

Transcend: Enhancing the Transgender Health Care Experience through Interaction Design

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Abstract

This paper explores what special user research and design considerations are needed to build a website that enhances the health information seeking experience for transgender people.

Incorporating themes of trust, credibility, and community identified through interviews and published research from the fields of Information Science, Health Communications, and Interaction Design, this paper serves as an overview of the data discovery, analysis, and design recommendation process of a community-based organization website.

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Table of Contents

Chapter 1: Introduction and Hypothesis	1
Chapter 2: Literature Review.....	2
Chapter 3: Methods.....	8
Chapter 4: Results	11
Chapter 5: Recommendations	21
Chapter 6: Design Impacts and Implications	25
Chapter 7: Next Steps	26
References.....	27
Appendix	30

Chapter 1: Introduction and Hypothesis

To successfully complete my thesis, I implemented user interaction design and user research methodologies to help redesign a website for Transcend the Binary, a Michigan-based transgender health organization. This paper and research will attempt to answer the question, what special considerations need to be addressed to design a website for transgender people and their providers? In addition to employing user research and design methodologies, I conducted a literature review of relevant information from the fields of public health and information science.

The objective of my thesis is to use user experience methodology to create a website information architecture that meets the organization's goals of connecting transgender people with competent healthcare providers, and equipping providers across Michigan with the knowledge to serve transgender patients.

Founded in 2008 by Darnell Jones, a cisgender pharmacist and his transgender patients. Transcend the Binary's board and leadership comprises gender diverse health care providers, journalists, and a graphics designer. The organization is bifurcated into two teams, a clinical care team and a communications team. The "Care Team", consists of two pharmacists, a personal trainer, health advocates, and a therapist. The Creative, Communications, and Outreach (CCO) team is tasked with communication and outreach. I worked closely with the CCO team to learn more about the organization, website, and needs.

A quality redesign required a survey of articles and books about transgender people, health seeking information, and user experience best practices. I begin with a review of relevant literature, followed by a review of research methodologies used, a report of research findings, and finally a recommended sitemap.

Chapter 2: Literature Review

A 2015 Survey from the National Center for Transgender Equality found that a third of the study's 28,000 respondents had experienced some form of discrimination in a health care setting. The study, the largest of its kind, reported a quarter of its respondents had avoided going to the doctor, due to fear of mistreatment (James, Herman et al 2016). Similarly, research conducted by Transcend the Binary found high levels of mistreatment or perceived mistreatment. According to the survey, conducted with transgender people within the state of Michigan respondents either experienced mistreatment in the health care setting, or their concern about mistreatment in a health setting caused significant anxiety (Lewis, et al 2017).

Despite reports of mistreatment, education and implementation of gender-affirming policies and procedures in health care has increased (Daniel and Butkus, 2015). However, there remains a lack of knowledge and a need for further education. Research by Dowshen et al, demonstrated an overall need for further education within the medical community (Dowshen, et al 2014). Research by McPhail outlined this need and suggested steps toward a better transgender health care experience through provider education. McPhail suggested better educated medical providers can significantly impact the health care experience (McPhail et al, 2016). Through training about better clinical practices, bedside manner, and recognizing socio-cultural barriers, health care providers can increase their patient's quality of life and health outcomes.

While documented lack of competent health care providers exists, research shows that transgender people seek out medical information online. Research by Scheuerman suggested transgender people use the internet as a place to build community, and find resources (M. K. Scheuerman et al, 2018). This idea of the internet as a both a safe space and meeting space, was found throughout research on LGBTQ people overall, but especially transgender people. Scheuerman (2018) implied the focus on digital space is due to a lack of formal support networks in the analog world, and an increase in virtual spaces that facilitate meeting, identity exploration, and exchanging ideas for sexual and gender minorities.

