

BEING AN ALLY: COMMUNICATION DESIGN'S ROLE IN IMPROVING
THE HEALTH INFORMATION SEEKING EXPERIENCE IN PEOPLE
WITH POLYCYSTIC OVARIAN SYNDROME

by

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DEDICATION

This thesis is dedicated to everyone affected by Polycystic Ovarian Syndrome and other chronic health conditions.

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LIST OF ABBREVIATIONS

Abbreviation	Description
PCOS	polycystic ovarian syndrome
LGTBQ	lesbian, gay, transgender, bisexual, questioning
COVID-19	coronavirus disease of 2019
UI/UX	user-interface/user-experience

ABSTRACT

Eighteen percent of reproductive-aged people assigned female at birth have PCOS (Polycystic Ovarian Syndrome). It is very likely that most people have or will have a relationship with someone that has PCOS. It is a complicated, difficult to treat, underfunded, chronic health condition. People with PCOS struggle to get diagnosed, have a good relationship with healthcare providers and find quality information. Helping people affected by PCOS access accurate information regarding their health can encourage hope and healing.

This research describes the creation of a prototype website aimed to improve the health information seeking experience of someone with PCOS. The prototype is an interactive digital tool and educational project named Allyist. Allyist's features and format are informed by human-centered design methods. The primary goals of the website are to help people test suspicions of having PCOS, thoroughly explain PCOS while also giving more specific information, improve the search for PCOS specialists, and provide personalized information that encourages self-advocacy.

User-testing with a small sample of people affected by PCOS revealed that participants had a favorable experience using Allyist. Results also show that educational visual aids that are simple and interactive are valuable to participants over personalized features. This suggests that most people are looking for straightforward health information online. Allyist can serve as a model for similar websites focused on other chronic health conditions.

I. INTRODUCTION

Defining PCOS + Who is Affected

Irregular menstrual cycles, weight gain, acne, darkening skin, abnormal hair growth, thinning hair, mood changes, fatigue, insomnia, gender dysphoria, disordered eating, and infertility are difficulties many with Polycystic Ovarian Syndrome (PCOS) encounter. Having PCOS increases the risk of developing heart disease, diabetes, certain types of cancer, and mental health disorders such as depression and anxiety. Individual experiences with PCOS vary tremendously—some can exhibit few if any symptoms and others suffer from most, if not all symptoms. Many of these symptoms alone can be overwhelming but suffering from multiple at the same time can be debilitating.

A study published in the *Journal of Clinical Medicine* has recognized PCOS as a major public health concern for reproductive-aged women (Hiam et al. 1). This syndrome is the most common endocrine disorder among people assigned female at birth, of reproductive age. According to the Office of Women's Health, between five and ten percent of women have PCOS. However, some research suggests it could be eighteen percent or more. This is a significant percentage of the population. Research suggests there is a similar prevalence of PCOS across the United States, the United Kingdom, Spain, Greece, Australia, Asia, and Mexico (Wolf et al. 9). Although the occurrence of PCOS is similar across racial and ethnic groups, biases and prejudices can influence the experiences of people who have PCOS and cause different outcomes for minority groups in the United States specifically.

PCOS is often described as “the thief of womanhood” because it affects the body in ways opposite to what society deems feminine. It also is commonly understood that

PCOS affects only women; however, it occurs in all people assigned female at birth and can include women, transgender men, and nonbinary individuals. While the social assumptions of gender can cause people with PCOS to feel gender dysphoria, PCOS affects everyone whether or not they identify as a woman. For example, facial hair growth may be favorable to transgender men, but they are still at risk for serious health complications such as cancer and diabetes. It is essential to include everyone affected by PCOS in research to avoid further marginalizing the PCOS community.

As discussed here, PCOS has a significant negative impact on the lives of those who suffer from it. It is a commonly misunderstood condition and affects a large part of the population. For these reasons, this thesis will use PCOS as a starting point for design research to assess if communication design can positively impact the healthcare seeking process.

Communication Design's Relationship with Healthcare

In the healthcare field and beyond, communication design can inform, educate, persuade, and provoke the public by using metaphor, abstraction, humor, design thinking, and collaboration. Communication design can visualize complex concepts and information on small and broad scales to encourage behaviors that lead to better health on the individual and global levels (Schrauwen et al. 11). This can include numeracy, terminology, data visualization, storytelling, illustration, and more. These visual design strategies are used separately and in conjunction to communicate health-related information to patients and the public.

Thoughtfully researched design is critical to improving and saving lives where communication matters. Communication design touches healthcare at many points, such

as prescription labels, medicine packaging, hospital wayfinding, advertising, educational apps, pamphlets and flyers, clinic logos, at-home testing kit manuals, and much more. In the book *Can Graphic Design Save Your Life*, it is argued that our daily life is a “minefield of potential catastrophes,” and our interactions with design occur on a subconscious level, but “the impact on our lives is massive” (Schrauwen et al. 39). Each of these design opportunities is vital in improving experiences and making healthcare more accessible and understandable.

Most people have experienced healthcare-related design through public health campaigns that synthesize complex information and make “life-saving messages accessible to all” (Roberts). Public health campaigns are not in service of consumerism and therefore are “tools of empowerment and a call to action” (Schrauwen et al. 210). This is seen most recently in COVID-19 public health messaging campaigns. These campaigns provide resources, tailored information for at-risk groups, and toolkits to help the public make informed decisions about their health” (Miller). “Stop the Spread” is a global campaign that aims to raise awareness about COVID-19 (“Countering Misinformation about COVID-19”). This is an international campaign with most countries’ health departments participating. Resources for these campaigns are online for anyone to download and use to distribute. “Stop the Spread,” and similar campaigns provide education to the public while also empowering people to share their knowledge and increase health and care in their communities. It has also been determined that COVID-19 campaigns that provide non-binding government advice like “Stop the Spread” are only marginally less effective than distancing measures enforced by law (Haug).

Other areas where design has made an impact are more specific to healthcare settings. Wayfinding and educational signage in hospitals can support people in distress. PearsonLloyd, a U.K.-based design firm, created emergency room signage and a handheld map to improve the experience of people in waiting rooms. Before, many patients felt frustrated and acted out in aggression to the hospital staff. New signage clearly communicated the process and journey of the patient in the emergency department. The improved communication system helped seventy-five percent of patients feel less frustration while waiting, aggressive behavior reduced fifty percent, and eighty-eight percent of patients gained a clearer understanding of the Emergency Department process (Ku and Lupton, 176).

Thesis Organization

After Chapter 1 introduces the thesis, Chapter 2 will provide context by elucidating on experiences of people who suffer from PCOS. This will describe the diagnosis process, relationship to medical professionals, access to information, and the health information seeking approach. Chapter 3 will go on to report on secondary research. This research consists of design for social change, communication design and public pedagogy, design for healthcare, health information seeking behavior, and case studies. Chapter 4 summarizes primary research, including survey results, and explains how that research led to the design solution and prototype. Chapter 5 showcases the prototype and discusses design choices and user testing. Finally, Chapter 6 reviews and examines research objectives as well as discusses future investigations.

II. STATEMENT OF THE PROBLEM AND LITERATURE REVIEW

The lived experiences of people that suffer from PCOS can be harrowing. Support groups, Facebook pages, personal social media accounts, and online blogs are brimming with people expressing worry, sharing horrifying anecdotes, pleading for answers, seeking complex medical advice, and begging for hope. After being immersed in this community, it is clear that people living with PCOS repeatedly endure negative experiences. PCOS's impact on individuals can be attributed to delayed and frustrating diagnosis experiences, unsatisfactory relationships with healthcare professionals, and a burdensome health information seeking process—all of which are detailed in this chapter.

The Diagnosis Process

As with most health problems, an early diagnosis can facilitate better health outcomes. The PCOS Awareness Association says, “An early diagnosis can help women with PCOS restore fertility, normalize their menstrual cycles, and protect against polycystic ovary syndrome-related risks for diabetes, heart disease, and endometrial cancer” (“PCOS Diagnosis”). Many people expressed that their early symptoms were dismissed, and they didn't get a diagnosis until later in life. In one study, one participant stated the following: “My pediatrician said that these symptoms were normal for my age, and they would work themselves out” (Soucie et al. 527). A qualitative study titled “*The diagnosis and lived experience of polycystic ovary syndrome*” published in the *Journal of Advanced Nursing* described the diagnosis and lived experience of PCOS. In this study, thirty-two premenopausal women with PCOS were interviewed. For example, “I've known I've had it for a long time, and it's actually on a third attempt to go to a doctor

who took me seriously. . . so I was finally 27–28 when I got diagnosed,” said one study participant. Unfortunately, experiences like this are not uncommon. Another participant from the same study said, “I’m 33 and found out about having PCOS two and a half years ago. . . around the age of 15 to 16 I stopped having periods for about two years. . . I had a few tests at the time, and my ovaries were checked, but nothing was, you know, I wasn’t given any diagnosis” (Tomlinson et al. 2321).

The diagnosis process for PCOS is typically long, stressful, and emotional and can be a strain financially, physically, and mentally. According to a *Journal of Clinical Endocrinology & Metabolism* survey, almost half of the respondents visited three or more doctors before getting answers, and a third of respondents said it took more than two years to get a proper diagnosis (Gibson-Helm et al. 547). There is a lack of research about how much a PCOS diagnosis costs; however, a study from 2016 found the total cost of routine testing for suspected PCOS was \$745 (Dizon et al. 12). If a patient undergoes these tests multiple times, the financial burden can become a deterrent to getting a diagnosis. Furthermore, if a patient does not have health insurance or access to healthcare facilities, this burden is even greater. Another study designed to describe patient perception and awareness of PCOS found that the “most common emotions associated with the diagnosis included “frustration” (67%), “anxiety” (16%), “sadness” (10%), and “indifference” (2%)” (Sills et al.). It is possible that many people do not have the resources, mentally or financially, to endure the diagnosis process, and it can deter them from getting the care they need.

Relationship with Healthcare Professionals

Patients that do persist and get a diagnosis often have a substandard relationship with healthcare professionals. This unsatisfactory relationship can be credited to a significant lack of research on PCOS, poor communication between patient and provider, and deep-rooted stigmas and marginalization in the medical community.

Until recently, limited research has been conducted on “women’s bodies and health problems that afflict them” (Dusenbery 11). Caroline Criado Perez, an award-winning writer, speaker, and campaigner specializing in behavioral and feminist economics, states that “medicine has functioned on the assumption that male bodies can represent humanity as a whole,” and as a result, “we have a huge historical data gap when it comes to female bodies” (Perez). Historically, PCOS was thought only to affect the reproductive system, but more recent research has shown it to be an endocrine disorder. Because of this history, it falls victim to a gender bias in research created centuries ago. Evidence of this fact is that PCOS is underfunded by the National Institutes of Health (NIH) in relation to other disorders with comparable prevalence, morbidity, and negative impact on quality of life.” PCOS research is also solely funded by the National Institutes of Child Health and Development, which is focused predominantly on “reproductive outcomes” (Brakta et al. 4422). Having limited research can lead to an exclusive and unknowledgeable community.

