



# Seasons of Cysterhood

An invitation and process by Krutika Galgalikar

*“Our bodies are the texts that carry the memories  
and therefore remembering is no less than reincarnation.”*

— *Katie Canon*

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Summer

## AN INVITATION

Dear Reader,

I hope this finds you in a season of good health.

This book is an exploration, a journey, and an invitation. It explores spaces of health and healing and invites you to discover your voice and purpose.

My name is Krutika Galgalikar. I am a design researcher, a person of color, and a women's health advocate. My life changed thirteen years ago when I first heard the acronym: PCOS. Polycystic Ovary Syndrome is a hormonal and metabolic condition caused by unknown factors and has no cure. I am on a mission to re-discover my identity as a PCOS patient and explore how design interventions can create conditions for holistic care.

My journey into becoming a social designer is guided by the values I believe in, the relationships I hold close, and a sense of curiosity that led me onto this path. I invite you to be a part of this journey.

Human lives run on the fuel of good health. Without good health, we cannot show up for ourselves, have a good quality of life, or maintain meaningful relationships. The World Health Organization defines health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (Source: World Health Organization).

It took me some time to learn that personal health is a process and that healing looks different for each of us. The health and wellness industry dominates the post-pandemic world in diverse ways. In 2023, we live in a time that is oversaturated with information all around us. From diet fads to wellness collectives to mindful practices, to self-care and so much more. Learning to sieve through all that to find what works for your mind and body requires patience and pruning.

This work is grounded in values of equity and courage. My intention is that this work helps people find the courage to lead themselves in times of uncertainty. I hope it empowers you to re-imagine what health equity could look like in a desired future state.

"Health equity means striving to equalize opportunities to be healthy, it means social justice with respect to health. Reductions in health disparities (by improving the health of the socially disadvantaged) are the metric by which progress toward health equity is measured." (Source: Health Disparities and Health Equity: The Issue Is Justice)

*What is the pattern that connects the crab to the lobster  
and the primrose to the orchid, and all of them to me,  
and me to you?"*

— Gregory Bateson

## THINKING IN QUESTIONS AS AN APPROACH

The foundation of my practice as a social designer is held by three pillars: curiosity, a sense of wonder and magic. The three of them form a connected pattern in my mind. Do you recall the last time you felt all three at once?

*A red robin during early spring,  
Waking up to a surreal sunrise,  
The bird swooping the lake to catch fish.*

*Was it a fresh cup of coffee?  
Or learning how stars are born?  
Why does music evoke a memory?*

The simplest of questions inspire a whole new search for meaning. I love questions. I love meaning. And I love it when a carefully curated plan comes together. My most significant learning has been to ask the right questions at every stage of research and discovery.

My love for questions has only amplified on this journey. Re-framing, rethinking, and repeating is the approach I took with this work. Every challenge led to emergence and inquiry. And the questions never ended.

## CORE VALUES



*Language helps give color to ideas.” — Karen Proctor*

A designer’s superpower is rooted in their lived experience and identity. Over the last two years, this transformative journey has led me to tune inwards into my values and purpose.

Through the power of values, I find myself in a constant conversation with the design process. Commitment, courage, curiosity, and congruence are a few values that form the foundation of my work.

“Change is not easy; it requires learning a new way of being and unlearning past habits, behaviors, and attitudes. It also requires some degree of risk in order to challenge the status quo and go in a new, untested direction. The courage involved in social change is great, and the willingness to take a leap of faith toward a novel idea or a different tactic requires an acceptance of ambiguity, transition, and even discomfort.”

— Leadership for a Better World

## SOCIAL DESIGN AS A RESPONSE TO SOCIAL CHANGE

“Social justice is a matter of life and death. It affects the way people live, their consequent chance of illness, and their risk of premature death. We watch in wonder as life expectancy and good health continue to increase in parts of the world and in alarm as they fail to improve in others. A girl born today can expect to live for more than 80 years if she is born in some countries – but less than 45 years if she is born in others. Within countries there are dramatic differences in health that are closely linked with degrees of social disadvantage.” (Source: World Health Organization).

As of 2021, the healthcare industry is worth \$808 billion in the United States. 65% of the revenue comes from patient care. (Source: PolicyAdvice). Despite this, about 1 in 10 people in the U.S. do not have access to health insurance. (Source: Office of Disease Prevention and Health Promotion). I wondered why barriers to access and affordability still existed.

This decision impacted women’s social, economic, cultural, and political lives in America. Women’s lives changed drastically with access to reproductive and menstrual health under attack. Such cultural and political moments often create a shift in our societies. They create conditions for social change. That summer, I reflected on how power dominated fear, anger, frustration, loss of control, and safety.

The reflections became the initial drivers for why I wanted to explore spaces of health and healing. This is when I shifted my approach from, “What does the problem look like?” to “What does the problem **feel** like?”. And once again, reframing the question made all the difference.

Social design offers a way to sense events that are happening around us. It requires awareness and compassion to understand communities’ circumstances in difficult times.

Most of all, social design is a response to social change.

Fall



## ABOUT THE CAUSE

Historically, individuals identifying as women, have been at a disadvantage in terms of their economic, social, cultural, and political statuses. I have heard stories of injustice towards women from my mother, grandmother, sisters, aunts, and friends, but also through my own lived experience of the multicultural landscapes of India, Singapore, Canada, and now the U.S. I want to address issues related to equity, health access, quality of life, medical trauma, and reproductive justice.

Reproductive Justice is the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities. It speaks to an individual's access over choice (Source: SisterSong). In the healthcare space, we often hear a lot about agency, the ability of an individual to choose the decisions about their body. Still, I think access takes priority because there can be no choice where there is no access.

Additionally, quality of life can be defined "as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns." (Source: World Health Organization).

**How might we measure and create conditions for an improved quality of life for individuals identifying as women?** This is the big-picture goal that I aspire to with my thesis.

For the last thirteen years, I have lived with the condition known as Polycystic Ovary Syndrome (PCOS), a hormonal, metabolic, and reproductive disorder affecting 1 in 10 women in the U.S. (Source: Endocrinology & Metabolism International Journal). The exact cause and cure are currently unknown. My experience with this condition includes pain, misdiagnoses, years of frustration, lack of support, and medical trauma. Through this thesis exploration, I want to inspire hope. For myself, but also the 116 million women living with it.

As I began researching, I was overwhelmed by the amount of information that exists. I created a "Fact Sheet" where I collected information and data relating to the cause, below are some highlights from the literature review:

## FACT SHEET

### Fact Sheet around Women's Health and PCOS in the U.S.

Only 3% of the 2,728 US digital health deals since 2011 have focused on women's health.

### Source

Rock Health Report.

5% of digital health investment is focused on women's health, and women are still under-represented in nearly all clinical trials.

Forbes

At least 1 in 8 couples struggle to conceive, and it costs approximately \$60,000 to successfully conceive a child through in vitro fertilization.

Women's Health Policy

PCOS is one of the most common causes of female infertility, affecting 6% to 12% (as many as 5 million) of US women of reproductive age. But it's a lot more than that. This lifelong health condition continues far beyond the child-bearing years.

CDC

Women with PCOS are at increased risk for endometrial cancer, diabetes and heart disease. PCOS is also associated with infertility, and it increases the risk of some complications during pregnancy.

New York Times

The women's health market is projected to hit \$60 billion by 2027.

Second Opinion

The National Institutes of Health (NIH) estimate more than 50% of women with PCOS will become diabetic or pre-diabetic before age 40.

PCOS Challenge

The publisher estimates that in 2017, there were approximately 113.2 million (NIH criteria) to 188.7 million (Rotterdam criteria) prevalent cases of polycystic ovary syndrome (PCOS) in females aged 15-49 years worldwide, and expects that number to increase to between 119.5 million (NIH criteria) and 199.1 million (Rotterdam criteria) by 2026.

Globe Newswire

Despite affecting millions of women and the serious health consequences, PCOS is unknown to most people and a staggering 50% of the women living with PCOS are going undiagnosed.

PCOS Challenge

The economic burden of PCOS is estimated at \$8 billion annually in 2020.

National Library of Medicine

These facts revealed the socio-economic trends in women's health in the U.S.:

First, the women's health market, although projected to hit \$60 billion by 2027, is growing at an alarmingly slow rate. Investment from venture capitalists, health technology companies, and the public sector is significantly low. Research is severely lacking across mental health, oncology, and heart diseases.

Second, the lack of funding for women's health-focused initiatives results in the economic burden of diseases such as PCOS, which has comorbidities such as Type 2 diabetes, infertility, anxiety, cancer, and cardiovascular diseases.

Third, providers and policymakers at the federal and state level need to understand that the social determinants of health impacting women are unique and change based on demographics.