In addition to using the internet as a means to build community, research suggested that transgender health information and resources are also discussed via social media. Research by Karami, Kitzie, and Webb (Kamari et al, 2018) proposes that transgender people write about everything from clinical experience, their health journey, and diet on twitter. The tweets analyzed in the study ranged from personal anecdotes to resources, and reviews of health services. Due to the limitations of LGBTQ health research, Karami et al proposed that social media is used as source of transgender health information. Writing, “identifying the health-related concerns and interests of transgender Twitter users can help medical and public health experts better understand the needs of sexual and gender minorities” (Kamari et al,2018).

Additional research by Hawkins and Haimson about transgender identity and health care navigation on Tubmblr reiterates the importance of digital space for the transgender community. Focused on mental health, the study stated, “participants found that just being on Tumblr and observing others’ transition-related content by scrolling through their feed was helpful for their mental health” (Hawkins and Haimson, 2018). Through hashtags and the ability to follow other blogs, “Tumblr created opportunities for do-it-yourself health and self-care during the transitioning process.” The Karmai and Haimson articles stressed the importance of digital space as a means to share resources and find support, in passive and active ways.

In addition to using the internet to build community, there are also instances of transgender people using the internet to navigate cultural and systemic barriers. A group of designers and researchers in the United Kingdom created GotYourBack, a native mobile application that helps transgender people find safe bathrooms. Though the application was never released to the public, its design process yielded important information. Outlined in an academic article written by Beirl (Beirl, 2017), the team behind the application utilized user experience design methodology to create a digital platform that allowed user to list and rate the safety of public bathrooms. Using Bluetooth and the “Toilet of Things,” the application helped people find gender neutral bathrooms, or gendered bathrooms with “supporters” nearby. Due to the level of public harassment and discrimination reported by transgender people, the mobile application attempted to solve this problem through geolocation and a community rating system. Beir’s article outlined a design process that included several iterations, beginning with a sketch, lo-fi prototype, and user interviews. Though the application was never released, the article is significant because it outlined the design process for a transgender specific product.

The transgender community is not a monolith and a variety of needs may arise throughout the design process. Thus, research on design for older adults, may be helpful. In her paper “Addressing Social Connectedness and Social Isolation Among Older LGBT Adults Through Software Design” Fatima Vergara (Vergara, 2018) explored the role of web design and health for LGBTQ older adults. Presented as part of her master’s thesis at California State University Long Beach, Vergara designed a social media application to help older LGBT adults connect with others. Her designs, though conceptual were well received by testers and illuminates the desires, possibilities, and challenges with designing for older LGBT adults. Vergara found that LGBTQ older adults were skeptical of some aspects of social media, like its privacy limitations. However, this demographic had a higher likelihood of social isolation. Thus, respondents found a simple application favorable. Due to a desire for human connection, Vargas reported that older adults were open to digital interaction, despite concerns about privacy.

To properly answer my research questions about the health information seeking habits of a community, I learned more about general health information seeking behavior, and how to design health information. People employ a variety of methods when seeking health information, research by Pang suggested there are four main health information seeking types, these include; quick fact seeking, all-around skimming, focused reading or knowledge digging (Pang, 2016). In addition to the four types of information seeking ways Pang put forth, there are two dimensions of health seeking behavior; reading engagement and research tactics. Reading engagement can be characterized as committing (either a short or long time) to reading information, whereas research tactics “captures that a seeker intends to gain a comprehensive understanding or merely seeks basic facts about the health problem” (Pang, 2016). Pang concluded the paper by asserting the user interfaces and information architecture should be designed to reflect reading and research behaviors, not just user archetypes.

Outside of general health information seeking behavior, transgender people may have unique information seeking behavior and barriers. Research by Pohjanen (Pohjanen,2016) suggested that due to social and psychological barriers, transgender people seek and share information related to their health and identity in unique ways. The barriers outline by Pohjanen included financial barriers that restricted access to the internet, or cultural barriers that included fear of being outed due to someone discovering that an individual had been searching for

information related to transgender identity. Additionally, there were barriers related to the information itself. Specifically, information that was “misinforming, misleading, one-sided or outdated” (Pohjanen,2016). Finally, Pohjanen found “sharing information played a big part in the information behavior of the transgender participants.” When presented with information they found helpful, study participants shared the information with others in their social network. This gestured toward the importance of community crowdsourcing in the information seeking and finding process.