A study published in Reproductive Endocrinology found that “a large percentage of respondents were unaware of the currently recommended criteria for diagnosis of PCOS,” and fewer than eighty-five percent of obstetrician-gynecologists were aware of depression and anxiety, and reduced quality of life scores associated with PCOS. This

study also suggests that “gaps in knowledge regarding PCOS-associated comorbidities” may lead to “inadequate information being provided to patients” (Dokras et al. 1383). This is backed up by a study published in 2017 that found that eighty-four percent of participants were dissatisfied with the information given about PCOS at the time of diagnosis (Gibson-Helm et al. 547). A study exploring the experiences of young women diagnosed with PCOS found that “participants stated the information they received. . . left them still searching for answers. . .they did not have a full grasp of PCOS and what they needed to do to ‘get control’” (Weiss and Bulmer 714). In a qualitative study about people’s experiences with PCOS, one participant said:

They told me it was a genetic condition, and there was nothing I could do about it . . .I thought that once you get a diagnosis, there’d actually be something done. Some sort of a management plan, you know, how do we go forward from here. . .but none of that has happened (Copp et al. 5).

Not giving adequate information to patients at the time of diagnosis leaves them perceiving the healthcare professional as thoughtless and unknowledgeable.

Research shows that people with PCOS have significant doubts in healthcare providers. A qualitative study titled “*The challenges with managing polycystic ovary syndrome: A qualitative study of women’s and clinicians’ experiences*” from *Patient Education and Counseling* described the challenges people experience managing PCOS. One participant said, “Usually when I tell new doctors that I have the condition, they all look at me and say, you don’t look like you have PCOS, and that’s about as far as the conversation goes. None of them have ever offered to do anything about it.” Another participant said, “It’s actually now at the stage where I don’t even see the gynecologist

anymore. I don't find any benefit out of seeing them." (Copp et al. 4). A recent study surveying people with PCOS found that most respondents were "dissatisfied with explanations for the cause of their PCOS. . . treatment of their symptoms. . . and overall care of their symptoms" (Hoyos et al.). Another study on the diagnosis and lived experience of PCOS suggests that relationships with healthcare providers are "frequently associated with considerable uncertainty. . . inadequate advice and lack of accurate information." This same study also revealed healthcare professionals displayed "little regard to the emotional and social consequences of PCOS" (Tomlinson et al. 2325). Finally, a study published in 2018 showed that people with PCOS reported greater distrust in healthcare professionals and had more arguments with them than people without PCOS (Lin et al. 1001). Patients perceive healthcare professionals to be unknowledgeable and/or inconsiderate, which contributes to the unsatisfactory relationship.

Healthcare professionals may also have implicit biases and prejudices that can contribute to an exclusive environment for their patients. Ninive Sanchez, Ph.D., a professor of social work at the University of Missouri, argues that the "lack of culturally and gender-sensitive standards of care" disfranchises those affected with PCOS (40). Gender, race, ethnicity, and socioeconomic class can affect a patient's relationship with healthcare providers. Contributing factors to racial and ethnic disparities in healthcare are attributed to "bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers" (Smedley et al.). Not enough is being done to overcome the biases that affect minority populations. Although research on PCOS is lacking in general,

published reports on PCOS show an under-representation of black women (Hussain et al. 2). The lack of representation in research leads to limited individualized care for patients.

Minority populations are not just underrepresented in relation to race and ethnicity, the (LGTBQ) community is also underrepresented in literature (Sanchez 42). This can mean that healthcare professionals do not understand patient needs and desires for treatment. For example, heteronormativity in healthcare can disappoint individuals with PCOS who are not seeking care for reproductive concerns. Many healthcare providers see achieving pregnancy as the goal of treatment when infertility is only one aspect of having PCOS. A study comparing lived experiences of PCOS found that several participants voiced frustration that their doctors did not recognize PCOS as an issue to be treated unless they were trying to conceive (Vleming 516). As discussed earlier, PCOS does not just affect women, although “sources on PCOS almost always address women.” Transgender people seeking healthcare for PCOS also face discrimination not just by single healthcare providers but through the healthcare system as a whole. A study published in the *Journal of Midwifery and Women’s Health* shows that transmen “had a general dislike of receiving gynecologic care” but had an “interest in maintaining their physical health despite the emotional challenges” (Dutton et al.). Creating an environment where marginalized groups of people feel discomfort and judgment will deter them from seeking care.

Seeking Health Information Independently

Both the diagnosis process and the poor relationship with healthcare professionals lead most patients to bypass the healthcare system and start seeking healthcare independently. If the information and care that the patients are getting from primary care

physicians are lacking, the patient will seek alternatives. In a study comparing lived experiences of people with PCOS, Ruth explains how she “gave up on western medicine” and “turned to alternative medicine and did her own research” (Vleming 518). Patients, diagnosed or not, will go to the internet to seek additional information about PCOS. In 2001, twenty years before this thesis was written, the resources people with PCOS accessed to get additional information were specialists and the internet (Sills et al.). A study published in 2020 documented that “the number of PCOS-related searches by Google has progressively increased over the past decade.” This same study found that 98.2% of their survey respondents searched for PCOS on the web (Hoyos et al.). It can be concluded that most patients with PCOS are doing research about PCOS on the internet, which could be exaggerated compared to other health issues because of the poor relationship patients have with healthcare professionals.

While most patients seek the best healthcare they can for their situation, the internet is not the best place to find quality health information. A study accessing online information on PCOS found that “there is a significant lack of quality, easy-to-read, evidence-based information for women with PCOS” (Chiu et al. 50). Not only is information found online low quality it can also be discouraging for people who do not identify as women. One study published in 2018 found the most popular online sources for PCOS are stereotypically feminine and did not find any gender-neutral language used in any well-known online resource (Vleming 516). If the internet is the last resource patients turn to, and it again leaves them dissatisfied, where will they go?

According to the patient’s perspective, it seems almost impossible to attain health information with PCOS. The pursuit of a diagnosis leads to having a lousy relationship

with healthcare providers and eventually attempting to treat yourself with information on the internet. In this impossible situation, empowering people with peer-reviewed educational material is a design opportunity. This is not an opportunity exclusive to PCOS. There are online resources for other conditions, such as endometriosis, that can be used as a model. Endometriosis is similar to PCOS in that it affects the same demographic of people, is misunderstood, and the path to diagnosis is long. Nancy's Nook is an online learning library where people can "charter a path to better endometriosis care." This website and Facebook group provides peer-reviewed information to empower people through education and connection and has "helped tens of thousands of patients take charge of their healthcare and get their lives back" (nancysnookendo.com).

Research suggests that if patients had access to a disease-specific website with accurate information, it could lead to a better quality of life for PCOS patients (Ching et al. 373). A study exploring the psychosocial effects of living with polycystic ovary syndrome found that people attaining information about their individual symptoms and concerns "was the first step in becoming comfortable with the disorder." The process of identifying the cause for all their symptoms was a starting point for pursuing help and "improving their health outcomes, but perhaps more importantly, for coming to terms with a chronic condition" (Weiss, 715). It is of great importance to create a better system for patients seeking care with PCOS.

Hypothesis

Eighteen percent of reproductive-aged people assigned female at birth have PCOS (March et al. 547). It is very likely that most people have or will have a relationship with

someone that has PCOS. Because PCOS is a complicated, difficult to treat, underfunded, chronic condition, the negative impact it has on lives is hard to measure. Helping people affected by PCOS access accurate information regarding their health can encourage hope and healing. This thesis will focus on the health information seeking journey of people with PCOS, concentrating on opportunities where communication design can make reliable, user-friendly, and accurate health information a shared public resource. Creating positive change in this process will encourage people to seek care and treatment while ultimately fostering a community of care within those affected by PCOS.

III. PRELIMINARY RESEARCH

Design for Social Change

Design shapes our world and how we engage with it. We touch design countless times a day, from the cars we drive, the billboards we pass, the pinging sound our phones make when they receive text messages, to the books we read to fall asleep. Because everything is designed, materials, processes, experiences, and communications are all tools that can have positive or negative impacts. Communication design, such as advertising, packaging, and UI/UX design, has the power to positively change behaviors and ultimately change the world.

Communication design balances visual complexity with logical processes. It organizes visual communication in our society. It is the joint between information and understanding, with the ultimate goal of changing attitudes and behaviors (Bennet). Design historically fulfilled the industrial revolution's needs and was used to promote commercial clients and the ideology of capitalist corporations. Design is still widely used this way. However, because communication design has a social impact, it has a social responsibility. It can be presumed that "the same design that fuels mass overconsumption also holds the power to repair the world" (Berman). With this conversation being in the design industry for decades, practices are changing.

Human-centered design methods that include the user in research, focus on co-creation, community, social and participatory design have been utilized by the design industry in recent decades. These methods of design deepen the research and make more effective communications, services, and products possible. This pivot in design culture was introduced in 1971 by Victor Papanek. In *Design for the Real World*, Papanek argues

only a small part of designers' responsibility lies in the area of aesthetics, and designers should be advocates for users. He also argues that designers should anticipate design's consequence on politics, health, income, and the biosphere. This idea is exhibited in the real world in the tobacco industry. Communication design has been complicit in promoting smoking while also having a key role in anti-smoking campaigns. This indicates that design can be used as more than a marketing tool and can help achieve sustainable behaviors for better health.

Today, the roles and responsibilities of design are moving past what Papanek discussed to explore what design can deliver "beyond the market-led design paradigm" (Thorpe and Glamman 218). In *The Open Book of Social Innovation*, it is argued that the market lacks incentives to solve pressing issues such as climate change, chronic disease, and inequality. For example, there is much innovation around self-management of diseases and public health and less around big systems like hospitals (Murray et al. 4). In terms of the healthcare industry, it can be argued that the market discourages change because changing systems requires cost and risk (Jones). Creating change in these types of industries will require more empathy and care from designers.

In an interview featured in *Designing With—in, Public Organizations*, empathic design research is summed up in one quote, "To understand someone else, I have to touch the other person, and that can only happen if I want to be touched myself" (Schaminée). Designers are no more naturally empathetic than others; however, practicing empathy in professional settings allows designers the ability to create stronger user connections. Is just practicing empathy enough? In *Design for Care*, Peter Jones argues that design is a creative practice that employs empathy as a research and design method. Jones argues

that getting designers to care more requires reforming the role of design and human-centered research and more creative and participatory approaches to design. This could mean the future of design research will require even more participation from non-designers.

Communication Design and Public Pedagogy

A designer's job should include empowering others to solve their own problems. Design for All Europe, an international platform aiming to create a more inclusive Europe, states that "good design enables, bad design disables." Sharing information is one way to empower people. Suppose designers put people first and start with the individual rather than systems. In that case, it is important to explore ways to give people a democratic voice in global infrastructures of information available today (Murray et al.). Anne Berry and Sarah Martin are co-creators of *Ongoing Matter*, an exhibition that seeks to encourage engagement with the Mueller Report. They argue that "In the era of 'fake news,' graphic design must address the gaps between information dissemination and the public's ability to understand it" (Berry and Martin). This means that making public information actually accessible to the public is the responsibility of designers. Using design and public pedagogy enhances the accessibility and communication of information which can increase knowledge and confidence in the recipient.