These facts show that the lack of investment in women's health has negative implications for the quality of life of women. Despite being discovered 90 years ago, PCOS has no cause or cure. (Source: PCOS Challenge).

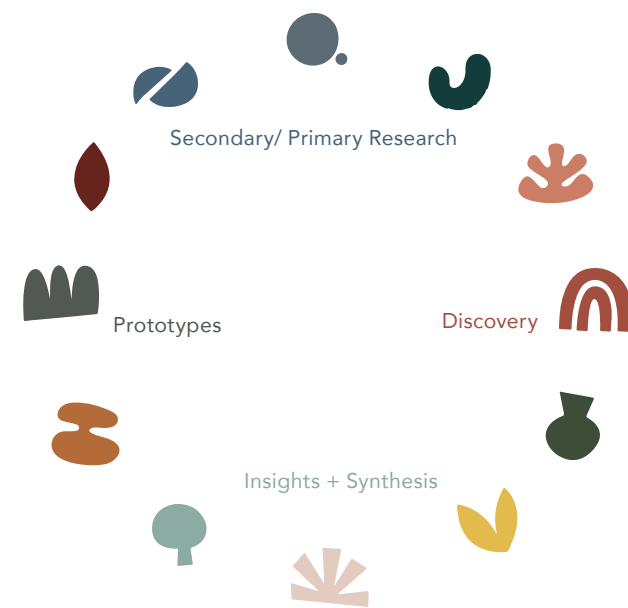
Medically, it is a misunderstood and underfunded condition that is missing appropriate health policy. "Many doctors are missing the diagnosis and it is leaving patients to struggle without appropriate care. The lack of funding extends into PCOS research, stifling advancements and the number of young investigators entering the field." (Source: "Systemic Problems in Healthcare Regarding PCOS", PCOS Challenge.)

"I had no support or resources to learn how to manage my PCOS. It wasn't until I was able to connect with other women who had it that I started to feel less isolated and learned how to advocate for myself." (Source: "When Missed Periods Become a Metabolic Disorder", The Atlantic.) Socially, it carries shame, stigma, and lacks support. PCOS can only be managed through lifestyle changes and social support.

When healthcare systems fail to serve a patient's needs, an individual can feel isolated and lost. In such situations, empowerment through advocacy, self-management, and social support tools can help navigate chronic conditions, resulting in an improved quality of life.

"When there is no relationship between diagnoses and cure, a mislabeled patient is bound to be a mistreated patient". — The Body Keeps the Score (page 167)

**How do we imagine a meaningful change in this system?**



## DESIGN RESEARCH METHODOLOGY



*Research is formalized curiosity. It is poking and prying with a purpose."*

— Zora Neale Hurston

## POWER IN COMMUNITY

In February of 2022, I searched for community. The support available in this field is overwhelming. More than one hundred articles, over two hundred podcasts, and over three-hundred influencers and organizations are actively trying to create change in this system.

This was when I came across PCOS Challenge. Based in Atlanta, they are the largest non-profit dedicated to making PCOS a public health priority in the U.S. Their core values of a patient-centered approach, leadership, collaboration, and accountability resonated with the kind of work I aspire to practice. Additionally, they work at the intersection of healthcare providers, receivers, civic systems, research, and development. The organization is a playing field for these stakeholders.

As I began researching the stakeholders, I observed that power distribution among the stakeholders was highly uneven, with civic systems and providers holding most of the influence.

### How do we begin shifting power?

While reading Ford Foundation's "Listening to women talk about their health", I was introduced to three conceptual ways of shifting power:

First, the perspectives of the global society provide a background of increasing democratization. This is manifested in the works of non-profits, communities, and NGOs. Second, health professionals seeking things like community medicine and challenging the biomedical model of care are significant in this shift. And third, women's movements with grassroots support and feminist thinking that challenge traditional social values and structures are key players in shifting power structures. These learnings guided my decision to partner with PCOS Challenge as a non-profit community for my thesis.

As I explored these spaces of health and uneven power structures further, a new thesis statement emerged.



**PCOS Challenge**

THE NATIONAL POLYCYSTIC OVARY SYNDROME ASSOCIATION

### THESIS QUESTION

**How might we co-create a dialogue that empowers individuals with PCOS to advocate for their needs in social and civic spaces?**



## PRIMARY RESEARCH

Otto Scharmer, a researcher, defines Generative Listening as “listening to connect with emerging future possibilities in a moment.” It is listening to understand that “I am connected to something bigger than myself”. When one listens to people generatively, one begins seeing their future potential.

In my practice as a social designer, the conditions for change are created with the simple act of listening. So when it came to investigating the PCOS healing space, I knew it had to begin with listening to individuals with PCOS and centering their experience through co-creation methods.

### Co-creators

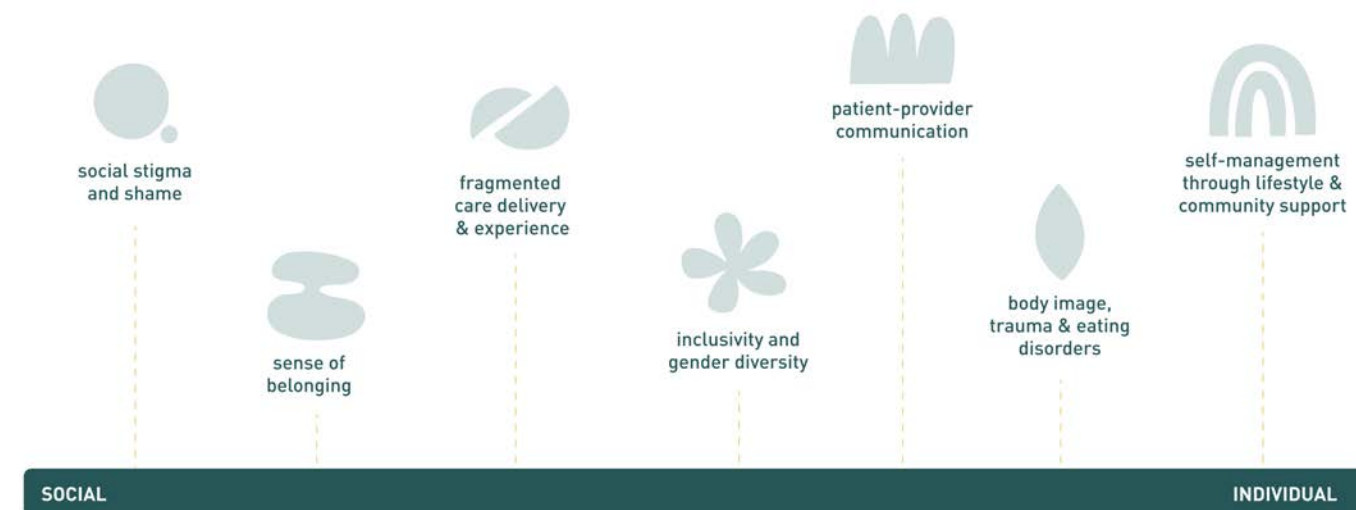
The PCOS community is huge with diverse stakeholders. My audience for this intervention is a small subset of the community. Establishing this helped me create a constraint that allowed me to be creative. The audience includes two major groups:

First, I am working with newly diagnosed individuals who have just discovered that they have PCOS. They are intimidated, scared and unaware of their options as a patient. They have just begun their journey into healing and are looking for community support and resources.

Second, are the existing champions or ‘super advocates’, who have been advocating for PCOS for at least 5-10 years. They have years of experience with the condition. They have also been consistently raising their voice for the cause on multiple platforms and have a significant influence in the community. I discovered an opportunity here.

**How might we connect these super advocates with newly diagnosed individuals to help them get sustained support around PCOS?**

### Emerging themes affecting an individual with PCOS across social and personal relationships



### Interviews

I conducted qualitative interviews with PCOS patients and advocates to identify emerging themes in the process. Some of the highlights are outlined below. These quotes represent a sample from the interviews I conducted. I had informed consent as part of my practice and some participants requested not to be directly quoted. However, the insights from those conversations informed the discoveries that follow this section.

“..I think social support is so key and is definitely a solution for mental health impacts [for PCOS], for stigma and moving forward with empowerment, I really feel like our relationships with other people can make a big difference for us..”

— Dr. Stacey Williams, Ph.D. Social Health Psychologist and PCOS Patient

“..thriving and feeling in a place where you understand why your body is doing what it’s doing, you understand the strengths, you understand the limitations and, and you get to that place of like self-acceptance and self-kindness and self-compassion and so I think that part with PCOS, that’s number one so, focusing on the mental health aspect..”