In addition to information seeking habits, there is a limited body of work about “trans-inclusive design”. Coined by Erin White, (White, 2019) head of digital engagement at Virginia Commonwealth University, trans-inclusive design is a method of designing fluid information and interactions that meets the needs of transgender people. White’s recommendations include a focus on privacy, flexibility of use that would allowing a user to change or delete a name, not asking for gender/sex if not relevant, and allowing for users to track and report harassment.

While White’s research focuses on designing for transgender people specifically, the concerns it addresses were similar to health information seeking behavior of a similar and overlapping demographic, LGBTQ youth. Research on the sexual health information seeking habits of LGBT youth by Magee, Bigelow, Mustanski (Magee et al, 2012) proposed that LGBT youth rely on online health information due to the limited availability of comprehensive sexual health information in other places. The study’s respondents reported using the internet when concerned about emergent and preventive sexual health measures. However, the cultural stigma and fear of being perceive as LGBTQ impacted how, when, and where they searched for sexual health information.

Due to the level of medical mistrust, research on how to build trust and how the public discerns trustworthy medical information was consulted. Research on websites and medical trust conducted by Singal and Kohli (Singal and Kohli,2016) shed light on the various models for building trust online. Singal and Kohli’s model suggests that there are two primary methods, generalized and institutionalized trust. A person’s level of generalized trust is seen to “influence the degree to which he or she will be willing to extend trust in the to a new website” (2016). While Institutionalized trust is trust in the internet itself. The model put forth by Singal and Kohli’s suggested that user must not only trust the information from a website but must also be invested in the trustworthiness of information from the internet.

Additional research on trust and credibility by user researchers Aidan Bryant and Vandhana Ramadurai (Bryant and Ramadurai, 2014) illustrated the importance of design in the trust building process. Bryant and Ramadurai's research outlined the anatomy of a trustworthy and credible website. In addition to up to date unbiased information, users expected an easy to follow navigation system, simplified presentation of complex information, and credentialed authors.

While design for transgender people may have unique features, overall the canon of user experience design gives great insight into standard web and information design best practices. Don Norman's *Design of Everyday Things* (Norman, 2013) outlined the core principles of human-centered design. Norman's work stressed the importance of designing for users, in all their complexities. His focus on simplification, creating systems that match user expectations, and designing for cognition create a guide for designing digital products that meet user needs.

In addition to *Design of Everyday Things*, Susan Weinschenk's *100 More Things Every Designer Needs to Know about People* (Weinschenk, 2011) outlines the "how and why" behind human centered design. Focused on cognition and perception, Weinschenk's work gives helpful guidance on how to design for experience. Divided into sections about how people see, think, decide, and interpret information Weinschenk views the design process as a mix of psychology and digital anthropology.

While, *Design of Everyday Things* captures the importance of human-centered design, *This is Service Design Doing*, uses similar principles to design human-centered services. According to Stickdorn et al, service design, is human-centered, ephemeral, collaborative and holistic. The service design model recognizes the multiple actors associated with a service that include, but are not limited to, the person receiving the service. Thus, stakeholders must be an integral part of the design process. Though it follows a similar model of discover, ideate, and prototyping, service design uses some unique processes. Stickdorn suggested participatory research methods such as persona workshops, vision boards, and other methods that bring stakeholders together and help articulate design problems. Focuses on balancing the needs of all stakeholders throughout the design process, the role of the service designer is a facilitator, peacemaker, and statesman.