What does public pedagogy look like in practice? It could be anything from digital storytelling, UX/UI web techniques, digital toolkits to educational workshops and games. The Center for Urban Pedagogy is an organization that creates Public Access Design projects. These are described as "visual tools that go directly to communities whose access to information, or lack thereof, can have major consequences for their

health, livelihood, and well-being.” These projects help everyday people participate in democratic processes and create real social change (“Public Access Design”).

In creating these types of projects, the role of the recipient changes. In this context, recipients are now active players and “producers in their own right” (Murray et al.). Because users have an active role and the problems that are being explored can be complicated, the implementation could involve a series of redesigns, and the result may never reach an optimum point. This means the responsibility of the problem is shared between the user and the designer. In this relationship, the designer has space to “usefully contribute their expertise while engaging users in taking on and continuing to develop results” (Julier). As discussed in Chapter 2, healthcare is a big network of systems and structures that often create disparities in care, especially in those with PCOS. Using public pedagogy to generate more awareness, education, and self-advocation could be a way to empower patients and facilitate social change around problems in healthcare.

Design for Healthcare

Communication design has currently and historically had a disjointed relationship with the healthcare sector. Resources on design within the healthcare space are hard to come by, and there are limited design-oriented conferences in the healthcare field (Jones). Because of this, designers are seen as outsiders in the industry, therefore making it difficult to work within the systems to create change. As described in Chapter 1, designers have made an impact by creating meaningful projects in the healthcare domain, although these few examples seem to be the exception. Because of the difficulty designers have working within and for the healthcare industry, projects that aim to

improve healthcare are approached by creating change outside of the larger institutionalized systems.

As discussed earlier, “healthcare has significant incentives not to change the system” (Murray et al.). Obtaining healthcare in the United States is incredibly challenging, possibly because patients face adversity in accessing care or have challenges interacting with the system. Furthermore, the COVID-19 pandemic has caused disruptions in routine care, “an estimated forty-one percent of U.S. adults reported having delayed or avoided medical care during the pandemic” (Czeisler et al.). In *Design for Care*, Peter Jones argues that care is not episodic but continuous, and care needs to be moved into the community and homes. Better communication should be enabled at the points where “people seek and receive healthcare” (Jones). This is especially true for people with chronic disorders and people who have limited access to care.

Online Health Information Seeking

Fortunately, or unfortunately, one of the first places people seek health care is online. The wealth of information available online has changed the health information seeking process. Before the internet, people sought health information from doctors, support groups, or other people with similar symptoms. Today, when someone has a health concern, the internet is most likely the first source of information. Research has found that the internet can serve “as a low-cost source of health information, especially for those facing problems in getting care through traditional channels” (Bhandari et al. 1115). Health resources on the internet are either over-commercialized or tailored to healthcare professionals. This can make health information online seem inaccurate or unduly complicated, making it inaccessible to the user. Research suggests that

administering responsible and accurate health information online is important for those that face obstacles in accessing care (Bhandari et al. 1115).

Evidence of this can be seen in a study researching the health information seeking process of African Americans published in 2019. In this study, it was concluded that “seeking information on health-specific websites was associated with more timely check-ups. . .and more positive preventative medical care belief, even after controlling for traditional barriers, such as poor provider relationship” (Hills and Shah 2468). Another study suggests that access to health information can predict health related behaviors because heightened knowledge changes how people think about their health (Lee and Lin). Research clearly shows that providing quality information to the online health information seeker drives individual behavioral changes, which in turn leads to social change in the healthcare industry.

There are countless design challenges in the healthcare space, yet an area where communication design could have a major influence is making public health information truly accessible to the public. It can be argued that the internet is a public platform, where interventions to create social change can include public pedagogy. One of the ways this can be done is by creating public access design projects. Using communication design to develop a better health information seeking process through education will increase accessibility in a system where it is limited. It will consecutively empower patients to advocate for themselves in our challenging healthcare system and enable patients to achieve continued long-term health support.

Online Information Seeking for PCOS

What does the health information seeking journey of someone with PCOS look like? As discussed earlier, the overwhelming majority of people with PCOS use the internet to search for health information; however, the internet may hold barriers to accessibility. So, where else could PCOS patients get information? A study researching the health information needs of people with PCOS found that the patients diagnosed by healthcare professionals expected “that they would receive information about their condition through this initial source” (Avery and Braunack-Mayer 4). As covered in Chapter 2, there is significant dissatisfaction with the health information patients receive at the time of their diagnosis. This can prompt patients to ask their healthcare provider for more information; however, research shows that patients who “sought information about their condition upset the doctor-patient relationship balance” (Avery).

Evidence does show that some patients might receive take-home information such as a pamphlet or a photocopied page out of a medical textbook (Avery). These resources are helpful because they are typically portable, simplified, and provide quality information. One study found that only forty percent of patients reported receiving information at the time of a PCOS diagnosis (Gibson-Helm et al. 547). Most likely, a patient will not come by these resources, and they will need to seek additional information unaided. A lesser utilized resource for health information is the library. In the previously mentioned study, it was found that participants were uncomfortable with using a library because it is associated with needing a higher level of education. Also, books about PCOS are more than likely outdated or overly complicated for the average patient (Avery). Patients may also seek peers to find information. Because PCOS is considered a

hidden disease, other people with PCOS can be hard to find; therefore, having a level of intimacy to talk about your health with others can be difficult.

Because PCOS patients are not getting their information needs met elsewhere, the internet is their last opportunity. A study researching online health information seeking found that when people's healthcare needs are not met, they have a high demand for online health resources (Bhandari et al. 1116). Patients who seek information online have access to an abundance of information; they can seek this information privately, leading to a sense of control. Yet, there are barriers to using the internet. The technology gap makes accessing the internet difficult for low-income and rural communities. Using the internet to find resources also requires aptitude that some may not possess. Poverty, lack of education, race/ethnicity, age, and disability are factors that impact health literacy. Health literacy is almost a requirement to search for health information online. One study found that people with higher health literacy are "more comfortable seeking out health information" and are better at "knowing what to search for and how to find it" (Lee). Also, individuals searching for information in times of distress or confusion make this online experience anxiety-inducing. Although it seems like the best choice given the options, most patients will try to overcome these barriers.

As stated in Chapter 2, the online resources for PCOS are low quality, commercially derived, and hard to read (Ching). Another study that analyzed online resources for PCOS took a closer look by reviewing sources ranging from nonprofit organizations, government sites, clinics, health associations, and commercial health information sites. It was found that websites often had conflicting information that suddenly disappeared or was outdated. This study also found websites wholly devoted to

PCOS had strong networking resources but lacked current and comprehensive health information (Dean). A study analyzing online data found that most patients search for causes, definitions, management, and history of PCOS with the most common PCOS-related google search, “What is PCOS?” (Hoyos et al.) Another study about experiences living with PCOS found that patients commonly searched in broad terms initially and then narrowed the focus to specific issues of concern (Wiess and Bulmer).

Finding information online can have some difficulty; nonetheless, patients continue searching. A study on the management of PCOS found that patients will use information from their provider in combination with their own research to manage their treatment (Crete and Adamshick 263). Another study found that the internet provided evidence that patients could offer to their doctors, which otherwise they could not access (Avery and Braunack-Mayer 7). A narrative of a woman was presented at a *Voices of PCOS* conference in 2007.

I just finished reading an article in Newsweek magazine about this disease.

Everything fit me perfectly, facial hair, obesity, and inability to conceive. . .As of yet, I have not been diagnosed, but you better believe I’m going to the doctor this week with this article in my hands. As many times as I have been misdiagnosed with the missed periods where the doctors would say stress, I finally have the answer I have been looking for over 8 years (Kittie 18).

People with PCOS utilize the internet to educate themselves and ultimately advocate for themselves with healthcare professionals. One study found that meeting the informational needs was essential to understanding and accepting a chronic condition (Weiss and Bulmer).

Designing for Online Health Information Seeking

Changing the healthcare system from the inside is a complex problem, as there are many roadblocks to overcome as a designer. Utilizing the internet for health information is a behavior that will continue and should be improved. Disrupting the online health information seeking process is an opportunity where designers can encourage change. Case studies and design methods related to online health information seeking will be discussed in this section.

It is not the medical community's primary responsibility to present medical information that is understandable. This responsibility falls on communication designers. Angela Coulter, a health policy analyst and researcher from the University of Oxford defined 12 recurring motivations that cause patients to seek information. These are to understand what is wrong, gain a realistic idea of prognosis, make the most of consultations, understand the processes and likely outcomes of possible tests and treatments, assist in self-care, learn about available services and sources of help, provide reassurance and help to cope, help others understand, legitimize seeking help and their concerns, learn how to prevent further illness, identify further information and self-help groups, and identify the best healthcare providers (Coulter, 319). Knowing these motivations helps designers empathize and understand the health information seeker.

In *Design for Care*, Peter Jones recognizes that designers need to consider empathizing with online health information seekers in that they are most likely in distress. Online health resources should be redesigned as services, and health information seeking should be treated as a starting point, not an endpoint. Information should not be static data but a series of encounters that create a flow. Designers should be asking,

“what’s next?” This could mean anticipating needs and providing a simple fact sheet that can be downloaded or printed. Jones describes that the best resources foresee needs and offer several media formats (Jones). Designers will never address an end-to-end solution, but designers should account for varied goals of health. Suppose a patient has not attempted to get care from a healthcare professional. This patient could be seeking information to aid self-care without medical interventions, or they could be seeking information to understand their body better and desire to be directed to specialists for their health concerns.

Challenges to the designer creating health resources online can include balancing information needs while designing for urgency to not overwhelm the user. Information should be tailored to include those with low health literacy, and obvious questions need to be anticipated (Kukreja). Karen B. DeSalvo, MD, MPH, MSc from the U.S. Department of Health and Human Services helped develop a guide that “provides actionable steps for creating more accessible consumer-centric digital tools that have the potential to ease the burden of navigating complex digital health information.” This guide states that online health seekers’ primary needs are to understand their health problems and find out how to take action. It is emphasized that information should be concise, language should be simple, navigation should be straightforward, and interactive elements and tailored information should be included (DeSalvo).

A current example of a quality online health resource is [Realself.com](https://www.realself.com) (see fig. 1), a website that serves as an advisor for people looking to get plastic or cosmetic surgery. The homepage is simple and provides a clear flow of information. Features include an interactive before and after tool to see potential results and a way to connect patients with

physicians. The transparent and honest way information is presented gives Realsafe a sense that it can be trusted. The importance of clear communication to create confidence is the biggest insight discerned from Realsafe.

