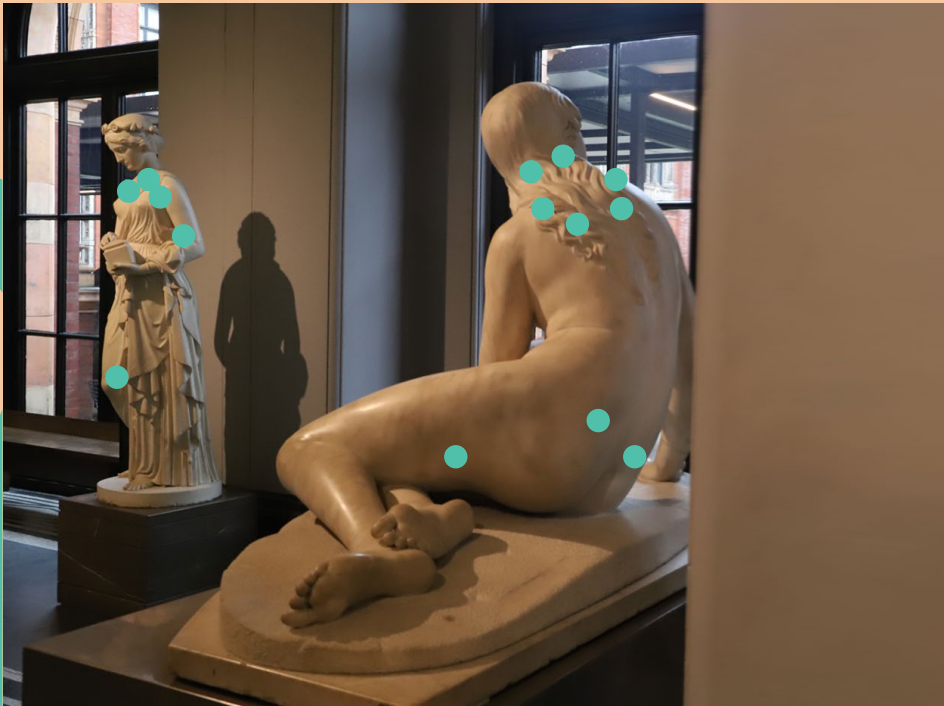
Female chronic pain patients were more likely to be diagnosed with **histrionic disorder** compared to male chronic pain patients.

Female patients were more often perceived as **anxious** than in pain. Women are more likely to be given **sedatives**... and men to be given pain medicine.

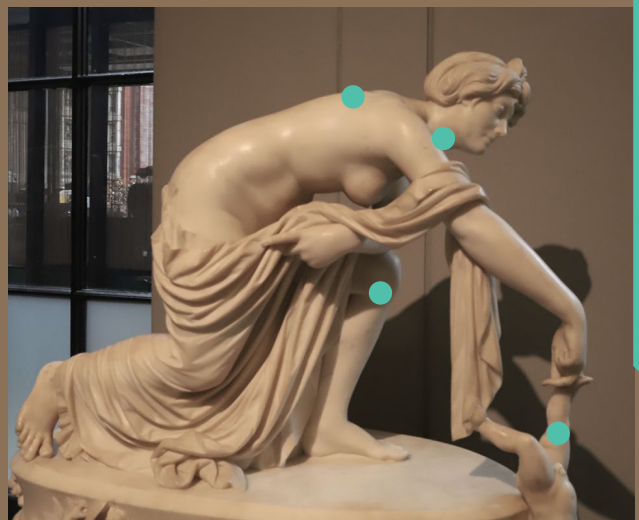
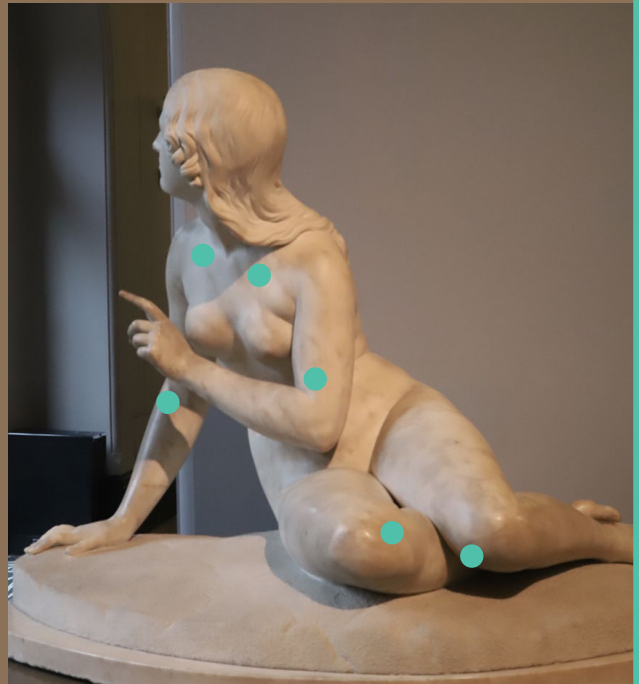
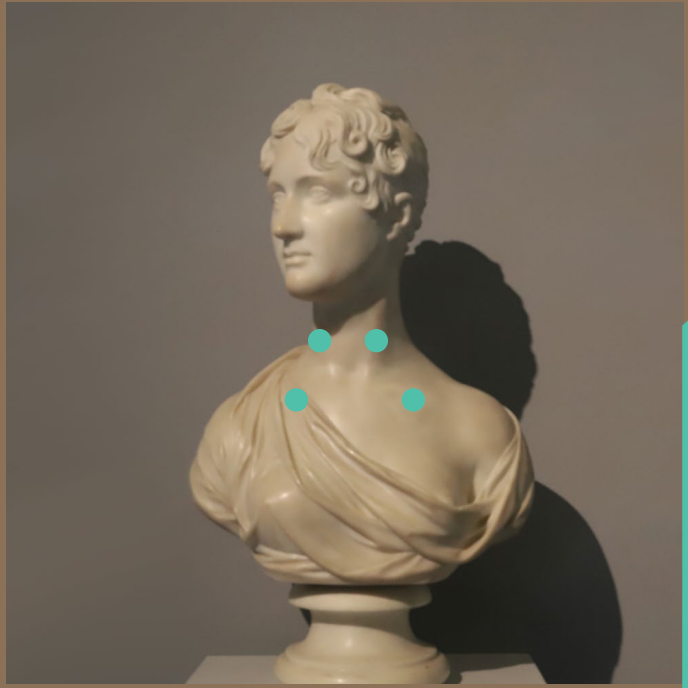
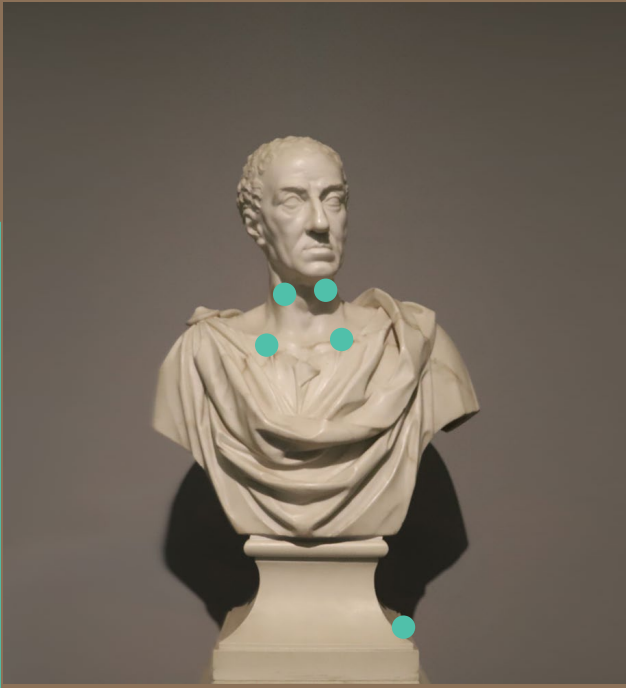
The question changes from “Why do women and men **differ** in their experiences of pain?” to “How do women dampen the effect of **powerful sex differences** in physiological pain mechanisms to achieve only small sex difference in their actual pain experience?”