Service design incorporates usability testing, an important aspect of the Human-centered research and design process. Jeffrey Rubin and Dana Chisnell's *Handbook of Usability Testing* (Rubin, J., & Chisnell, D. 2008) outlined user testing methodology and the importance of incorporating user testing findings. By user testing throughout a design process, according to Chisnell and Rubin, designers can learn about the "goals and priorities of its customers" providing a competitive advantage and saving time. While Chisnell and Rubin are clear there is no one size fits all way to conduct usability testing, they create a series of suggestions and guidelines. These include, creating a hypothesis, development of research questions, defining a representative sample of end users, testing representation of the actual work environment, analysis of data, and creating design recommendations based on research findings.

Rubin and Chisnell's work on usability testing was similar to suggestions found in Krug's *Rocket Surgery Made Easy* (Krug, 2010). Krug suggested testing product ideas early and often, as a way to learn more about user challenges and guide a product timeline (2010). Krug even proposes conducting user tests on competitor websites, and websites that are not connected to the researcher's immediate product area. According to Krug, learning more about a competitor's website, or a feature you'd like to implement on your site could be a way to drive product innovation.

While service design focused on researching and designing for stakeholders, *A Web For Everyone* focused on designing for users with a variety of abilities. A foundational book in the emerging field of accessible and inclusive design, *A Web for Everyone* (Horton, S., & Quesenbery, 2014) provided guidelines to designing for users with disabilities, language diversity, and neurodiversity. Though each user is unique, Horton and Quesenbery suggested implementing helpful wayfinding text and icons, clean presentation, flexibility of use, and plain language among other things, can contribute to an accessible digital experience.

Similar to Stickdorn's service design model, accessible design pays special attention to user's context of use, incorporating them into the design process from start to finish. Horton and Quesenbery stress that accessibility is not a process of adapting code after a product had been built. Instead, accessibility is defined as a design thinking framework that captures the experiences of users, incorporating them throughout the design process.

Chapter 3: Methods

To successfully complete my thesis, I implemented user interaction design and user research methodologies to help Transcend the Binary, a Michigan based transgender health care organization, build a website that met the community's and organization's needs. These methods included a content inventory, heuristic evaluation, analysis of the site analytics, user interviews, competitor analysis, and contextual inquiry. The methodologies used helped me better understand user behavior and best practices to drive the site redesign. In order to understand information seeking habits and where users currently get health information, I interviewed users. To get a baseline understanding of the site's mission and function, I conducted a content inventory, heuristic evaluation, and analyzed site metadata. Finally, to create a usable and familiar product, I conducted a competitor analysis. The various methodologies used will be explained in this section, while specific results will be explored in the results section of the paper.

Content Inventory

Though the organization's website is small, I needed to understand its current state. Using a spreadsheet, I conducted a content inventory, documenting the site navigation levels, media, links, file formats, and calls to action. The results of the content inventory are located in Appendix A.

Heuristic Evaluation

To better understand the site's strengths and limitations, I conducted a heuristic evaluation. I evaluated the site using Jakob Nielsen's set of ten criteria for optimal user experience. Using this model, I evaluated the site's user interface included, but not limited to the site navigation, forms, flow, and content. The results of the evaluation can be found in the results section of the paper.

User Interviews

In order to answer my thesis questions about the ways in which transgender people access medical information and how to best present this information, I conducted user interviews. Interviewees consisted of the site's main demographic, transgender people in the state of Michigan over the age of 18. User research participants were recruited through social media,

email blasts through the organization's listserv, and word of mouth. All user interview participants were screened via a Google form submission. The form, found in the appendix of this paper, asked key demographic questions about the participant's disabilities, age, race, location, and gender identity. Additionally, the form included brief questions about the person's experience of discrimination based on racial, gender, and sexuality.

User interviews were conducted via phone or the video-conferencing tool Zoom and lasted from 60-75 minutes. The questions focus on learning more about user's information seeking habits, where they currently find health information, and ended with a few questions about the site's current state. To incentivize participation, participants were given a \$25 Amazon gift card after completing the interview.

After a month of promotion, 16 people replied to the call for participants. Several were not in Michigan and had not lived in the state. While 12, respondents met the study's user demographic profile, 4 did not respond to my request for an interview. In total, 8 users were interviewed, their responses and insight can be found in the results section of the paper.