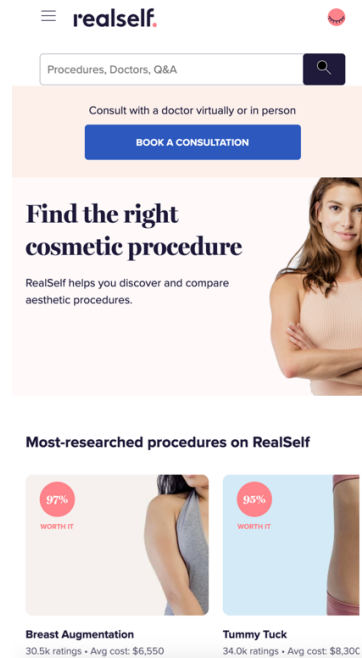


Fig. 1: Screenshot of Realself.com. Realself.com, 15 Aug. 2021, www.realself.com/procedures

Another case study is patientslikeme.com. It is a health management, community, and real-world data platform. Patientslikeme.com might seem overwhelming to a new user; however, excellent data visualization and tailored communication create value to the user. The site collects users' information to create easy-to-read data that the user can use to aid in health decisions. It will also collect and track individualized data to create a doctor visit guide for the user. (see fig. 2) This is especially important to support people in advocating for themselves. Creating easy-to-understand data and giving users a way to use that data is the most significant feature this site offers.

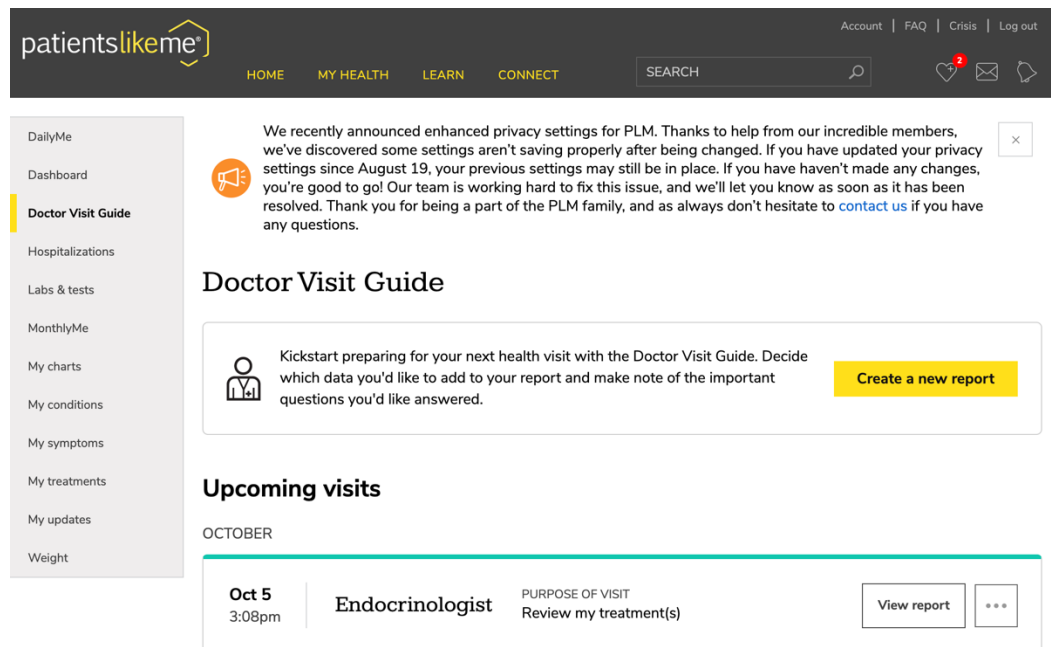


Fig. 2: Screenshot of Patientslikeme.com. Patientslikeme.com, 15 Aug. 2021, www.patientslikeme.com/doctor_visit_guide

Finally, loveisrespect.org is an excellent case study on creating engaging and straightforward information while also taking great consideration for accessibility. Loveisrespect.com is a national resource to help prevent domestic abuse for young adults and teens. Because the information that is being sought may endanger the user, there is an easy and quick way to exit the site (see fig. 3). Finding alternate language versions of the site was easy as well. They also took into consideration accessibility in their online quizzes. It is clear that in addition to clicking on the answer, the user could also use the keys Y for yes and N for no. Another critical feature to note is the option to expand or contract information (see fig. 4). This is helpful to balance the needs of multiple users. If that topic does not interest the reader, it can be easily skipped while also allowing for more information to be accessible.

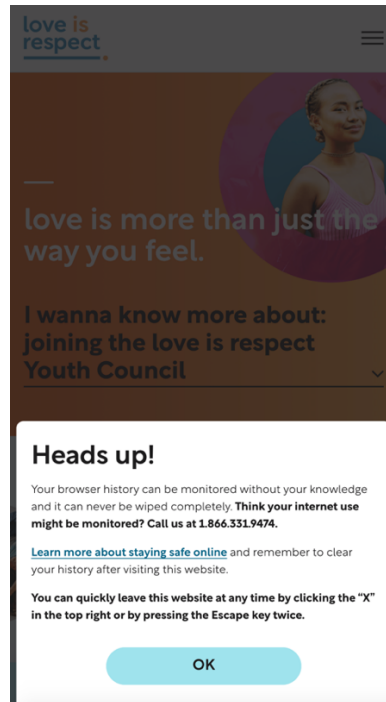


Fig. 3: Screenshot of pop-up on LoveisRespect.org. LoveisRespect.org, 15 Aug. 2021, <https://www.loveisrespect.org/>

Here are some red flags to look out for if you're wondering if your partner or relationship is too good to be true.

✓ **My partner wouldn't take no for an answer.**

^ **My partner showers me with compliments (aka love bombing).**

It's nice to hear how wonderful you are (because really, you are quite wonderful!) but there's a difference between a genuine compliment and a *tactic* to get you to let your guard down. We often hear from heartbroken survivors of abuse who just want their partner to go back to being the sweet, [loving person](#) they were in the beginning of the relationship. Unfortunately, we know that's highly unlikely because abuse is all about power and control, so it's not at all uncommon for the sweet, loving behavior to also be a tactic of abuse.

Fig. 4: Screenshot of LoveisRespect.org. LoveisRespect.org, 15 Aug. 2021, <https://www.loveisrespect.org/resources/too-good-to-be-true/>

Research presented here clearly shows the need for design to take action and create better processes for the online health information seeker. Healthcare around the world, and especially in the United States, creates less than satisfactory outcomes for patients. Because of this, patients will exhaust all the options in their power to try to create better results for themselves. Communication design has a responsibility to create more effective resources to empower people to control their health. Design should take careful considerations and work with people affected as much as possible to create new and innovative communities of care.

IV. METHODOLOGY

Process

The preliminary research and literature review in the previous chapters provide great insight into the PCOS experience and potential ways communication design can improve that experience. The hypothesis will now be developed further through primary research, which includes a survey that informed design research tactics like journey mapping and competitive analysis. With the purpose of testing the hypothesis, a prototype was created that applies communication design principles and methodologies to create a digital tool for people with PCOS. This research process is detailed in this chapter.

Survey

In the interest of further understanding the health information seeking journey of someone with PCOS, a survey was circulated. The survey questions (see appendix A) aimed to gather specific and tangible insights on the diagnosis process and subsequent health information seeking process of someone with PCOS. The survey was distributed by Qualtrics, a secure survey tool used by professionals and higher education institutions, and there were sixty participants. Participants were recruited from a PCOS support group on Facebook (“PCOS Support Groups - Austin Area”), personal social media accounts, myPCOSteam, a social media network for people who have PCOS, and www.supportgroups.com/pcos. This method and recruitment sources were chosen due to the research constraints caused by the COVID-19 pandemic. Keeping all communication and recruitment online was the best option to avoid in-person contact.

The number of responses was on par with the amount expected. All participants identified as female and were eighteen years or older. There were fewer participants in the 18–25 age range than there were for other age ranges. These factors, along with the online delivery method, gave limitations to the study. Having data from people who do not identify as female, who do not frequent the internet, and who are younger would give this research a more comprehensive foundation to gain insight.

Survey Results

Out of the sixty participants, twelve percent were in the 18–25 age range, thirty-seven percent were in the 26–35 age range, twenty-six percent were in the 36–49 age range, and twenty-five percent were in the fifty plus age range. Sixty percent reported they had been diagnosed with PCOS, and thirty-seven percent reported they were not diagnosed. Two participants did respond with “other” and said, “I think I have it, but my doctor says I don’t” and “I have not been officially diagnosed, but when I told the gynecologist that I thought I might have it, she told me ‘well you probably have it, but the treatment would just be birth control which you are already on, so we don’t need to officially diagnose it.’”

Q10 - If you were diagnosed, did your doctor's office provide you with informatio...

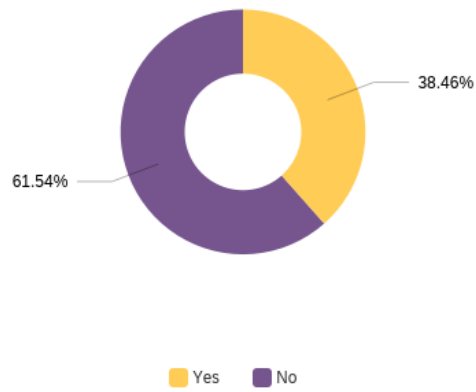


Fig.5: Survey Results: If you were diagnosed, did your doctor's office provide you with information?

Was the information sufficient that you received at the time of diagnosis?

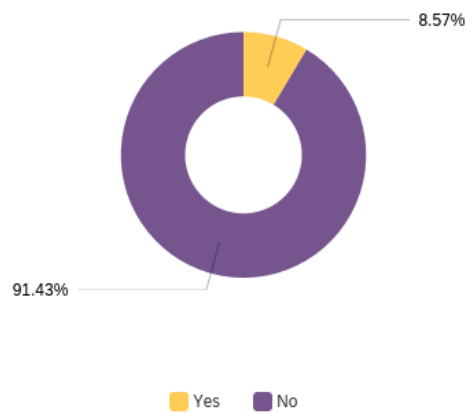


Fig.6: Survey Results: Was the information sufficient that you received at the time of diagnosis?

Q12 - If you were diagnosed, did you leave the doctor's office understanding PCOS...

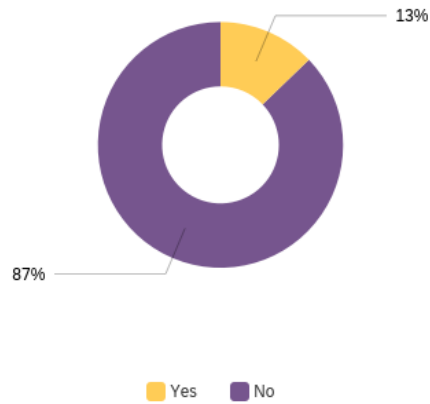


Fig.7: Survey Results: If you were diagnosed, did you leave the doctor's office understanding PCOS?

Q13 - Do you trust healthcare professionals to give you accurate information regarding PCOS?