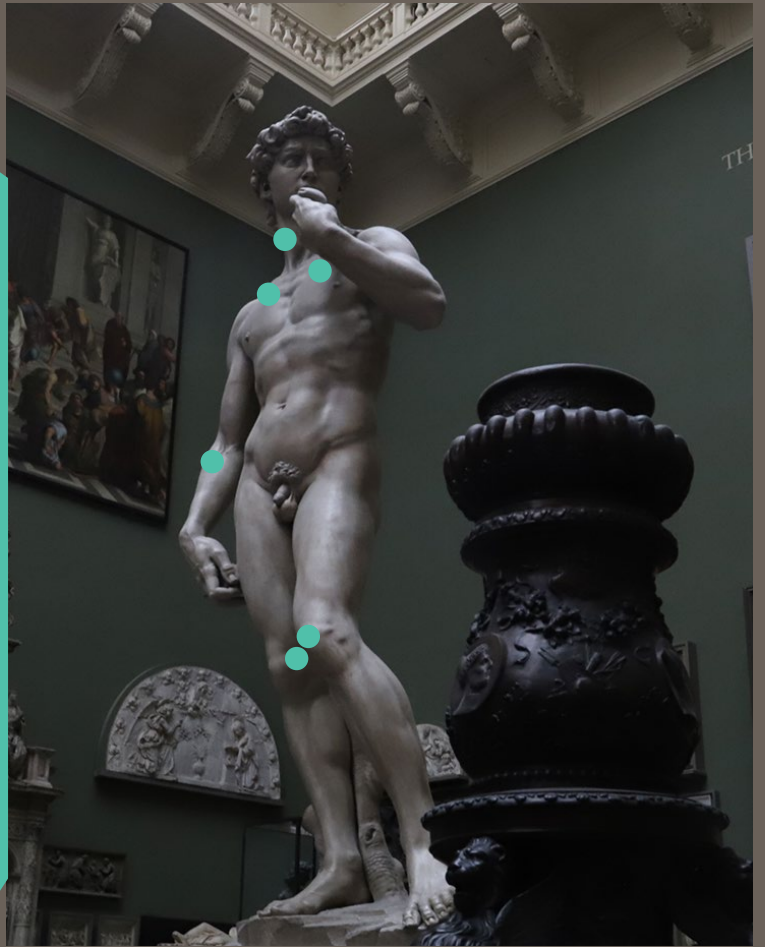
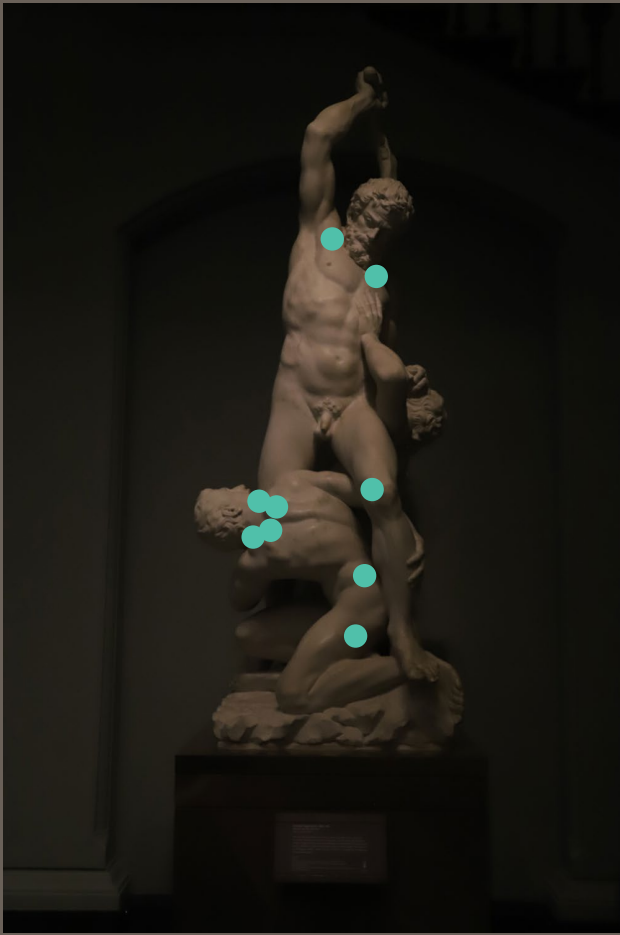
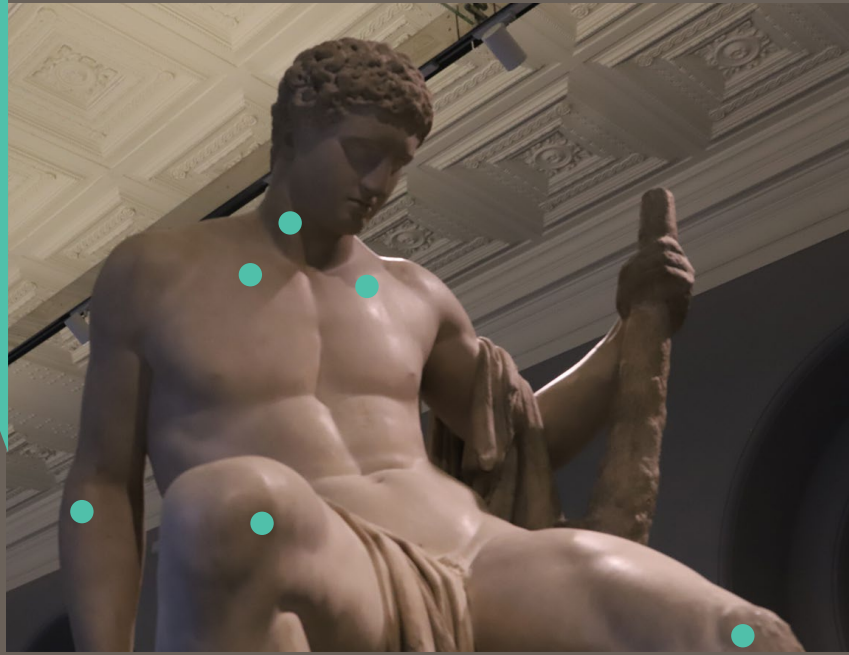
Women were frequently thought to be equipped with a “natural capacity to **endure** pain.”