— Dr. Kendall Soucie, Ph.D. Social Health Psychologist and PCOS Patient





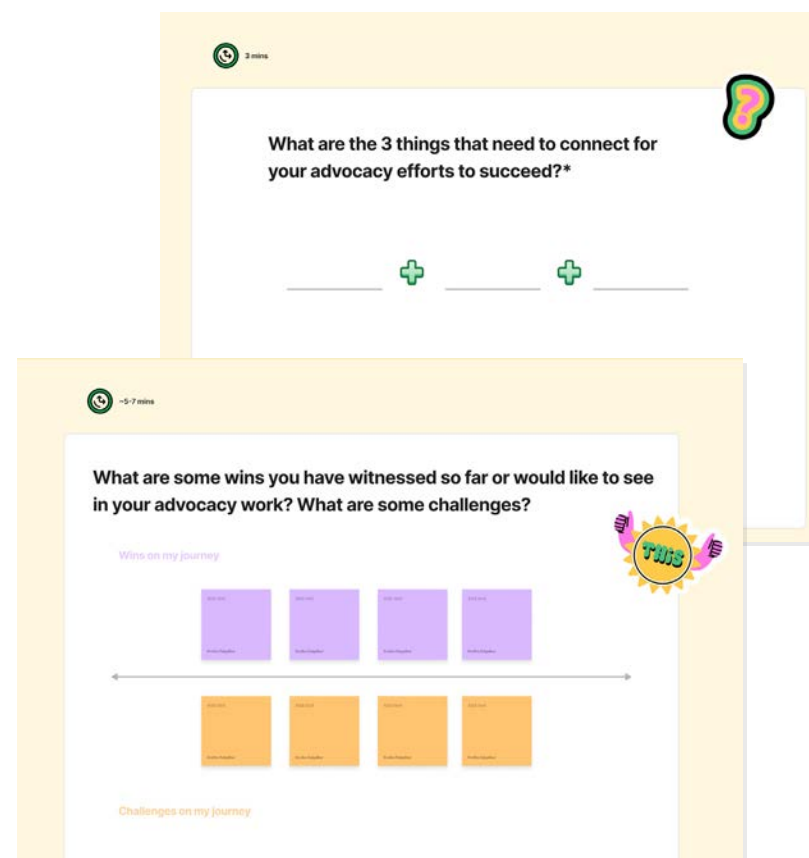
## PRIMARY RESEARCH

### Workshop

Next, I hosted individual virtual workshops using remote collaborative tools such as Figma. Their responses were captured live on a shared screen view. The goal was to map and discover user journeys of PCOS patients and advocates. A reason for keeping this confidential was to allow for privacy of these individuals. Often, health and healing journeys can be extremely intimate for people. I wanted to create a space that allowed for safety and open expression.

The session had 6 parts, which took about 45 minutes:

- Acknowledging the present
- Connecting with personal identity
- Identifying needs as an advocate
- Mapping wins and challenges
- Reflecting on social support
- Describing PCOS abstractly



### Findings

"I think of my younger self and imagine what she would have needed. I want to redefine the PCOS experience." — PCOS patient, Super advocate

"I can't do it on my own. Their (friends and family) advocacy is important too. They need to step up and be an advocate and get involved." — PCOS patient, Super advocate

"PCOS is like a giant red sign. A bright red stop sign, like an alert, an ambulance sound, something that indicates danger." — PCOS patient, Super advocate

"A huge challenge is getting people to understand and empathize." — PCOS patient, Newly diagnosed

"Resilience, inner confidence has to be built". — PCOS patient, Newly diagnosed

"I need small things like reassurance, patience with myself, love and happiness to sustain me in my PCOS journey." — PCOS patient, Newly diagnosed

"[some wins] ..acknowledging that I look good in the mirror!! Celebrate myself in the small wins, everyday gratitude." — PCOS patient, Newly diagnosed

"Words of affirmation and acts of service as a support love language from loved ones is very important." — PCOS patient, Newly diagnosed

"I began advocating with each new emerging PCOS symptom, and while fighting for myself, I became an advocate for others." — PCOS patient, Super advocate

## DISCOVERY

As I dug deeper into research, the following themes revealed as potential problems in the ecosystem:

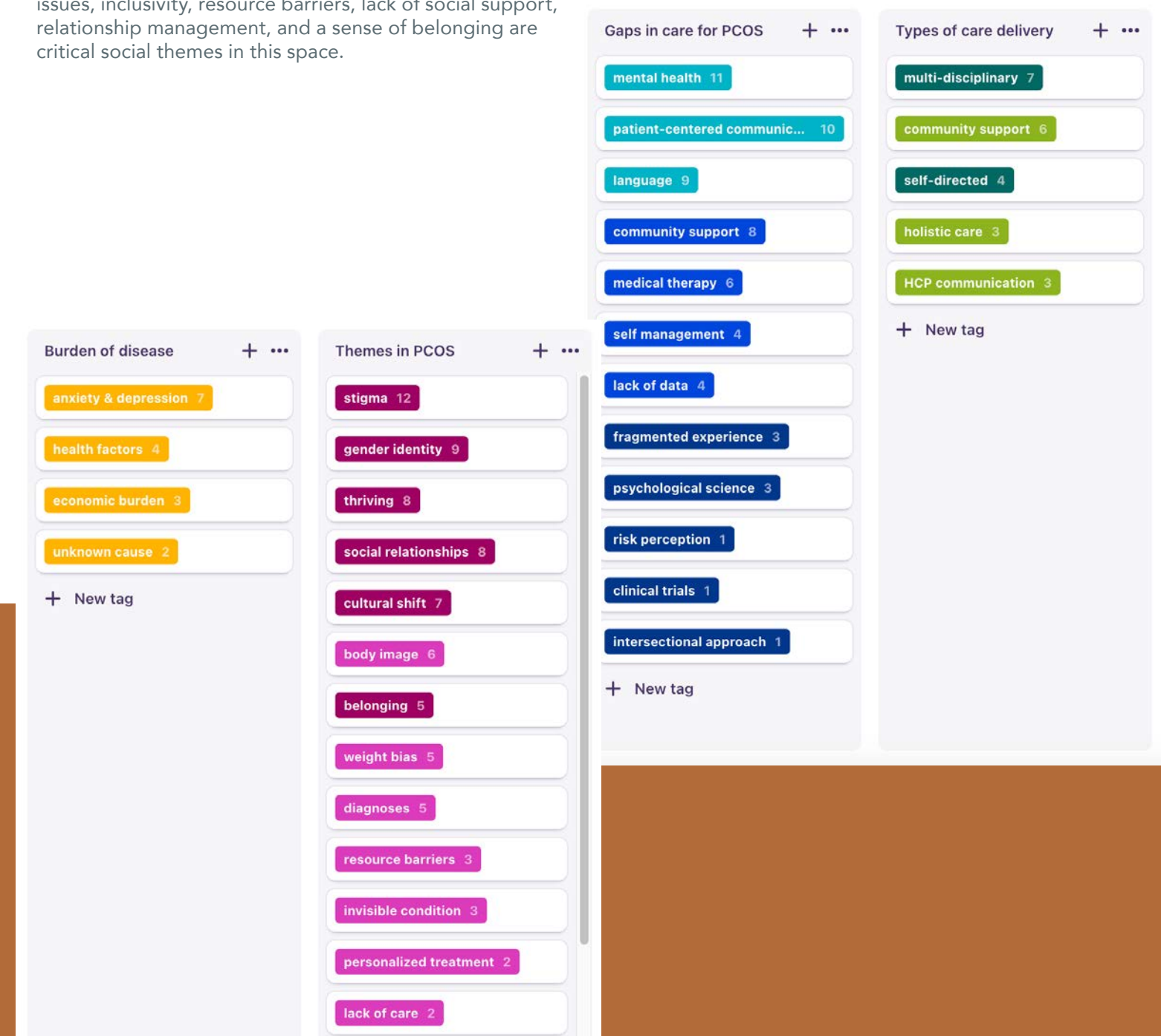
**Gaps in care for PCOS patients:** Due to the lack of funding and clinical research in the PCOS space, there are insufficient treatment options and models of care for patients. Mental health management, community support, self-management and patient-centered communication are areas that need to be addressed and improved.

**Types of care delivery:** A multi-disciplinary approach that takes a holistic angle and psychosocial lens by involving different providers working in silos has the potential to address the various gaps of care mentioned above.