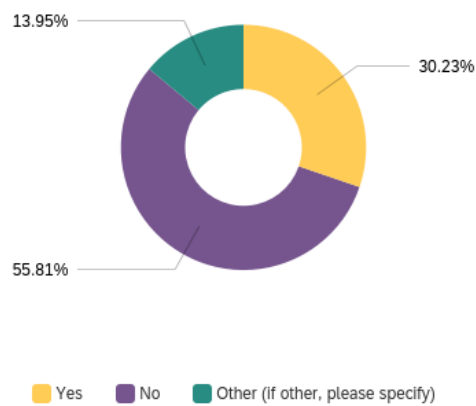


Fig.8: Survey Results: Do you trust healthcare professionals to give you accurate information regarding PCOS?

Q14 - Where do you get most of your information in treating PCOS?

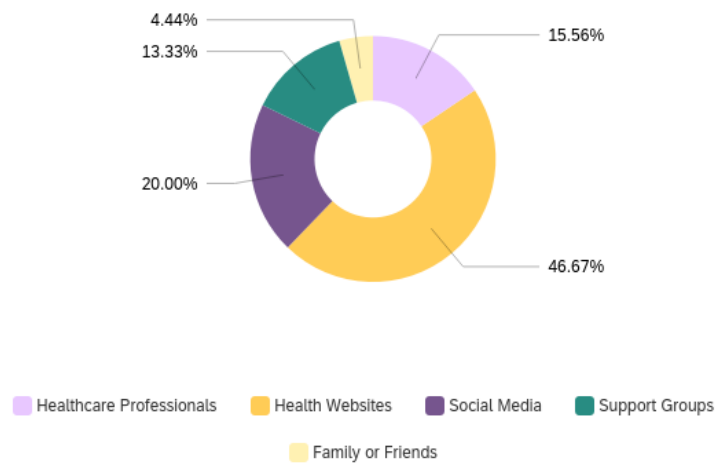


Fig.9: Survey Results: Where do you get most of your information in treating PCOS?

Q15 - Is finding information about PCOS difficult?

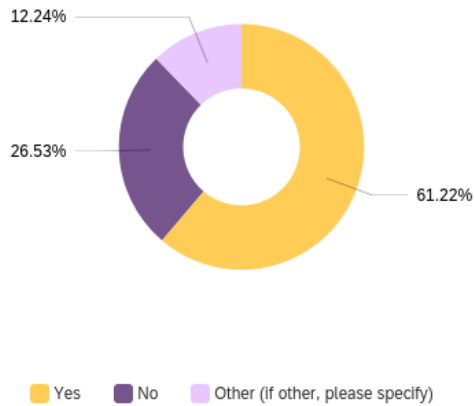


Fig.10: Survey Results: Is finding information about PCOS difficult?

Crucial understandings from the survey are as follows: thirty-eight percent reported receiving information from their doctor's office, and only nine percent found that information to be sufficient (see fig. 5 and 6). Only thirteen percent reported leaving the doctors' office understanding PCOS (see fig. 7). This is equal to the number that said trusting healthcare professionals to give them accurate information, which is also thirteen percent (see fig. 8). Health websites are the resource where the most reported they get their information in treating PCOS (see fig. 9). Sixty-one percent reported that finding information about PCOS is difficult (see fig. 10), and sixty-four percent reported that they get overwhelmed with information when searching online.

Journey Mapping

A journey map was developed using previous research (see fig. 11). This journey map depicted the diagnosis and health information seeking process of someone with PCOS was developed. For this design strategy, the person in the journey is referred to as the user. This journey map represents the typical journey and will not account for all experiences. To start the journey, the user will either suspect they have PCOS or have already been diagnosed. This is represented as two journeys in the figure. When the user suspects they have PCOS, they typically seek health information via online resources, healthcare professionals, and online support groups. All of these options led the user to receive unsatisfactory information, sometimes repeatedly. Searching online gave the user too much information leaving them overwhelmed and left to sort the accurate information from misleading sources.

The user also goes to doctors repeatedly until they finally get a diagnosis. The user won't understand PCOS after diagnosis and explores other options, which gives

more unsatisfactory information. So, even if the patient is fortunate and eventually receives a diagnosis, they are still in a perpetual cycle of seeking health information. This journey shows the unfulfilled needs of the user and how discouraging it can be for someone with PCOS to struggle in their efforts for better health.

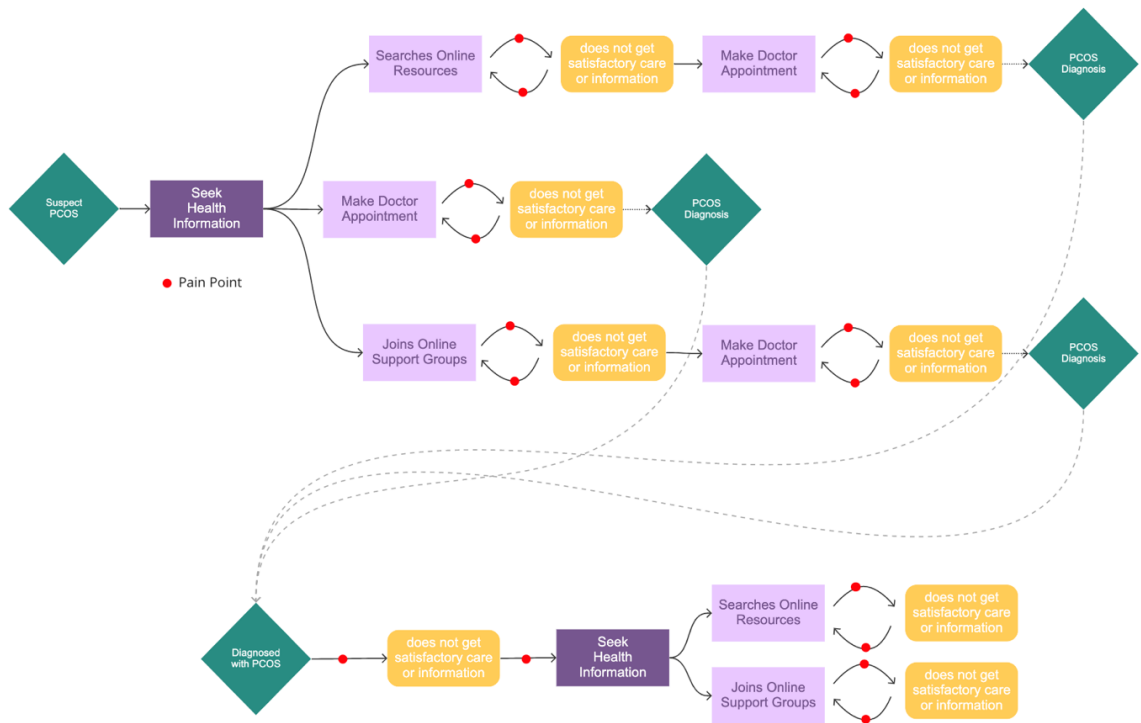


Fig.11: Journey map of the PCOS health information seeking experience

Design Methods Informing Prototype

After developing the journey map, other design strategies were used to narrow the focus of the prototype. These included developing a Human-Centered Need Statement, drafting a Frame Your Design Challenge, and analyzing current solutions.

Nielson Norman Group, a world leader in research-based user experience, describes a need statement as “a powerful, fundamental tool for defining and aligning on the problem you are going to solve” (“User Need Statements”). A need statement will

summarize who a particular user is, the user's need, and why the need is important to that user. Using research presented in earlier chapters, the need statement for this thesis was developed. It is as follows: People with PCOS (Polycystic Ovarian Syndrome) and people in the care circle of someone with PCOS need a way to effectively seek health information so that they confidently advocate for themselves during doctor visits and cope with a chronic illness. Creating a need statement is an integral part of the process because it serves as a guide for developing the prototype. It makes the goals of the prototype clear and is a point of reference to keep progress on track.

Next, a "Frame Your Design Challenge" was drafted to articulate the problem more and define the scope (see appendix B). The Frame Your Design Challenge is a design method featured in IDEO.org's Design Kit. ("Frame Your Design Challenge") IDEO is a global design company that has developed tools to help others practice human-centered design. Key insights from this challenge include considering a digital solution. This is a consideration because evidence showed in previous research that the internet is the most used resource for people seeking health information about PCOS. Another consideration brought up in the challenge is that if the solution is digital, creating a physical version for people who have limited internet access would make the solution more accessible to all. After completing all the steps in the challenge, possible solutions emerged, such as creating an app or digital toolkit with physical counterparts. This challenge was a crucial step to take because it narrowed the scope down. After completing the Frame Your Design Challenge, it became clear the outcome would become a social pedagogy project, and the format would be digital.

The final design research method was a competitive analysis (see appendix C). A competitive analysis gave insights into what is already addressing this problem and highlighted how other solutions are successful or ineffective. It also provided context by showing the environment the prototype would exist in. This competitive analysis compared four leading apps and websites that are directly designed for people with PCOS. It does not include sites such as WebMD or PCOS awareness organizations. Although these sources might be where people seek information, they do not share the same purpose or audience as this project. The main conclusions from this method are that these resources have barriers to access like making accounts necessary, limited visual aids, and exclusive language. Three out of the four examples made setting up a profile mandatory before you could see any information, only one example provided any visual aids to complement the information, and only 1 example used inclusive language and presented information in a gender-neutral manner.

V. OUTCOME

Design methods and research discussed in previous chapters guided the development of a prototype. This chapter discusses the design process of the prototype, functions of the prototype, user-flow, design decisions, and user-testing results.

Design Process

The design process of the prototype includes creating a low-fidelity and high-fidelity prototype. These prototypes are the early stages in developing a website that serves as a digital social pedagogy project. This project is a tool for those seeking online information about PCOS. It educates and empowers those with PCOS giving them control and support.

These prototypes test whether the idea of using a website as a tool to help people seeking PCOS information is successful. Possible features were considered next. A flow of these features was detailed in a low-fidelity prototype. After the flow and hierarchy were finalized, a high-fidelity prototype was created. In the high-fidelity prototype, the visual design of the website is developed. After the high-fidelity prototype is created, it is then user-tested.

Functions of the Prototype

A user's experience should be useful, usable, desirable, findable, accessible, and credible ("Improving the User Experience"). When considering the prototype's functions, the primary goal was usefulness. The goals of the project are defined, referencing the need statement formed in Chapter 4. The leading goals of the project are:

- Help people test their suspicions of having PCOS
- Thoroughly explain what PCOS is while also giving more specific information

- Improve the search for PCOS specialists
- Provide personalized information that encourages self-advocacy

The previous goals and the frequent motivations that cause patients to seek information discussed in Chapter 3 guided the conceptualizing of the final features:

- Diagnosis Quiz
- Interactive What is PCOS? page
- Symptom Simplifier
- Find a Specialist
- Profile and Resources
- Advocate Pack

The Diagnosis Quiz is a short 10 question quiz that asks the user about their symptoms and family history. This will legitimize the user seeking help and their concerns. This quiz cannot give a definitive diagnosis but will use friendly language to give the user their probability of having PCOS. It will then give reasons that contributed to the diagnosis. The user can save their quiz results to their Profile if desired. This quiz can help the user recognize how their symptoms may be connected and caused by PCOS. This is intended to give them more confidence when speaking to a doctor because they have a better understanding of their body.