quotes from dianne hoffman & anita tarzian's scientific study the girl who cried pain



As early exploratory research, I took photographs of busts at the V&A museum in London and superimposed the 18 tender points required for a fibromyalgia diagnosis.



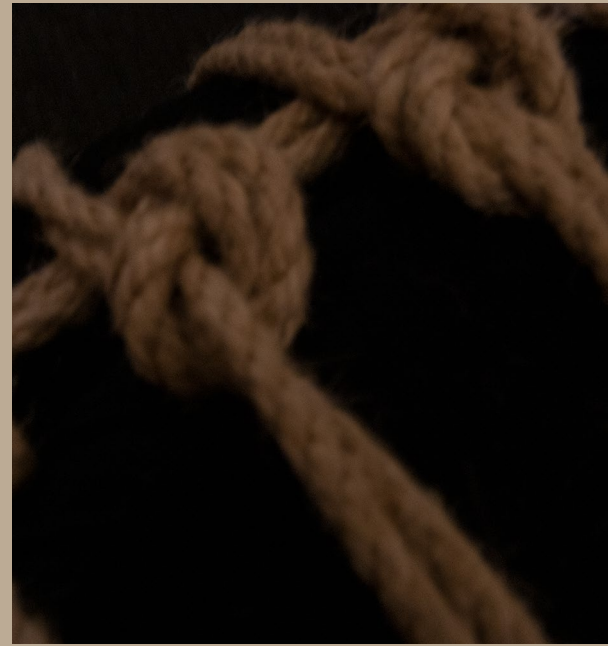




experimenting
with
shibari

shibari (tying)

is a bondage practice derived from the japanese kinbaku (tight bonding). it is both sex practice and art form. I am interested in it as a technique to visualize knots and create pieces, as well as a commentary on pain, control, and tensions.



I experimented with two types of rope, jute (left) and nylon (right). Jute is stronger but coarser, its natural fibers creating tight knots but also fraying more easily unless treated. Nylon runs more smoothly along the hands while tying but can slip more.



I practiced self-tying a futomomo, a specific type of knot for the leg that starts at the ankle and binds around the thigh and shin.

In shibari, the rigger (the one tying) is in control of the pain. the rope bunny (the one being tied) relinquishes control, often shifting from the sympathetic nervous system (fight / flight) to the parasympathetic (relaxation, life-sustaining processes.)

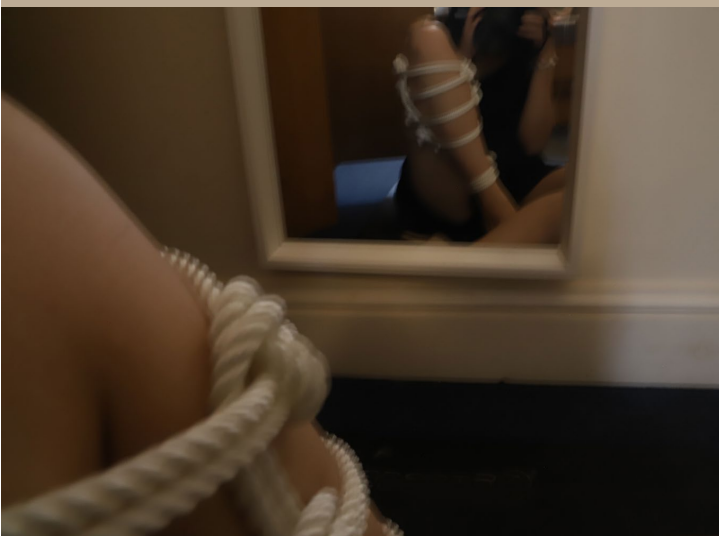


Self-tying means one is rigger and rope bunny. To me, it is a relationship of trust and control with yourself. It can be used as a method to increase awareness and understanding of your body. In this relaxed and self-aware state, pain becomes an internal process to flow with, to accept, to mitigate, not an external stimulus to be afraid of. We become more in tune with our body and its processes.