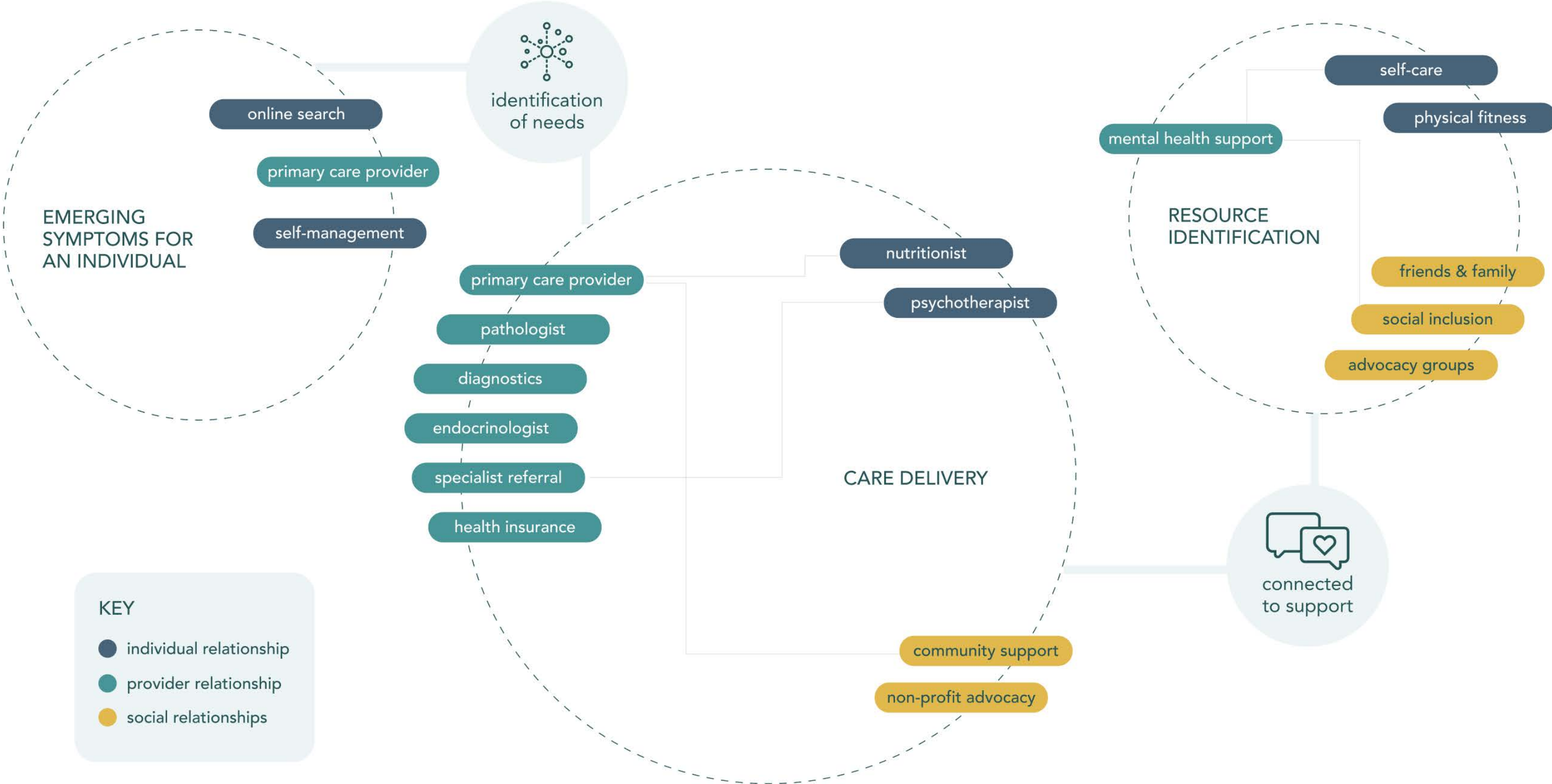
**Social issues in PCOS:** Stigma of the disease, body image issues, inclusivity, resource barriers, lack of social support, relationship management, and a sense of belonging are critical social themes in this space.

**Burden of disease:** The US has a healthcare-related economic burden of PCOS. Because PCOS is linked with other conditions such as diabetes, heart disease, cancer, anxiety, and depression, these issues have a substantial economic burden on patients.

At this point, I noticed patterns of connections and dependencies. The ecosystem of care delivery for PCOS involves support on an individual, provider, and community level. Areas of influence could include an individual's relationship to self, to their healthcare provider, and to their more extensive social support system of friends and family.



ECOSYSTEM MAP



START



CONNECT



SUSTAIN

## INSIGHTS



*Everything about us — our brains, our minds, and our bodies — is geared towards collaboration in social systems. This is our most powerful survival strategy, the key to our species, and it is precisely this that breaks down in most forms of suffering.”*

— Dr. Bessel Van Der Kolk

Along with the research I uncovered, I also reflected on my own lived experience with PCOS. My instinct as a designer and a patient, guided me to explore the value of social relationships.

I examined how my community partner connected support for PCOS individuals and their relationships with care systems to sustain them.

I synthesized the findings from the research and arrived at the following insights and questions:

Stigma and lack of social support lead to isolation, anxiety, and depression in individuals with PCOS. Social stigma, weight bias, interpersonal relationships, body image, and lack of inclusivity and care affect the mental health of individuals with PCOS. I wondered, how might we co-design an intervention that provides social and individual support for individuals with PCOS?

Self-management, awareness, self-care, and learning about your body’s needs can empower individuals with PCOS to advocate for their condition. This area could focus on self-care and management through reflection and advocacy.

Poor patient-provider communication and fragmentation of care delivery lead to patient dissatisfaction with treatment. Diverse providers (nurses, doctors, nutritionists, and therapists) work in silos when treating PCOS. A multi-disciplinary approach can provide patients with holistic care. How might we design a multi-disciplinary model of care that can provide patients with holistic care?

Non-inclusive language in healthcare systems leads to the exclusion of diverse gender identities. How might we introduce a system of inclusive language for individuals with PCOS so that they feel supported and cared for?



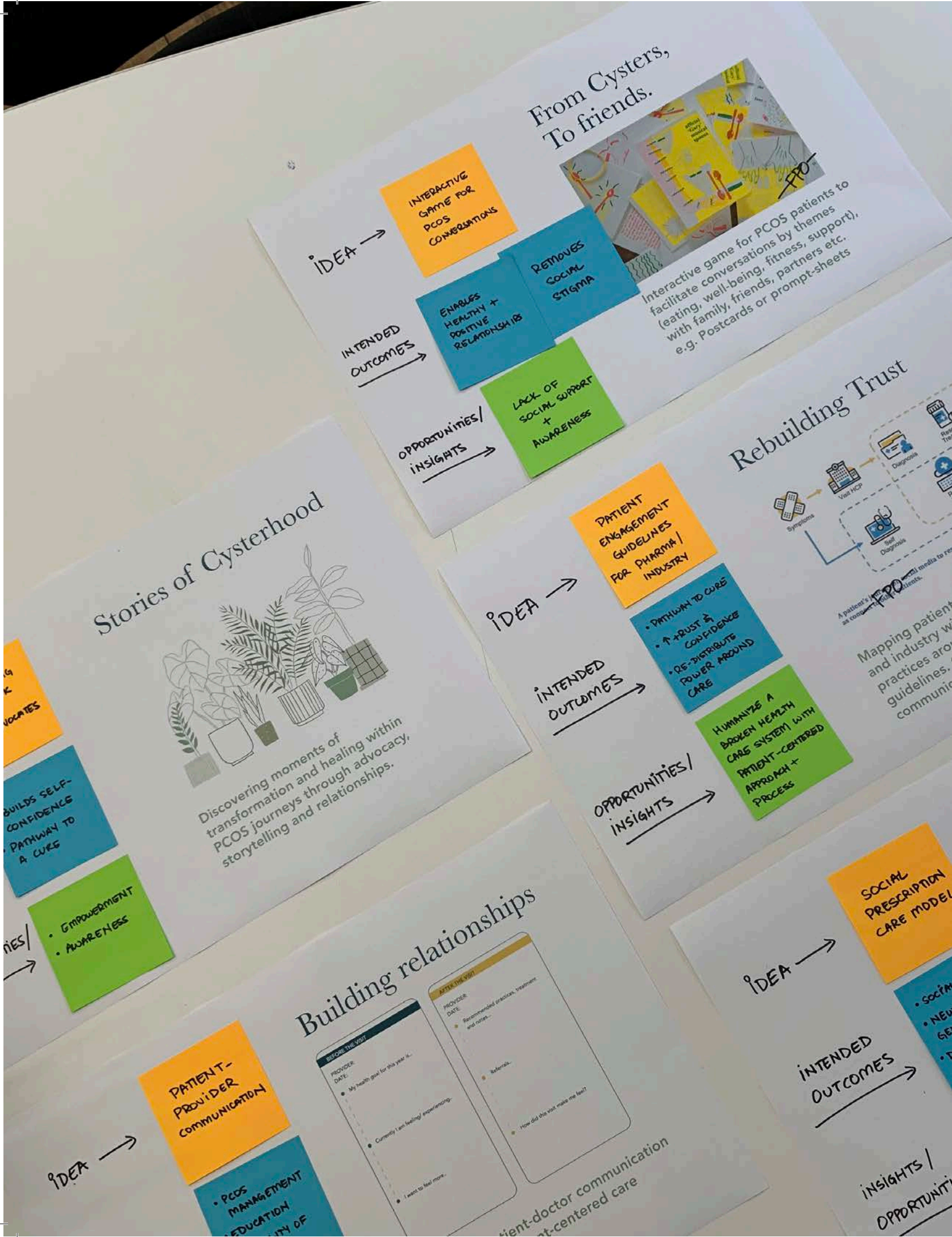
**How might social relationships offer support when healthcare systems fail existing patients?**

As I sat with all the research, I had an intuition as a designer.