What is PCOS? page consists of interactive information that briefly explains what PCOS is. This will assist the user in understanding what is wrong and a realistic idea of prognosis. This is a brief page that gives honest information about the disorder in a friendly, accurate, but non-clinical manner. It is meant to be easily understood. It will

include both copy and interactive visual elements. Including both approaches to learning will help the site be more accessible to all types of learners and literacy levels.

Symptom Simplifier is an interactive page that includes an outline of a body. The user is to click in an area of the body they are experiencing a symptom. A pop-up will then appear, enabling the user to learn what could be causing the symptom, how to remedy it, and what tests to request for treatment. This allows the user not to become overwhelmed looking at all the symptoms at once. It helps users not to become anxious about symptoms they may not be experiencing. The user can also save the symptoms they are experiencing to their profile.

Find a Specialist is a feature where the user can search for the best healthcare providers. The site will allow for custom searches, or you can search based on the information in your profile. You can customize your search based on location, type of specialist, and insurance. Users of the site review the specialists in the database, so the user can be confident that the specialist is knowledgeable about PCOS. This can help to reduce barriers to access care. It can also reduce the time spent looking for specialists and time wasted at unsuccessful appointments.

The Profile and its resources will help others understand and provide reassurance to the user, so they have help to cope. The Advocate Pack is a downloadable packet that includes resources, symptoms, and tests to request. This will help the user make the most of consultations. This is an individualized guide for the user to advocate for themselves at the doctor's office. The information it uses is collected from the user's interactions with the site. It can be downloaded, emailed, or viewed digitally.

Low-fidelity Prototype

A low-fidelity prototype was created using the previously defined features (see fig. 12). The focus of the low-fidelity prototype was to determine the user flow. The user flow is the “path taken by a prototypical user on a website or app” (optimizely.com). The flow of the site takes information architecture into account. Information architecture is focused on the organizing, structuring, and labeling of content to understand how items relate to each other. (“Improving the User Experience”).

Understanding the user goals is vital to developing the user flow. As stated in the “Designing for Online Information Seeking” section of Chapter 3, the needs for the online health seeker are to understand their health problems and find out how to take action. It is essential to have empathy for the user. The users' needs are the focus in anticipating what they might be searching for next and what might be most important to them at that moment. It is important to keep in mind that searching for online health information is frequently done during times of concern and distress. Building the flow and navigation to be straightforward and comfortable can make a difference to the experience of the user.

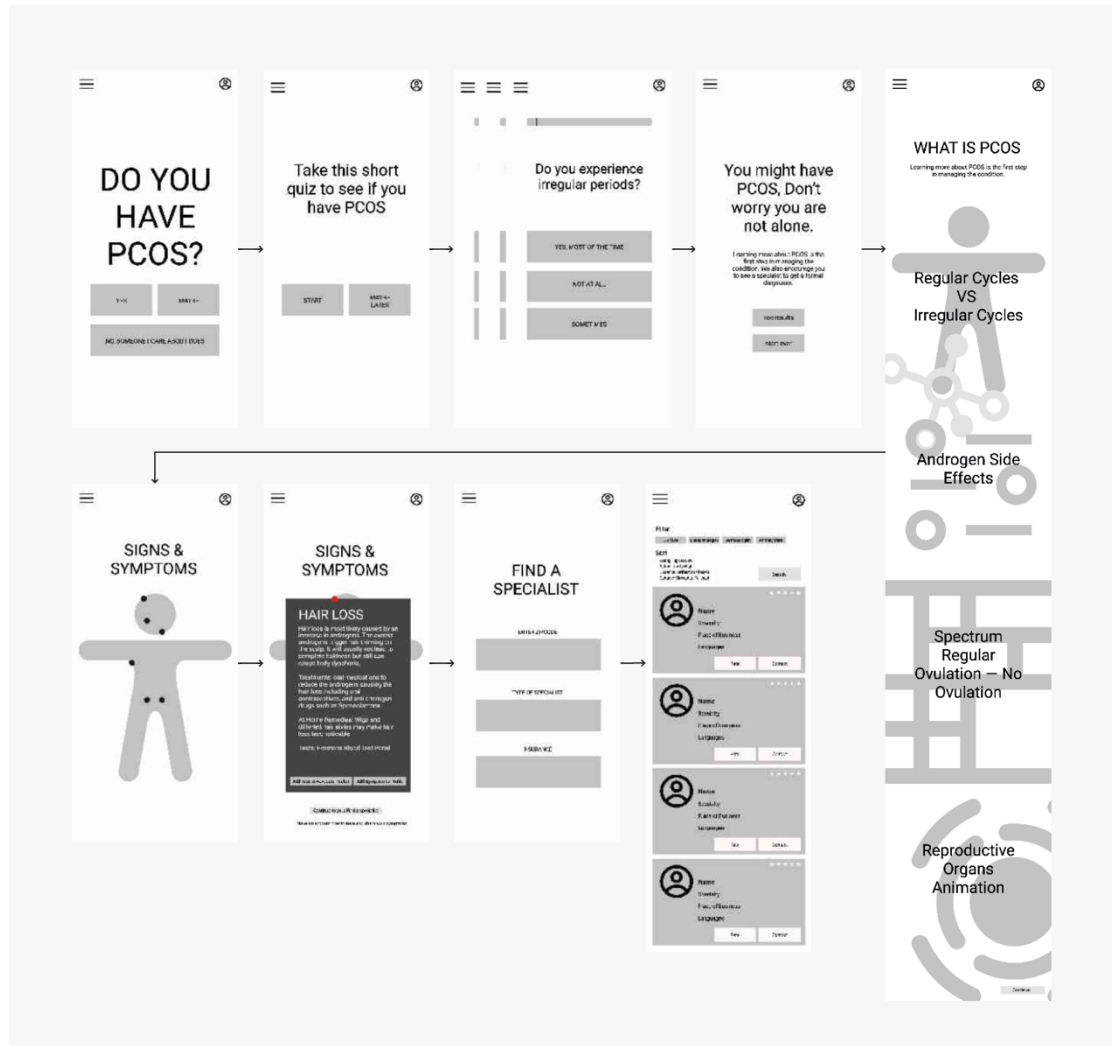


Fig.12: Low-fidelity prototype.

The low-fidelity prototype was not formally user-tested, but its development helped prepare for the creation of the high-fidelity prototype. Experimentation included different flows and hierarchies. Because it is a low-tech, simple prototype, different flows could be created and examined repeatedly until the final flow evolved.

User-flow

The homepage starts the user flow (see fig. 13). Here the user is asked if they have PCOS. Different flows are determined from the user's answer to this question. If the user says "maybe," it is most likely, they have not been diagnosed with PCOS and could benefit from taking the Diagnosis Quiz. The user can then skip the quiz, which will take them to the What is PCOS? page or go on to take the quiz. A results page will appear after the completion of the quiz. Here the user learns whether it is likely or not that they have PCOS. The user can go on to see more detailed results. This is where the user will learn more specifically what factors are likely causing the diagnosis. The user is now encouraged to make a profile. This will save their results and give the site more information about them, such as age and location.

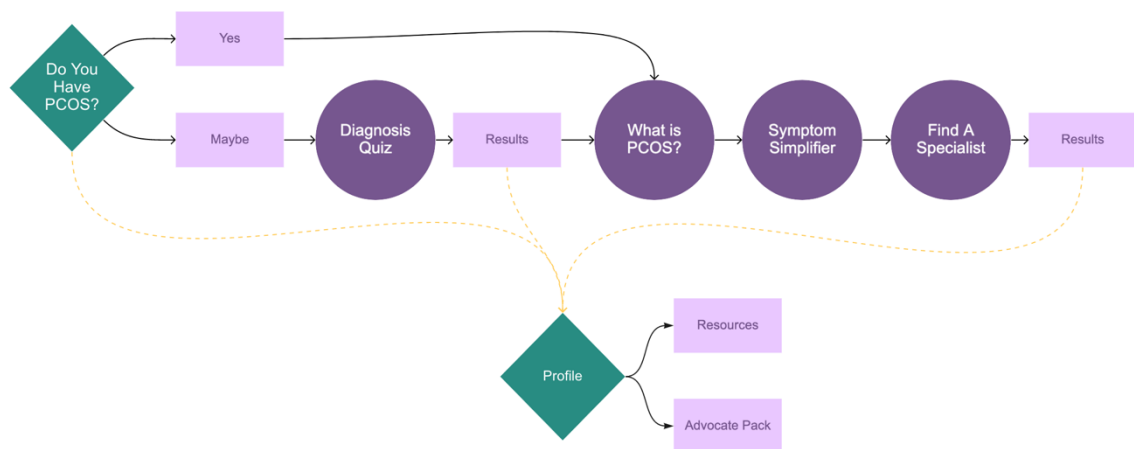


Fig.13: User-flow of Allyist.

After their account is set up, the user can go on to learn more about PCOS on the What is PCOS? page. From there, the user is encouraged to simplify their symptoms. After the user is done interacting with this page, they are prompted to find a specialist. If

the user has completed all the steps in the flow to this point, they can let the site search for them. Information from the user's profile and interactions will inform the search. For example, if symptoms were saved that warranted the need for an endocrinologist, that type of specialist will show up in the results. From here, the user can contact the specialist to make an appointment.

Before the user's appointment, they will be prompted to view their Advocate Pack (see fig. 14). This is a pack of resources the site will collect for the user to refer to during their healthcare appointments. The flow for someone who is already diagnosed is mostly the same. Instead of being directed to the Diagnosis Quiz first, the user can choose which feature they want to interact with. This is important because if the user is returning, they can be easily directed to the feature they desire. After the user flow is close to being final, the high-fidelity prototype is created.