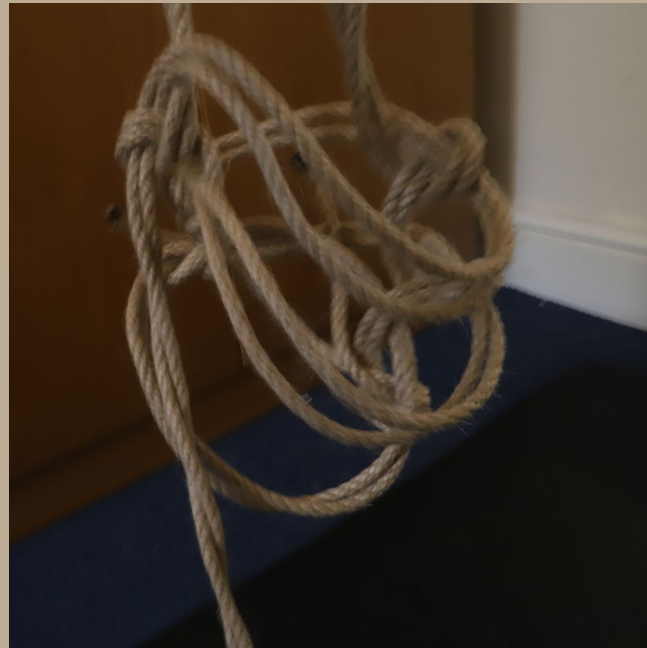
self.
t.ies



some experiments with the mirror.
self-tying, self-photography.



When taking off the futomomo, some of the shape of the tie can be retained, which creates an interested, intricate harness.



The way that I conduct research involves mixed media. Sometimes it is reading. I continued to read up on pain, such as Elaine Scarry's *The Body in Pain* and Steve Haines's *Pain is Really Strange*.



I also visited a community centre that was offering acupuncture sessions, and interviewed two older women who were in the session as well as the acupuncturist, trying to understand alternative therapies to treating pain.

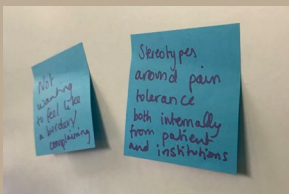
I went to many museum exhibits. Japan House had an exhibit that involved knots. The Science Museum had an exhibit on medicine, in collaboration with the Wellcome Centre.



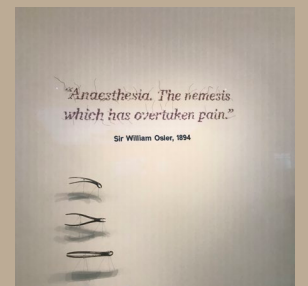
I talked to experts.

I had an interview with Alice Gregory from the Helix Centre, who is also starting a project on women's health.

I brought a prototype of the vocabulary cards to a doctor who has been practicing for 30 years to get his take on what resonated.



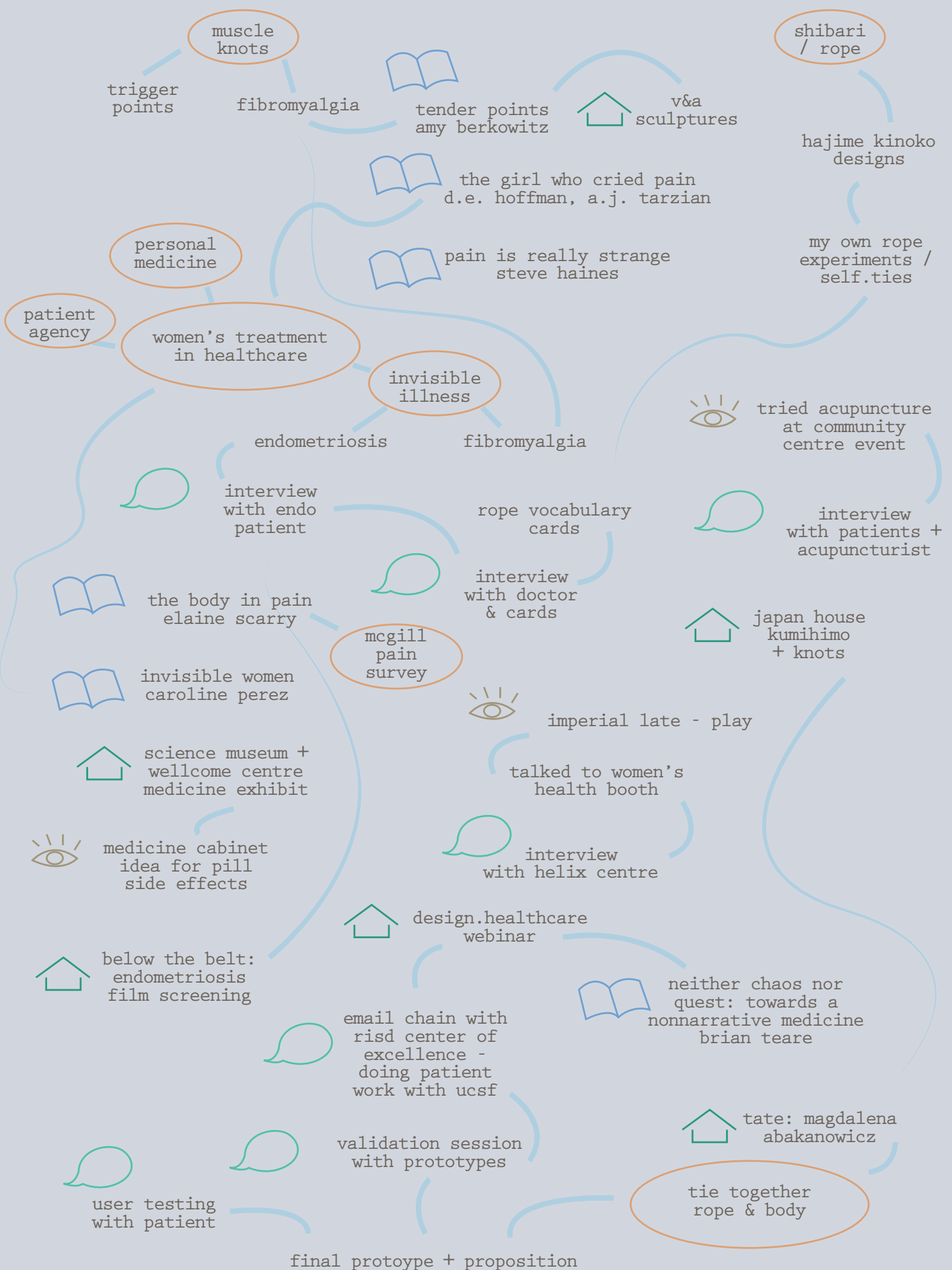
I attended a Design.healthcare session run by the Helen Hamlyn Centre, with guest speakers from UCLH (University College Hospital), RISD (Rhode Island School of Design), and the Helix Centre. It focused on honoring personhood in the healthcare setting, and one of the projects specifically, about helping second language English learners communicate to doctors, resonated with mine.