Winter

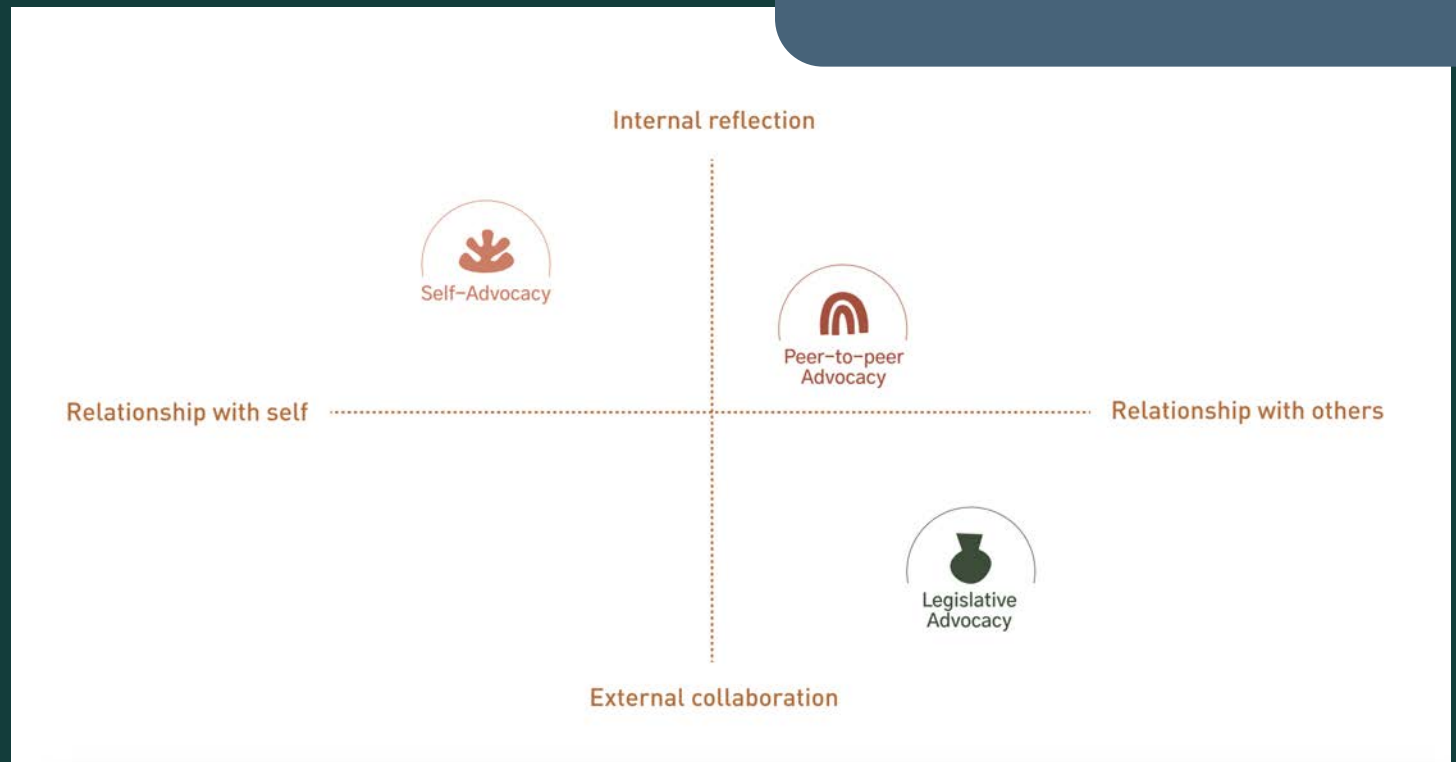




**PROTOTYPES**

The findings from initial research became the anchors for ideation. I brainstormed conceptual ideas that could serve the insights and learnings I had discovered. Out of all the prototypes, I was particularly drawn to the concept of advocacy. I explored what advocacy meant and looked like within health activism.

**Advocacy**  
 n. the act or process of supporting a cause or proposal  
 (Source: Merriam Webster)



When mapped on a scale of relationships, advocacy has several layers. It requires equal parts of internal reflection from an individual and external collaboration with others. I wanted to re-imagine what advocacy looks like at the self, peer, and community levels.



## PROTOTYPES

### Prototype 1: 10 mins of activism each day

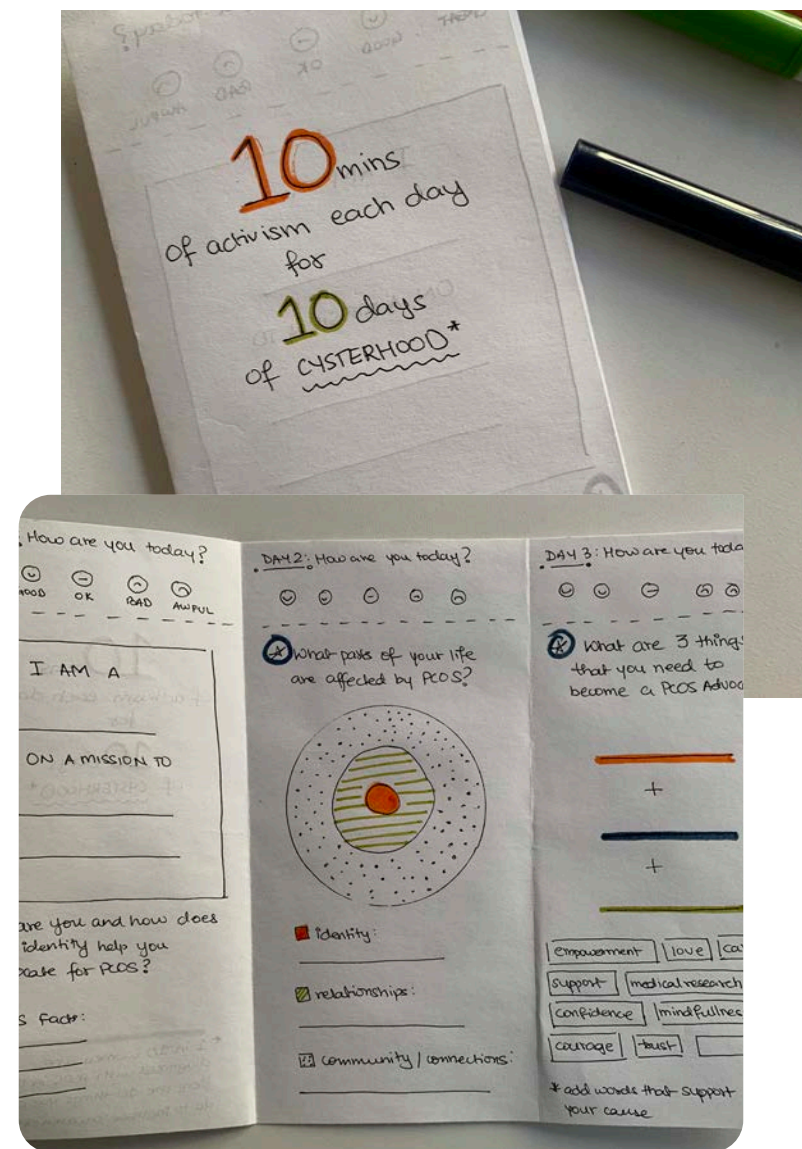
I began by prototyping a paper intervention called "10 mins of activism everyday for 10 days of Cysterhood". This featured small prompts that helped PCOS patients discover their advocacy voice. This low-fidelity sketch had three levels of interaction.

Level 1 explored self-discovery. Level 2 included activities on how to begin the conversation around PCOS with friends and family with the goal of removing social stigma. Level 3 had a call to action around what an individual can do with community support to create awareness.

While I was creating this for PCOS advocacy, I realized that these prompts could work for advocacy in different spaces of health inequities. I identified that:

Individual confidence + social support  
= Community awareness

This prototype helped me think while making. The creative serendipity that emerged from this process guided the next iterations.