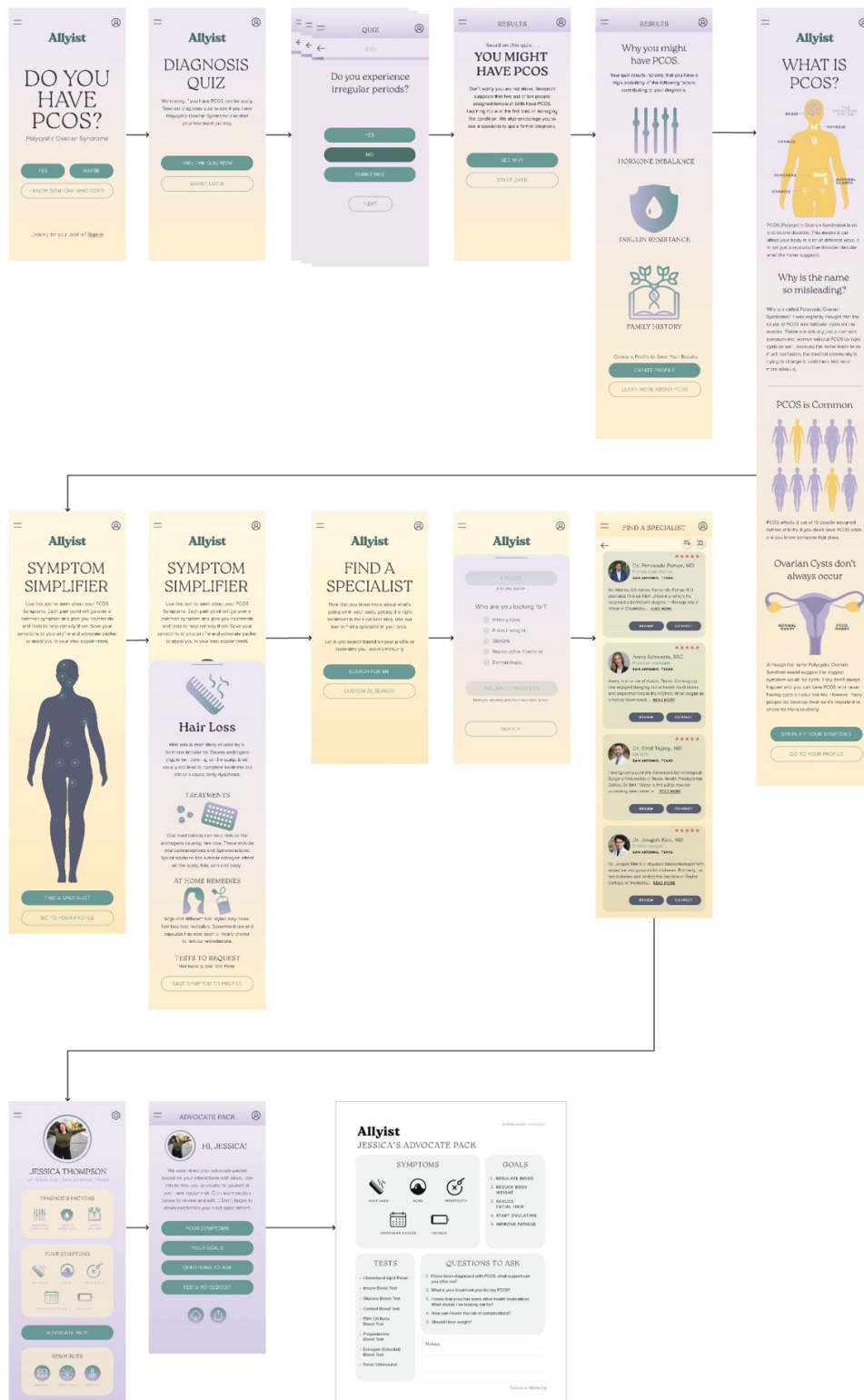


Fig.14: Advocate pack mockup.

High-fidelity Prototype

The goal of the high-fidelity prototype is to get as close as possible to the actual user interface (see fig. 15). A high-fidelity prototype usually includes the visual design, realistic interactions, and content. Creating a high-fidelity prototype is beneficial because it will “often look like real products to users.” It will give a “clear idea of how a product is supposed to work,” and user testing “participants will be more likely to behave naturally” (blog.adobe.com). The process of creating the high-fidelity prototype is to determine a name, define the visual design, and finally, design the interactions of the prototype.

Referencing the need statement and goals of the project bolstered the name contemplation process. Allyist was the decided name of the prototype. This name is a combination of the term “ally” and the suffix “ist.” The meaning of the name is derived from the definition of its components. Merriam-Webster defines an ally as “one that is associated with another as a helper: a person or group that provides assistance and support in an ongoing effort, activity, or struggle” and the suffix -ist as “of, relating to, or characteristic of.” This name thoroughly represents the project.



miro

Fig.15: High-fidelity prototype.

Next, a visual design was conceived. The first step was to create a color palette and decide on typefaces. The next step was to decide on the hierarchy and spacing of elements. Icon and button design came last. Decisions for the visual design came from compiling inspiration into mood boards, creating word lists, and finally, experimentation. It was important to create a welcoming, humble, gender-neutral, and uncomplicated visual design. The color palette specifically was made to bring a sense of calm to the user (see fig. 16). Soft colors such as pale yellow and light purple are contrasted with brighter green and darker purple. Gradients of these colors were also used throughout the design. The color palette is both neutral and unalarming.

The typeface choices were decided as Roca for headlines and Proxima Nova for body copy (see fig. 17). Roca is a typeface family designed by Elena Genova and is “influenced by the same fonts as Praline—Windsor and Cooper Black—the hits of 60s and 70s—with a hint of Bookman” (“Roca”). This typeface was chosen because it consisted of multiple weights, and the curvature of the letters helped guide the reader from letter to letter. These characteristics make the design seem sympathetic and approachable. This is beneficial to people who could be looking at it in times of worry. It is paired with Proxima Nova. Proxima Nova was designed by Mark Simonson and is “a hybrid that combines modern proportions with a geometric appearance” (“Proxima Nova”). It was chosen because it is versatile and gives pleasing contrast to Roca. Finally, icon and button designs were created. The icons and buttons were designed with rounded edges and organic shapes to reinforce the friendly and approachable atmosphere.

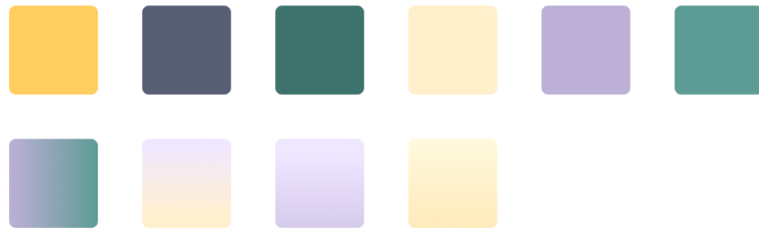


Fig.16: Color choice for prototype.

H1 HEAD

H2 HEADLINE

H3 Headline

H4 Headline

H5 HEADLINE

H6 HEADLINE

Body 1

H2 Headline

H3 Headline

H4 Headline

H5 HEADLINE

H6 Headline

Body 1

Fig.17: Typeface choice for prototype.

The prototype interactions were designed using Figma, a prototyping tool that allows for collaboration and a realistic interactive prototype. For instance, on the Symptom Simplifier, a window will slide up and down for each symptom, giving the user the feeling that they are interacting with an actual website. Figma also supports gifs, which are used to replicate the educational visual aids. These realistic interactions made the prototype seem tangible and complete. After the interactions were designed, the high-fidelity prototype was finished and ready for user testing.

User-testing

User testing is used to evaluate a design, solution, or product. The purpose of user testing Allyist is to see if it could be a potential solution for the PCOS health information seeker. According to Adobe XD Ideas, to know if a solution is successful, “real users must test its interface and its functions” (Herman et al.). An ideal participant for this testing is someone affected by PCOS who uses the internet to search for PCOS information. Participants for Allyist user testing were recruited from personal Facebook accounts, myPCOSteam (a social media network for people who have PCOS), and www.supportgroups.com/pcos. Qualtrics was used to collect email addresses from anyone interested in participating. After the recruitment, an email was sent to the participants with further instructions. Because this user-testing was being conducted during the COVID-19 pandemic, methods used avoided in-person contact.

The participants were asked to complete three tasks on the [Figma prototype](#) to understand the experience of using Allyist. (“Allyist Prototype”). The three tasks are to 1) take the Diagnosis Quiz and save results, 2) interact with the What is PCOS? page and Symptom Simplifier, and 3) navigate to your Profile and Advocate Pack. After the participants attempted these three tasks, they were asked to complete a follow-up survey. This survey was distributed by Qualtrics. User-testing questions should “help you understand both the demographics and experience of your candidates” (Herman et al.). The demographic information collected in the survey consisted of age, gender, PCOS diagnosis, information seeking frequency, and device usage. Other questions asked aimed to collect information on the experience of using the prototype.

User-testing Results

There were seven participants involved in user-testing. Eighty-six percent of the participants have or suspect they have PCOS. This is consistent with the goal of 5–10 participants. This goal is realistic because of the limitations of time and COVID-19 social distancing. The demographic information collected shows that all participants were aged eighteen or more, with fifty percent above fifty years old and fifty percent below fifty years old (see fig. 18). Six out of the seven participants identified as female, and one participant identified as male. A hundred percent of the participants use smartphones to search for information, and there is variation in how often the participants search for information.

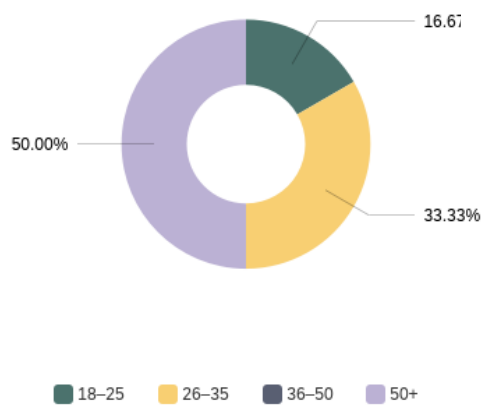


Fig.18: User-testing Results: Demographic Information–Age

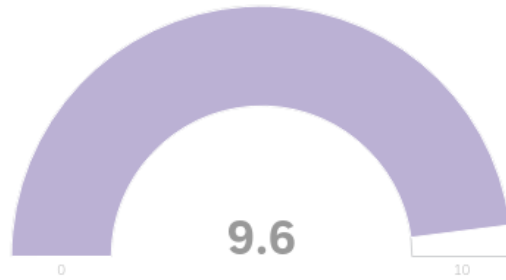


Fig.19: User-testing Results: Overall, how would you rate your experience with Allyist?

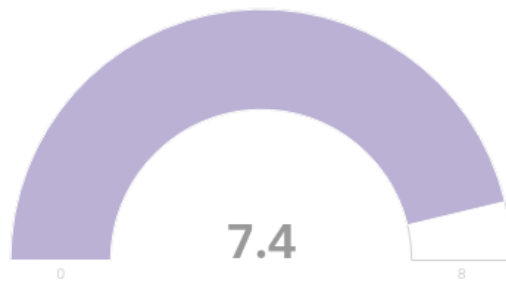


Fig.20: User-testing Results: How easy do you find it to navigate Allyist?

The overall experience participants had with Allyist was favorable, averaging 9.6 out of ten (see fig. 19). Participants found the What is PCOS? page and Symptom Simplifier the most valuable features, and the Profile and Advocate Pack the least valuable. Participants found Allyist to be easy to navigate, rating it on average 7.4 out of ten (see fig. 20). One participant mentioned adding a forum “so people can share experiences.” Comments offering positive feedback are “great idea and layout concept” and “simple easy to understand information.”

VI. CONCLUSION

Discussion

It is crucial to practice communication design in ways that allow people to participate in shared-decision making with their healthcare providers. It is also important to create projects that help bridge the gap between communication design and health industries. This thesis used PCOS as a starting point for design research to assess if communication design can positively impact the health information seeking process. The results presented in Chapter 5 provide supporting evidence that communication design can positively disrupt the health information seeker's journey and assist long-term health. Allyist is an example of combining communication design methods with public pedagogy projects to positively affect the health information seeking journey of a marginalized group of people.