From that session, I was able to start a dialogue with the researchers from the RISD Center of Excellence, who are in turn collaborating with UCSF (University of California San Francisco) and their hospital system.

The following page shows my research timeline,

mixed media research timeline





This leaves me with three tracks to my project. The first creating a visualisation of muscle knots out of rope that is wearable and exquisite.

The second is a visual vocabulary of pain that can both be used as a way to mitigate gaps in understanding during a medical consultation, which needs to be fast-paced, and a therapeutic and diagnostic tool at home, which can be slower-paced.

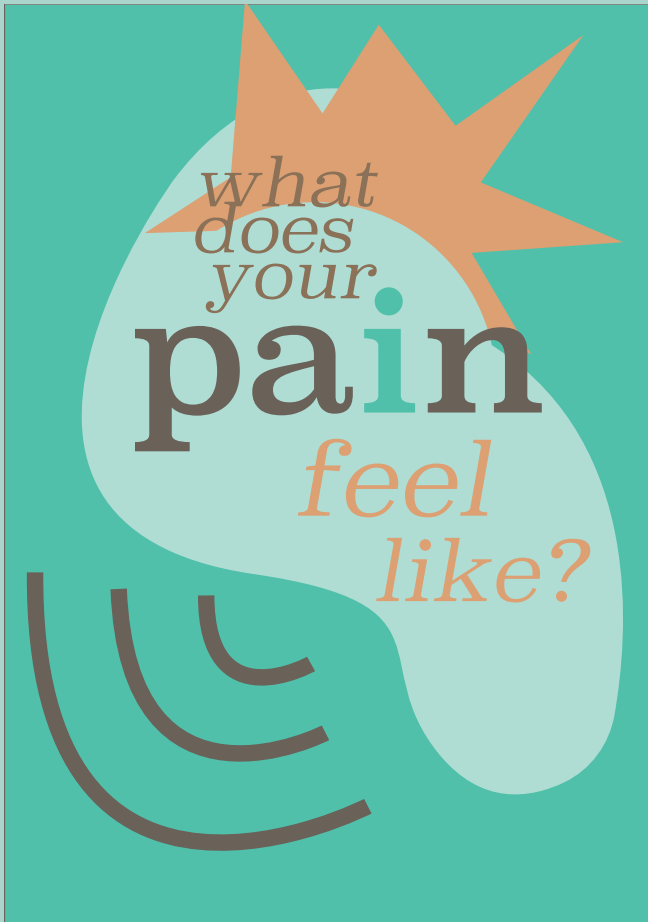
The third is taking this imprecise and amorphous concept of chronic pain and fatigue and somehow making it more technical, in engineering terms.

*

I focused on the second track first. Curating advice from several online forums on how to best prepare for a doctor's visit, I picked common pain words to create visual vocabulary cards and also made a guide of symptoms. This was the first edition of what I would call the "toolkit."

I tested the words with a patient and a doctor to come up with a hierarchy.

The doctor suggested that because of a limit on time to seeing the patient, while the words are helpful, they may not be able to be used in full during the session itself. He suggested they could be digitised and put in an app that the nurse in the waiting room can use while the patient is checking in. This is the first "waiting room use case." I also propose an "at home use case" where patients can mull over the words at their leisure at home, before their doctor's visit.



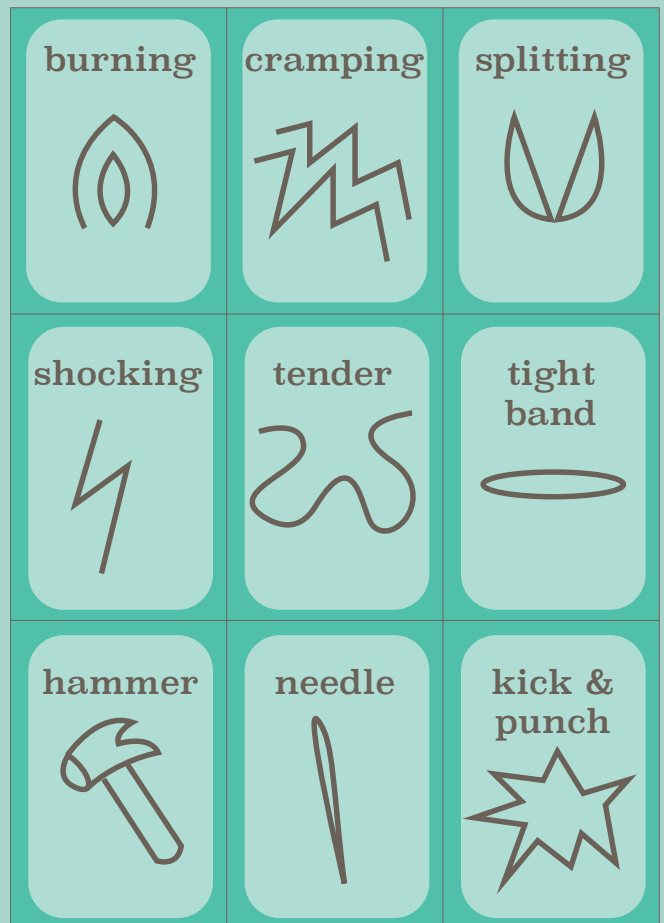
guide to describing symptoms

1. feel use specific words (see cards)	2. location show where (see harness)
3. duration ___ days ___ weeks ___ months	4. frequency every ___ day(s) after ___ whenever i ___

pain scale

mild medium intense
distracting disrupting debilitating

limitations
when does it get better? worse?
what activities does it impact?