### Prototype 2: The Newsletter

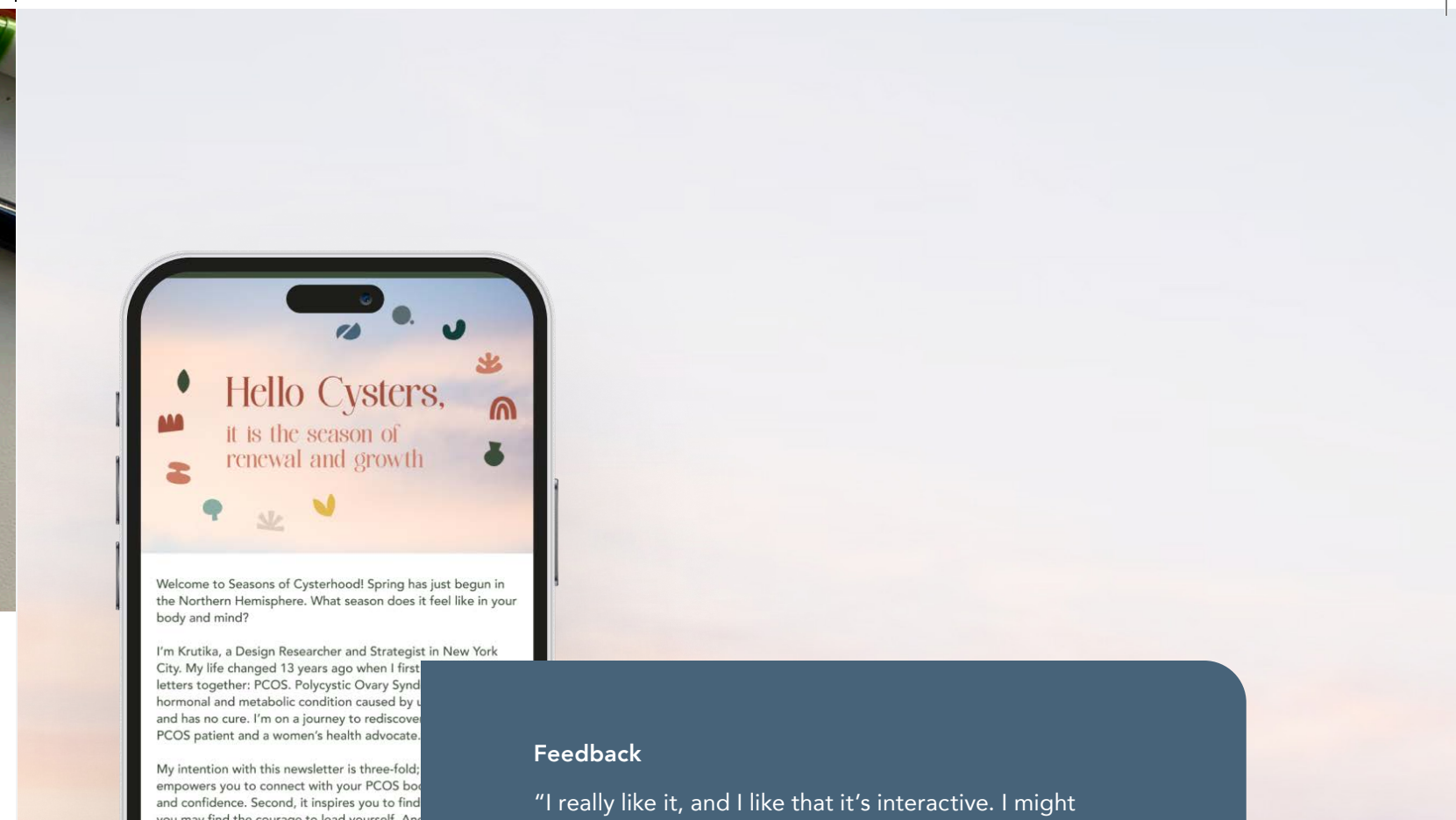
I created and tested a PCOS-focused seasonal newsletter that measured advocacy at different levels. It included facts, education, and empowering prompts that helped individuals connect with their identity. It also encouraged a social element of PCOS care packages that friends and family could send to individuals with PCOS. And finally, it encouraged legislative advocacy through local letter-writing.

The newsletter aimed to end social isolation and increase education, accessibility, and awareness around PCOS. I tested this prototype successfully with patients and advocates.

Community feedback opened up a new dialogue and provided new ideas. Individuals were interested in seeing more content around PCOS

The goal was to be in a continuous conversation with members of the community. This prototype really resonated with the community and they desired to see more.

A high point in this journey was interacting with PCOS super advocates who had been doing significant work in this community for a while. They spoke of their advocacy journey and community engagement that led them to raise their voices for this cause. My conversations with them fueled me with inspiration. I was motivated to create a space that would amplify these voices.



### Feedback

"I really like it, and I like that it's interactive. I might connect with PCOS Challenge to see if you can make this a regular or quarterly thing, and embed links, educational info, etc., for participants to click on to learn more. Maybe adding in some advice from experts in the PCOS area could be neat, too? This is such a beautiful idea. I love your design work-the colors, and the connections are just perfect!!! The bingo and affirmations are perfect!"  
— Dr. Kendall Soucie, Social Health Psychologist, PCOS Patient

"I love it! The idea of a PCOS Newsletter warms my heart. I love the colors. They are soft and peaceful. I think what's working well are all of the positive portions, such as the bingo self-care and the mirror words. Maybe just make sure you don't overshare the timing of when people get it. Let them have a month to digest it. Also, make sure that it's not useless information and you're actually adding to someone's PCOS life. Maybe feature a medical expert or patient to improve it?"  
— Renetta DuBose, Broadcast Journalist, PCOS Patient

"I love the warm visuals, and the flow of information works so well. Maybe consider adding more resources and have them by different categories. Example, nutrition, exercise etc. Or maybe an expert inclusion of 'this month we spoke to..' I wish there was a way to get together with the community and do activities together."  
— Dr. Kim Hopkins, Researcher, PCOS Patient



## PROTOTYPES

### Prototype 3: Care Packages

Another concept that excited me as an intervention was the idea of care packages. I wondered how acts of service could be a manner in which PCOS individuals could feel supported and loved. The idea was to create an e-commerce platform that would host PCOS-focused products that helped patients manage the condition. Examples of these products were spearmint tea, vitamins and supplements, yoga mats, habit trackers, and so on. Initially, I imagined a collaboration with PCOS influencers, and small business owners who could benefit from this idea.

However, when I tested this idea with my community partner I had to acknowledge some of my privileges and biases. The reality was that a significant population of individuals living with PCOS do not have access to basic healthcare. Asking marginalized communities to engage with a service that required a financial commitment did not feel aligned with the values of equity that I strived for. This bias check led me to explore more tools for PCOS advocacy with accessibility in mind.



## THE INTERVENTION

“

*Whether we learn how to love ourselves and others will depend on the presence of a loving environment. Self-love cannot flourish in isolation.” — Bell Hooks*

Seasons of Cysterhood is a conversation that empowers individuals living with Polycystic Ovary Syndrome (PCOS) to discover moments of transformation and healing through advocacy, storytelling, and relationships. This conversation is about finding the courage to lead oneself with curiosity and compassion.

The concept is a metaphor for how PCOS bodies go through different cycles and seasons. And that every season demands a new way to adapt. It is also a nod to the fact that individuals with PCOS have to tune inwards to be aware of the needs of their bodies.

**From the foods we eat to the relationships we hold close. How might we thrive in each season?**

My intention with this dialogue is three-fold; First, I hope it empowers individuals to connect with their PCOS body with curiosity and confidence. Second, it inspires them to find their voice so they may find the courage to lead themselves. And finally, I wish to collectively imagine what healing through advocacy looks like for individuals with PCOS. This work is a call for co-creation and community action.

The intervention is a collection of small practices that individuals can use to find their advocacy voice. It has three core components; self-advocacy tools, peer-to-peer advocacy, and Community advocacy. I have made resources and toolkits available on the website which can be accessed by any individual seeking support around PCOS.

**Self-advocacy:** This component encourages self-reflection. Advocacy begins by identifying the needs of our own bodies and minds. It begins by finding safety and confidence within oneself. It has an interactive health card bingo that an individual can utilize to form nourishing habits. This also features an ever-evolving resource guide that focuses on PCOS support categorized by different symptoms and needs.