User testing results show that participants had a positive experience using Allyist. Results also show that educational visual aids that are simple and interactive are valuable to participants over other personalized features. This suggests that most people are looking for straightforward health information online. Complex content found on health websites can be designed to improve the experience of users. Interactive visual aids can be applied to health websites to create engaging content that is easy for all to understand. The use of visual aids can also be utilized in ways to create interactions that will not overwhelm the user while still providing thorough content. Using communication design in these ways improves accessibility.

Because fewer participants found the Profile and Advocate Pack useful, it can be assumed that people could be wary of using features that require personal data collection.

Creating more transparency regarding data collection could lessen these concerns. Most resources targeted to the patient are commercialized and looking to make a profit.

Creating more democratic, public pedagogy projects might be a solution for providing educational resources to people. This can be accomplished by practicing participatory design. While this thesis focused on PCOS, the results indicate that similar solutions for chronic health conditions can be successful. These results can inform future projects aimed to improve the online health information seeking process of other misunderstood health issues.

The limitations of this research include altering research methods to abide by COVID-19 restrictions, time restraints on the development and distribution of user testing procedures, and the lack of diversity in both the initial survey participants and the user testing participants. Because in-person contact was limited due to COVID-19 concerns, research methods such as card-sorting, physical prototype user testing, and observational research could not be conducted. Using these research methods could have allowed for more extensive insights on both the audience and prototype. Time restraints on the development and distribution of user testing affected the number of participants recruited. Although the initial survey had more respondents, it still lacked diversity in gender. Due to ethical concerns, research was only conducted on people aged 18 or older. Representation in research from people under the age of 18 will also lead to more comprehensive results, especially since most people with PCOS start their health information seeking journey at a younger age. Having all recruitment completed over the internet gave a bias to the research. Including people who do not frequently use the internet would give different perspectives. Even with these limitations, it can be

concluded that Allyist has the possibility to enhance the health information seeking journey of someone with PCOS. Further research with extended access to in-person contact and increased diversity will allow for more conclusive and definite results.

Further Research

Future research is needed to assess how Allyist could be improved. The first step in this research is creating a collaborative advisory board to improve features and evaluate the information presented on Allyist. This advisory board would be made up of other designers, healthcare professionals, and people affected by PCOS. Recruitment of board members and other collaborators could happen online in PCOS spaces, such as myPCOSTeam.com and Facebook support groups.

With the help of the advisory board, a more robust prototype is possible. This could be a simple website that is mobile friendly. After the information and features are improved on the new prototype, it would be beneficial to test the Advocate Pack in a healthcare setting. This will show if the Advocate Pack is effective in encouraging the user to self-advocate. Also, creating a specific user testing procedure to measure the educational impact of Allyist will show if it improves the general knowledge of PCOS.

Another point of future research to consider is how to make Allyist more accessible. Designing more visual and audio aids in Allyist could increase accessibility to the disabled population. Also, creating a physical adaptation of Allyist would allow those who have limited internet access to use the services.

Exploring how to make Allyist discoverable to the public is also important to consider. With the help of the advisory board, creating awareness would be the first step. Creating a campaign to increase engagement is one option. Creating awareness could also

mean partnering with nonprofit PCOS organizations, such as PCOS Awareness Association or the Resilient Sisterhood Project. Another collaboration to consider is Allara, a company that provides a virtual care team to people suffering from PCOS. They recently launched in 2021 and have a waitlist with thousands of people. They currently do not take insurance, and the price point can be a financial hurdle to patients. A collaboration between Allyist and Allara could improve the affordability and accessibility of this care.

Funding and management of Allyist will also need to be considered. The advisory board or partner organization could help with creating a way for volunteers to help run the site. Options for funding include crowdfunding and grants. Grants to consider applying to include the Sappi Ideas that Matter grant or the National Endowment for the Humanities Digital Project for the Public program.

Exploring the use of Allyist's model on other health concerns is also important to future research. Health concerns such as endometriosis, fibromyalgia, chronic fatigue syndrome, and lupus are all chronic conditions that are often misunderstood. It is worth exploring if solutions like Allyist are beneficial for those communities.

On a larger scale, understanding avenues where communication design can create positive impacts in the world should be researched. In the recent wave of human-centered and participatory design, designers should not shy away from complicated problems. Health has a tremendous impact on quality of life. In large systems and structures, like the healthcare industry, designers have a responsibility to create better outcomes for people, whether solutions are commercially profitable or not. Communication Design

cannot solve every health care problem; however, it can influence behaviors and be a catalyst for system change.

APPENDIX SECTION

APPENDIX A: INITIAL SURVEY QUESTIONS

Q1 What is your age range?

- 18–25
- 26–35
- 36–49
- 50+

Q2 To which gender do you most identify?

- Female
- Male
- Transgender Female
- Transgender Male
- Gender Variant, Non-Conforming or Non-binary
- Other (if other, please specify)
- Prefer not to answer

Q3 Have you been diagnosed with PCOS (Polycystic Ovarian Syndrome)?

- Yes
- No
- Other (if other, please specify)

Q4 If you have not been diagnosed, do you suspect you have PCOS?

- Yes
- No
- Other (if other, please specify)

Q5 Does someone you care about have PCOS?

- Yes
- No

Q6 If you were diagnosed with PCOS, how physically difficult was the process? (10 being the most difficult)

Q7 If you were diagnosed with PCOS, how emotionally difficult was the process? (10 being the most difficult)

Q8 If you were diagnosed with PCOS, how long did it take to get an official diagnosis?

- 1 Doctor Visit
- 2–3 Doctor Visits
- 4–10 doctor visits
- 10+ doctor visits

Q9 Where did you first learn of PCOS?

- Healthcare Professionals
- Online Health Resources
- Social Media
- Family or Friends
- Other (if other, please specify)

Q10 If you were diagnosed, did your doctor's office provide you with information regarding PCOS?

- Yes
- No

Q11 If yes, was the information sufficient?

- Yes
- No

Q12 If you were diagnosed, did you leave the doctor's office understanding PCOS?

- Yes
- No

Q13 Do you trust healthcare professionals to give you accurate information regarding PCOS?

- Yes
- No
- Other (if other, please specify)

Q14 Where do you get most of your information in treating PCOS?

- Healthcare Professionals
- Health Websites
- Social Media
- Support Groups
- Books
- Family or Friends

Q15 Is finding information about PCOS difficult?

- Yes
 - No
 - Other (if other, please specify)
-

Q16 Where do you search for up-to-date information about PCOS? (choose all the apply)

- Healthcare Professionals
- Websites
- Support Groups
- Books
- Family or Friends

Q17 How often do you search for information about PCOS?

- Daily
- 2–3 Times a Week
- Once a Week
- Monthly
- Never

Q18 Do you get overwhelmed with information when searching online?

- Yes
- No
- Other (if other, please specify)

Q19 Do you find support connecting with other people regarding PCOS in online groups?

- Yes
- No
- Other (if other, please specify)

Q20 How accurate do you find information in online support groups to be?

- Very Accurate
- Sometimes Accurate
- Rarely Accurate
- Never Accurate

Q21 How accurate do you think information on PCOS online is?

- Very Accurate
- Sometimes Accurate
- Rarely Accurate
- Never Accurate

Q22 How user-friendly do you think finding PCOS information online is?

- Very User-Friendly
- Sometimes User-Friendly
- Rarely User-Friendly
- Never User-Friendly)

APPENDIX B: FRAME YOUR DESIGN CHALLENGE

What is the problem you're trying to solve?

- The health-information seeking process of someone diagnosed with PCOS

Step 1. Take a stab at framing this challenge as a question:

- How might we improve the health-information seeking process of someone diagnosed with PCOS

Step 2. Now state the key outcome you're trying to achieve:

- Provide a way for those affected by PCOS to educate themselves on the condition
- Encourage those affected by PCOS to advocate for themselves

Step 3. Write down important aspects of the context or constraints that you need to consider:

- Accurate information about the condition is hard to come by because of lack of research
- Many healthcare professionals lack knowledge on the condition
- Could be limitations on what information can be available in healthcare contexts
- Because most people search for health information online the solution makes more sense being digital
- If solution is digital there needs to be accessibility intentions. Like creating physical kit as well.

Step 4. What are some possible solutions to your design question?

- App
- Digital Tool/website

Need Statement

- People with PCOS (Polycystic Ovarian Syndrome) need a way to effectively seek health information so that they can cope with their chronic illness.

APPENDIX C: COMPETITIVE ANALYSIS

Feature	Ask PCOS	PCOS Support	PCOS Tracker	Every PCOS Body
Company Profile	AskPCOS is the first App dedicated to the condition of Polycystic Ovary Syndrome (PCOS) that is based on the best available evidence.	myPCOSteam is a social network and support group for those living with PCOS. Get the emotional support you need from others like you, get practical tips to manage your life with PCOS, and insights about treatment or therapies. myPCOSteam is the only social network where you can truly connect, make real friendships, and share daily ups and downs in a judgment-free place.	The PCOS Tracker helps you track your daily & monthly PCOS & PMS symptoms. You can download & share your tracked data as and when needed.	everyPCOSbody was created as an ALL inclusive resource for up to date information on the often misinformed syndrome; PCOS (Polycystic Ovary Syndrome). There is a lot of misinformation out there, even Doctors aren't always up to date on all the intricacies of PCOS. Our motto "All the PCOS, None of the BS!" Our app provides a complete PCOS resource at your fingertips!
Rating on Apple Store	1.0	2.2	4.5	4.3
Key Advantage	Information from Experts	Provides Support	Visual Aids	Community Based
Target Market	Women with PCOS	People with PCOS	Women with PCOS	People with PCOS
Onboarding	have to make an account to access information	Make an account online or on the app. Seems like people have trouble doing so looking at reviews. Can register using facebook account.	Have to make account and answer questions before using app	
Business Model	unclear	?	?	run by volunteers and members of community
Strengths	Good Information Designed by experts	Provides emotional support	Provides the user with data and data visualization to understand body and symptoms better. Can connect with fit bit and apple healthkit	Inclusive Users like the information available Doctor directory Seems to be accurate information Contributors are part of the community and are sharing and organizing information to share
Weaknesses	Only targets women Poorly designed Login issues Not alot of visual aids to information Boring interface and interactions	Most people seem to have trouble signing up and using the app. Does not provide information or trusted information resources.	Seems like a standard period tracker app. Not much specific to PCOS. Focus on periods and period symptoms when there is much more to track with PCOS Not designed very well References and links page is very haphazard and confusing	Poorly Designed hard to navigate information is organized strange
Link	https://apps.apple.com/au/app/askpcos/id1395816147	https://play.google.com/store/apps/details?id=com.myhealthteams.mypcoteam&hl=en_US&gl=US	https://apps.apple.com/us/app/everypcosbody/id1483081178#?platform=iphone	https://apps.apple.com/us/app/everypcosbody/id1483081178#?platform=iphone

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