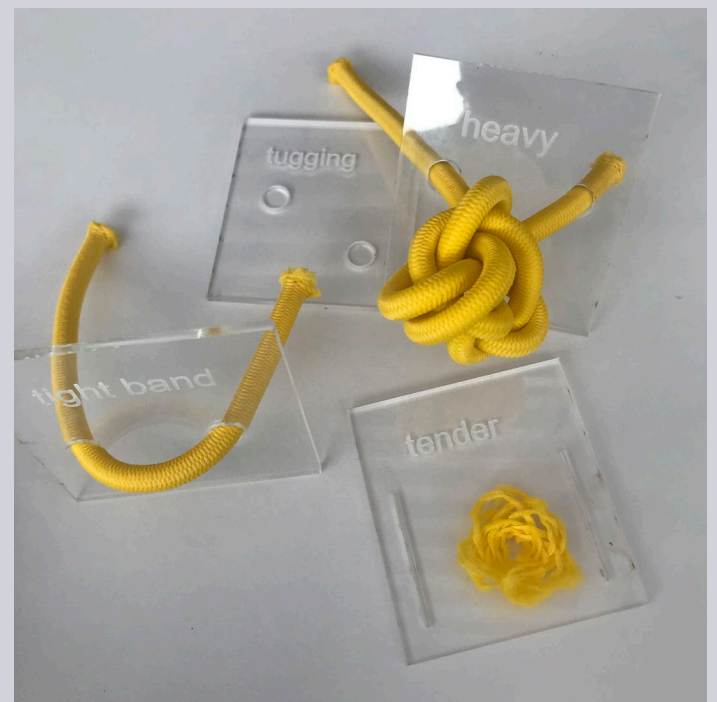


The first edition of the toolkit, along with a guide to describing symptoms, aimed to equip patients before a doctor's visit.

From reading *The Body in Pain*, I learned of the McGill Pain Questionnaire, a medical survey of 78 pain words in 20 categories. There is also a short form of the questionnaire with only 20 words. Comparing them with my curated words, there is a lot of overlap, and I finally narrowed down on a list of 20. After consulting with the doctor, I made this final list that broadly spans the different categories. Then, I began to try to visualise them on acrylic. My goal was to have a mixture of etched graphic and holes for rope to be threaded through.



After testing the first edition, I realized that I wanted to eliminate the sharp corners so that the cards are more user friendly. No need to cause more pain with the cards! I also saw that the rope visuals were the most effective, as they allowed for touch as a form of discovery.





Following a suggestion, instead of picking words that spanned all categories, I focused on 4 categories that could be more easily visualised with rope. Starting with these 4 demonstrates the concept. In the future, other materials can be used for other categories.

- The categories were
- 5 - constrictive pressure (pinching, pressing, gnawing, cramping, crushing),
 - 6 - traction pressure (tugging, pulling, wrenching),
 - 10 - sensory miscellaneous (tender, taut, rasping, splitting), &
 - 18 - sensory miscellaneous (tight, squeezing, tearing).

(From 18, numb & drawing were excluded as they also weren't easily depicted with rope.)



Whenever I got stuck on how to visualise something, I switched to a different type of rope to get my brain thinking in a different way.

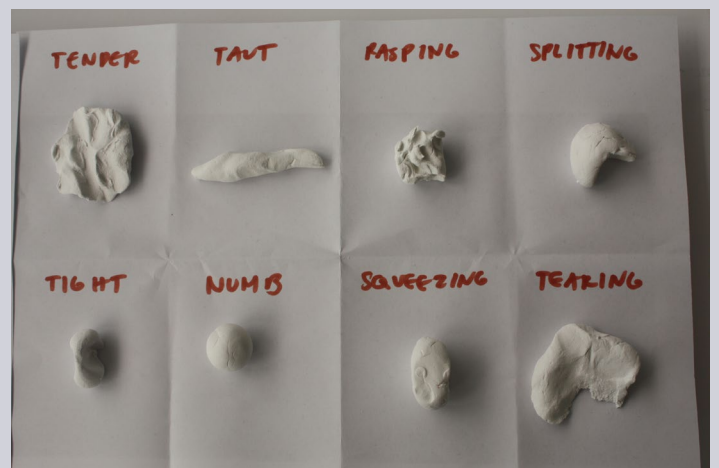
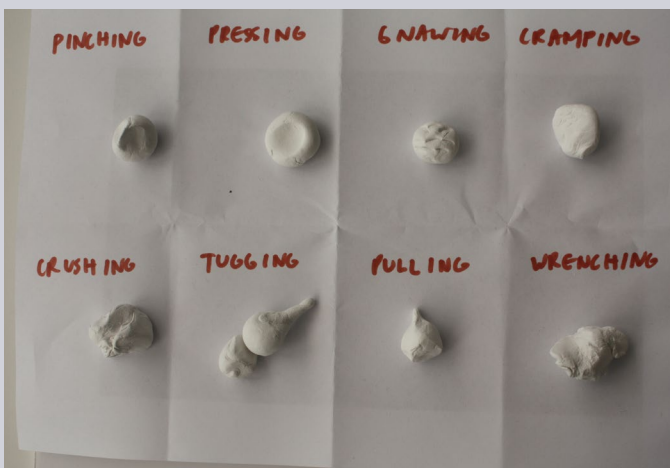
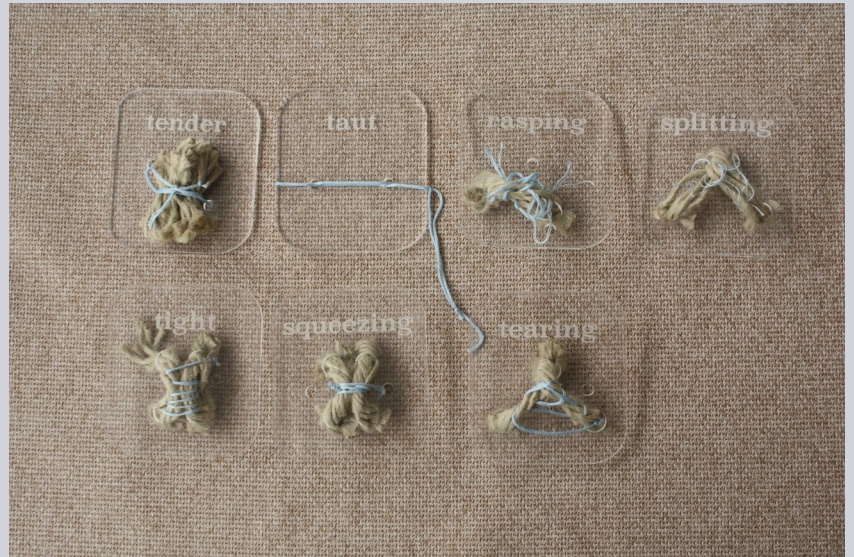
I found that one tone wasn't enough for the intricacies of the words, and that holes instead of slots in general were better for the rope.