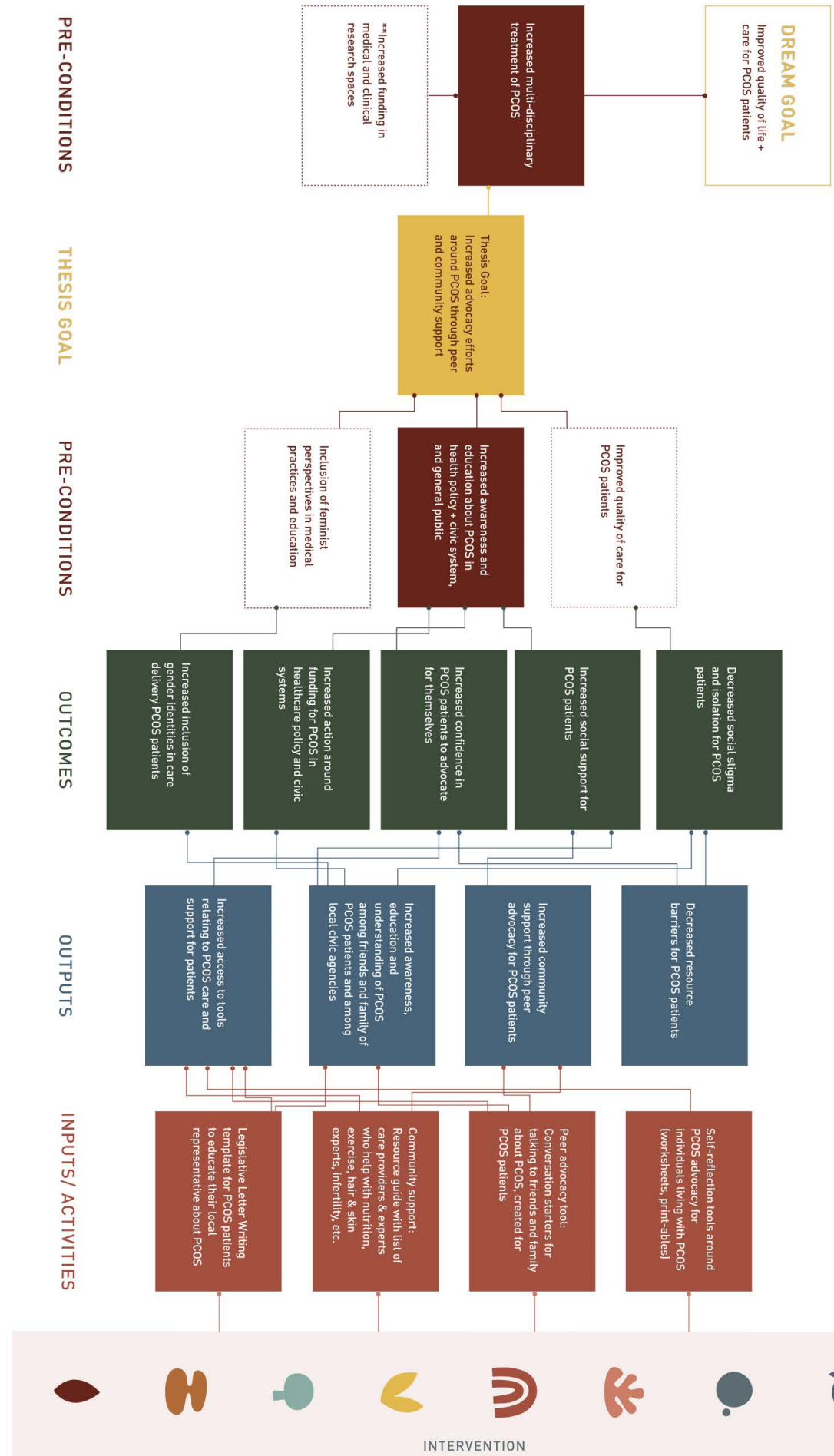
**Peer-to-peer advocacy:** This section promotes dialogue with friends and family. PCOS is best managed through support from your loved ones along with lifestyle changes. Currently, in development, I want to design a care ritual that allows individuals to lead conversations about PCOS with their close support systems. This involves a small game that explores acts of service as a conversation starter for PCOS patients and their social circles.



**Community advocacy:** This component encourages collaboration with civic systems through legislative letter-writing. It includes educational content around legislative advocacy, a how-to guide with postcards, and explains the impact of community action.







## CHALLENGES

Every season has its obstacles, which can also become moments of growth and reflection. There are things one can control and others that cannot be tamed. A significant challenge was the resource of time when collaborating with others. It was extremely hard to schedule time with others, plan my agendas, synthesize the learnings and continue on to the next step. The learning here was improvisation.

I will forever be grateful to Karen Proctor’s Leadership class where we learned how to navigate environments of uncertainty through the art of improvisation. There were times when all curated plans had to be abandoned and improvised in the moment. I believe these constraints really taught me how to adapt. This also taught me more about the nature of social design. The conditions of change are unpredictable.

Another learning was the idea of ‘moving at the speed of trust’. A key ingredient in this journey has been building meaningful relationships. Trust requires patience and collaboration. When I first met my community, I led with curiosity.

I was curious about what had already been going on. What initiatives and activities were already in place? I observed the existing practices to assess how I could use my skills to amplify the voices of this community. Parts of this interaction also required others to trust me with their story. This process took almost six to nine months before I approached them with my thesis requests.

## MONITORING & EVALUATION PLAN

The social impact of this intervention can be imagined via a Theory of Change. The intervention has a primary goal of increasing advocacy efforts around PCOS through peer and community support.

A critical qualitative indicator for this intervention would be to measure how this tool helped the PCOS community to lead conversations around PCOS with their friends, family and local legislators. Additionally, a key quantitative indicator would be to measure how many people engaged with this tool.

### Monitoring questions

Key question: How might we increase the engagement of individuals with legislative writing and advocacy tools for PCOS?

- How many people downloaded the tools?
- Which tools were most successful? (i.e. Which tools were downloaded the most? Self-reflection, peer support, or legislative letter writing templates)
- How many letters were written in a district?
- How many people are signing up for Advocacy Day 2024 with the partner organization?

### Evaluation questions

Key question: How is this intervention helping communities increase awareness and education around PCOS?

- How do people become PCOS advocates after this intervention?
- How do PCOS patients feel about PCOS advocacy tools?
- How are local legislators responding to constituents’ letters about PCOS
- What are some health policies that have changed or evolved since this intervention?
- How does legislative letter writing impact health policy?

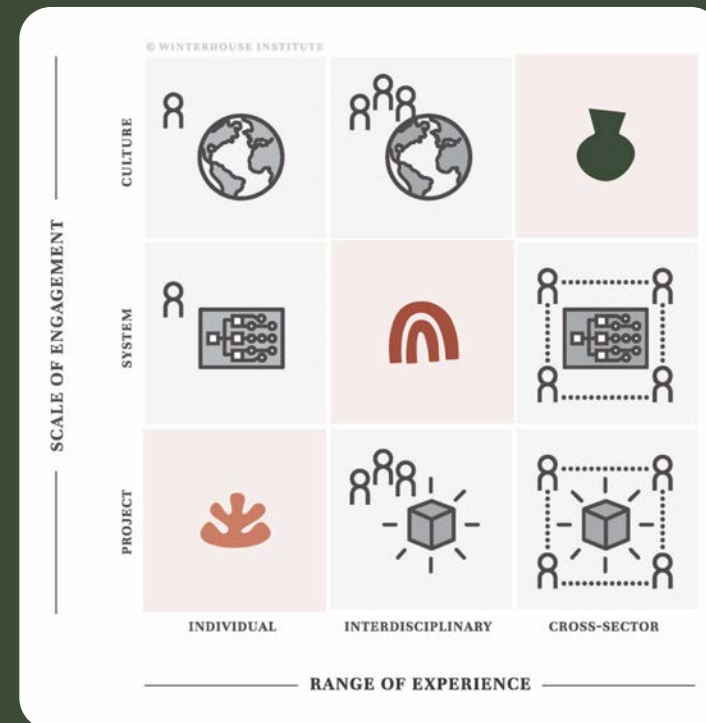
## SOCIAL IMPACT & SCALE

I find myself coming back to the Winterhouse Institute's Social Design Pathways, as a means to measure the scale of impact and engagement I want to imagine with my thesis work. It has helped me identify the resources I need to reach the number of people and realize the pathways of change.