In the next few sets, I used the tan rope that almost acted as body, and a blue embroidery thread that almost acted as rope. The two tones and sizes depicted better certain nuances to visualisations.

I was happy with how my visual language for pain with rope has developed in general, but there were certain words that were giving me trouble. In addition, in user tests, some users found it hard to distinguish between certain combos of words, so in my next iteration, I focused on trying to make each word more unique.

When I got stuck again, I switched briefly to a different medium (clay) to get some concepts across and to get out of my head.





Here is the current working set.



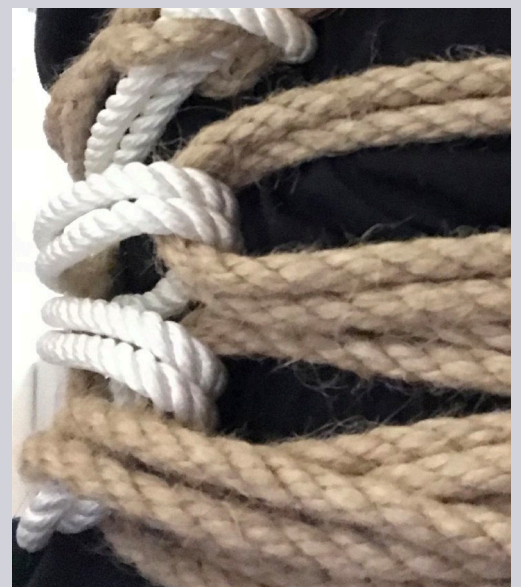


In parallel, I also developed the rope harness. This was meant to be a more artistic visualisation of my muscle knot.

As I developed the harness, the design language of large tan + small blue from the cards also came across to tie the two concepts together.

I began to see how they could work in conjunction as well. Perhaps there could be a mannequin and rope version that sits in a physical therapist's office that the patient and professional work on together, along with the set of cards.

The cards can inform the design. Patients can continue to change the design each visit. They could have a board version at home that complements the mannequin at the doctor's office. I call this the "physical therapist use case."





The complex back shows the entanglement of how my muscle knot feels. The simple front shows how my pain is displayed externally: in neck strain and in bad posture around the stomach area.



Other visuals I made on different days. The right image shows use with the cards: I felt pinching, crushing, gnawing.

validation

The primary audience of the work are patients of fibromyalgia, endometriosis, and other invisible / chronic pain syndromes who would like to regain agency of their pain and their bodies.

The secondary audience are doctors, pain professionals, and other healthcare workers who can become more aware of the patients' side.

The tertiary audience are people in positions to make change - seed funders or governments that fund medical researcher, research institutions and hospitals.

I have a two-fold evaluation process.

With patients - I want to know if the project does what it aims to do, which is to give voice and visual to their pain. Can they use the cards to communicate their pain?

With the wider medical field, I want to know if the project can be sited and used. Do they see a future for this project? Can they see where it would incorporate into the medical system?

Will it not only raise awareness about invisible illnesses and ignored women in healthcare, but also motivate people to take action, such as by demanding better of their healthcare professionals or petitioning for increased research funding?



I continued my conversation with two researchers at the RISD Center of Excellence from the Design.healthcare session, Julie Woods and Sahib Singh.

They discussed their project on patient equity that is partnered with UCSF and listened to me explain my project and show them my prototypes.

The reception generally was positive, as they understood my point of why the project is needed. I had some concerns about the time constraints with doctors and where to site the intervention, and together in the session, we ideated on a new proposal. The toolkit will be part of workshops run by pain clinics, which patients of chronic pain visit regularly.

Participants can create and share artwork that shows their pain, building empathy, self-validation, and understanding.

Meanwhile, a psychoanalyst, therapist, or other pain professional can take these learnings and share with the patient and their doctor, improving the treatment plan.

This is the “workshop and pain clinic use case.”

At the end result of the session, they were open to bringing me into the conversation to talk to the UCSF pain clinic when they start that leg of the project. They also wanted me to eventually run a workshop at RISD.





Finally, I did a user test and validation session with the endometriosis patient from the start, having her test out trying to explain her pain using the cards.

At first, I had her pick three and walk me through her reasoning. Then, we expanded to five. She found that visually the cards helped her pick out words, and she thought some were self-explanatory. However, she is someone already comfortable with articulating her pain, and she was using the words to relate back to words she already used to describe pain. She did find a few words similar as well.



When asked about the workshop and pain clinic concept, she was enthusiastic. She said that because many chronic pain patients have to depend on others, and also because chronic pain is a journey of acceptance, she would look forward to using the toolkit to become "active in giving shape to [her] pain and words."

Together, we ideated on a refined version of the "waiting room use case" where the cards can be installed in a desk and patients can select them as they wait, "instead of reading stupid old magazines."



Because we were in a semi-public space, we got interrupted twice during the session, which also was an interesting way to see how the cards gave a first impression.

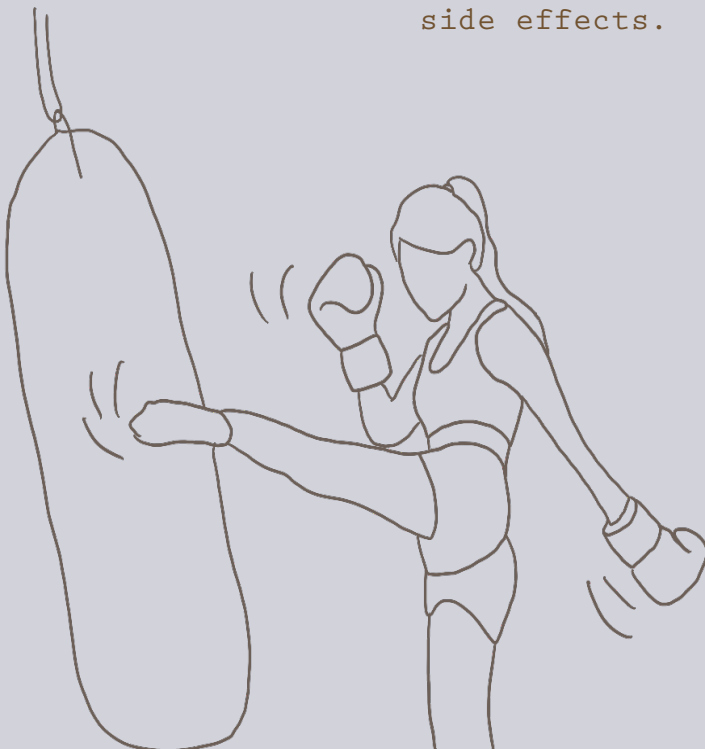
One person thought it was a jewelry making session, another thought it was a game. I was also able to recruit one to describe his muscle pain.

I made engineering diagrams to quantify some of the issues that patients face. Exploded axonometric diagrams of the most common pills given to patients of fibromyalgia and endometriosis reveal dangerous side effects. A sankey diagram shows drainage and fatigue that patients cope with.

I also created a video to touch upon both the cultural and medical journey of pain. It begins to explore the landscape of issues, including patient agency, mental repercussions, and how women are ignored, mistreated, and misunderstood in healthcare.

I hope the impact of this exploration and project will be pain workshops that can be set up at pain clinics, and also that this toolkit can be given to patients who have chronic pain so that they can regain agency of their bodies.

Wider, I hope that this inspires medical research into better alternatives to treat pain and better medicines without all these adverse side effects.



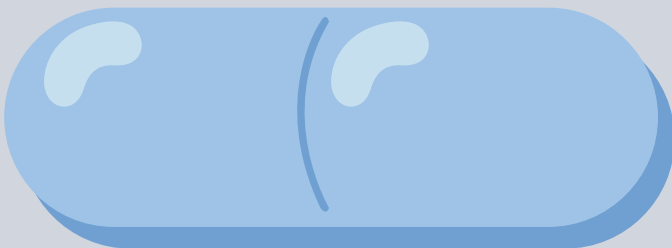
fibromyalgia: antidepressant pill

exploded axonometric

standard

serious

feeling sick / nauseous
feeling tired / weak
difficulty sleeping
excessive sweating
difficulty peeing
loss of appetite
loss of libido
blurred vision
constipation
diarrhea
dizziness
dry mouth
headache
hallucinations
feeling confused
yellow skin / eyes
bleeding from gums
irregular heartbeat
weight gain / loss
change in periods
pee / cough up blood
feelings of euphoria
thoughts about self-harm
thoughts about suicide
eye pain / eyesight loss



source: nhs

endometriosis: birth control pill

exploded axonometric

standard

serious

feeling sick / nauseous	
allergic reactions	
breast tenderness	
irregular periods	
ovarian cysts	infection
mood swings	depression
change in libido	blood clots
drowsiness	womb damage
dizziness	stomach ulcers
diarrhea	weight gain
bloating	breast cancer
hair loss	cervical cancer
headache	ectopic pregnancy
acne	heart failure, strokes
	increased blood pressure
	vaginal bleeding / pain



source: nhs

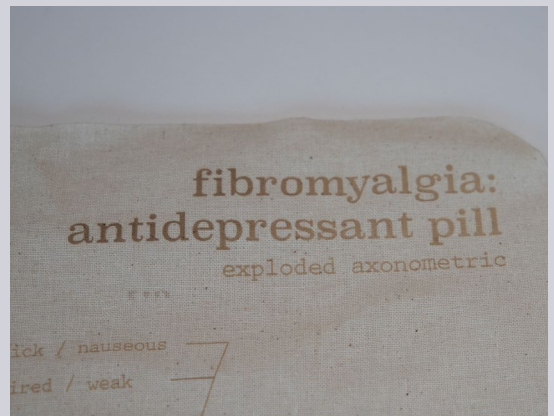
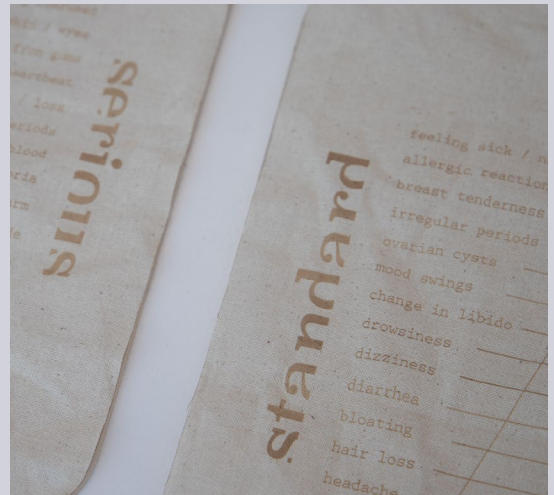
sankey diagram. energy flow through day.

good day



bad day





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