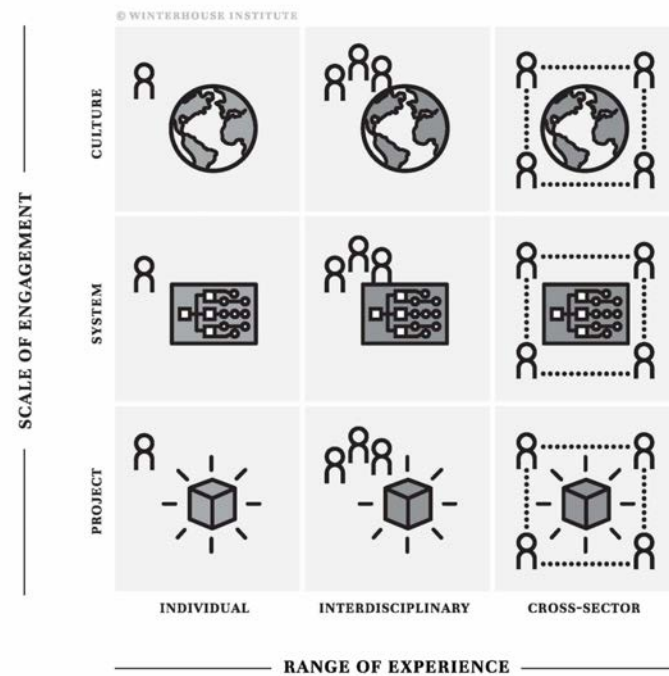
At the base intersection of the Project to the Individual level, this work hopes to raise awareness and education about the issue.

At the intersection of Systems Engagement and Interdisciplinary Experience, this work aims to build more PCOS advocates who can champion a patient-driven movement.

And finally, at the intersection of Cultural Engagement and Cross-sector experience, this work has the potential to grow and gain the support of all stakeholders involved in the care delivery system (i.e. government organizations, healthcare institutions, patients, and the associated community).



Spring



Social Design Pathways was initiated in 2013 by the Winterhouse Institute and co-developed collectively with hundreds of international designers and educators. Pathways provides a clear and powerful framework for social impact design educators, students and practitioners to map out the resources and range of expertise required when addressing complex social problems at various levels and scales.

Social impact design practice is contextual and differs based upon several variables, including the goals, level of intervention, scale, etc. Pathways helps to illustrate this through its two axes:

Range of Expertise (x-axis): refers to the collections of expertise brought to bear on a problem — an individual designer, an interdisciplinary team, or a cross-sectoral collective.

Scale of Engagement (y-axis): describes the level and scale at which the design intervention aims to make change happen — at a project, system and/or cultural level.

Dear reader, if you have made it this far, thank you. This journey has been about learning the value of discovery. Discovery of conversations, of relationships, dialogues, and interactions, and of trust too. These learnings have left me feeling nourished, hopeful, and connected. I wish to continue nurturing these practices and relationships with care and thoughtfulness.

## LEADING WITH CURIOSITY

Through this work, I have found my position, as an advocate, as a patient, and a supporter. I know the path ahead will challenge me and change me in ways I could never imagine. As Octavia E. Butler once wrote, "All that you touch you change. All that you change changes you. The only lasting truth is Change." I aspire to accept this with my full heart and energy.

### Celebrating the wins

Some of the wins on this journey were not directly related to my thesis but they are part of my bigger journey as a social designer. When I joined PCOS Challenge as a volunteer, I was thrilled to be invited to be a part of the Patient Experience Initiative (PEI) Committee. This included patients and researchers with lived experience of the condition. I learned so much from this small committee of 5 individuals. We met almost every Monday afternoon to dream up PCOS initiatives that could advance the cause. These conversations were my favorite part of a Monday.

In September 2022, we led a PCOS panel conversation on the importance of storytelling in raising awareness in research and care. This highlighted the patient experience to other stakeholders in the community. We were joined by so many PCOS patients who interacted with us. Their questions, words of affirmation and encouragement really helped remove the stigma and sense of isolation that one experiences in this condition. This experience was the first time I advocated for a cause I truly believed in: connecting community support for holistic care around PCOS.

I have also learned that social change happens at a deeper level when one starts listening to the pattern that creates life. I wish to carry this idea of listening to understand as I begin my journey into becoming a social designer. I hope to build my practice through the simple act of listening to the moment. As Marc Rettig once said in his mixtape, 'listening is applied love'.

Another thoughtful event was PCOS Advocacy Day in March 2023. Here, I spoke with members of the Congress about the importance of funding for women's health conditions such as PCOS. I also heard the painful stories of hundreds of women who have suffered with this condition. This interaction made me feel heard, and I learned that in being vulnerable, one can truly connect with others. I learned how healthcare and civic systems can come together to create change. This informed my thesis intervention too.

All these small moments of transformation have led me to becoming a part of the Patient Advisory Board at PCOS Challenge. My work as a women's health advocate has only just begun. In the coming months, I plan to continue my work with PCOS Challenge on a number of their new initiatives that involve engagement with different systems and stakeholders. I wish to inspire, facilitate and lead compelling narratives.

## THE PEOPLE AND SUPPORT

This journey was made special by the presence and support of some incredible people.

### PCOS Challenge and the community

Huge thanks to William Patterson & Sasha Ottey for creating an empowering platform that has transformed the lives of individuals with PCOS. To the Patient Experience Initiative Committee: Dr. Kendall Soucie, Holly van Hare, Dr. Stacey Williams. I have learned so much from you all. Our Monday afternoon conversations were a delight.

### Mari Nakano

Thank you for listening to each of my intellectual dilemmas, pivots and for always encouraging me to keep going. Thank you for being a wonderful advisor and mentor.

### DSI Faculty

My time at this program was enriched by faculties who have unveiled the world of social innovation for me: Marc Rettig, Hanna du Plessis, Karen Proctor, Despina Papadopoulus, Stephanie Yim, Jaime Cloud, Alison Cornyn, Sahar Ghaheri, Kara Meyer, Taylor Ourada, Cathy Richards, Kate Reed Petty. Thank you for guiding me through this transformative experience.

### Miya Osaki

Thank you for helping me navigate the world of design, for holding space and for always challenging me to grow.

### The Merry Coven

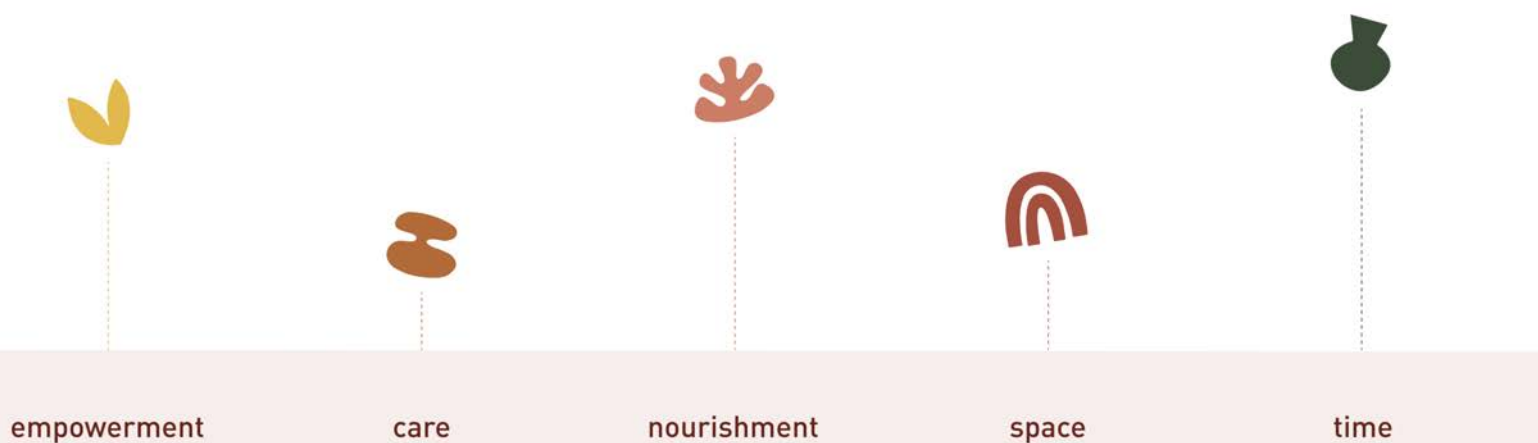
To my home away from home: Riddhi, Pallavi, Sophia & Brittany. Thank you for supportive cups of coffee, delicious meals and endless laughter. You inspire me.

### Friends

This project is a love letter to my personal board of directors and sisters: Meghana, Parika, Simran and Ina. Thank you for consistently believing in me and being my source of strength.

### Family

I am grateful to my parents, for their unconditional love and support even when they did not know what design for social innovation meant. This project culminated at a significant point in my life. This milestone is dedicated to my late uncle, who inspired me to work for the greater good and taught me the value of education. It has been a privilege to have his blessings.





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This work is a part of the graduate thesis project at the School of Visual Arts' Design for Social Innovation Masters Program. It has been created in collaboration with individuals living with PCOS. For more information, contact the designer below.

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