Competitor Analysis

Digital health communication is a well-established field, even for an emerging subsection like transgender medicine. I conducted a two-step competitor analysis to better understand what content structures, media, and information structures are currently used by patients and providers. First, I asked the organization's care team to create a list of thought leaders in the field of transgender health research and clinical care. Then, I created a list of these organizations and evaluated their website's messaging, feel, features, and navigation. Second, I conducted a Strengths, Weakness, Opportunities, and Threat (SWOT) analysis of each site, highlighting strengths and opportunities for growth. Analysis of this information can be found in the results section of the paper.

Ethnographic Research/Contextual Inquiry

To better understand the patient intake process, I went through an intake simulation with Transcend the Binary. Completing the process like a potential patient, I contacted the organization through a form found on the website. Then, scheduled a meeting with a health advocate using Doxy, a Health Insurance Portability and Accountability Act (HIPPA) approved

video service. This was a key step to learning more about how the website facilitates client interactions, connection with health care providers, and establishes trust throughout the user journey.

Chapter 4: Results

Content Inventory

In order to redesign the website, I had to better understand its current state. Thus, I completed a content inventory, cataloguing the site's content and features. The site consisted of seven top level navigation labels and a footer that included contact information and social media links. In addition to biographical information about the organization and leadership, the site included a press area, brief overview of services offered, and PDFs of intake forms. Designed to attract transgender people, and their providers, parts of the site were dedicated to provider education and academic researchers. Though this section was the least developed, it featured copies of a public art exhibit, trainings, and other opportunities offered by the organization. The trainings and exhibit information are also a significant part of the organization's business model. By charging providers for trainings and institutions for the rights to host the art exhibit, Transcend the Binary is able offer free services to the community.

There were only seven top level navigation labels and the longest navigation tree was four pages. Additionally, the content inventory uncovered repetition within the site map. For example, multiple calls to action led users to the same sections within the site. A heuristic evaluation conducted after the content inventory explores the quality of the site navigation and content, this will be discussed in the next section.

Heuristic Evaluation

Utilizing user experience heuristic created by Jakob Nielsen, I conducted a heuristic evaluation to gain a deep understanding of the site's current state and limitations.

- Criteria 1: Visibility of system status. Always keep users informed about what is going on.

The services section of the website had icons that look like clickable buttons. However, they were static images. Additionally, the site had broken navigation links throughout. There is a weak brand identity because the organization's mission is not prominent or identifiable. Additionally, more information was needed about services and trainings. The site content eluded to a plethora of services, however there were no details about the

services offered. Also, information about the organization's history was located in the media section, not clustered with information about the organization's leadership.

- Criteria 2: Match between system and the real world. Speak the users' language, with words, phrases and concepts familiar to the user, rather than system-oriented terms.

The "services we offer" tab does not give in depth information about services. Many calls to action lead people to the services tab, however the site does not give information about the services offered.

- Criteria 3: User control and freedom, allow users to recover from mistakes.

There were several broken links throughout the site, however users are able to recover with the use of an internet browser back button. Also, there are sections of the website where the site navigation is not visible. This prevents users from navigating to other parts of the website.

- Criteria 4: Consistency and standards. Users should not have to wonder whether different words, situations, or actions mean the same thing.

Though the site is small, there is no consistency between page layouts. Additionally, pictures and biographies of the organization's leadership are not consistent.

- Criteria 5: Error prevention. Even better than good error messages are a careful design which prevents a problem from occurring in the first place.

There are calls to action and links that lead to standard error messages.

- Criteria 6: Recognition rather than recall, Make objects, actions, and options visible. User should not have to remember information from one part of the dialogue to another.

Site has one central contact form; all information is visible. However, clients are emailed pdf intake forms. Making a web intake form could shorten the intake process.

- Criteria 7: Flexibility and efficiency of use accelerators, allow users to tailor frequent actions.

The site has a relatively straight forward site navigation.

- Criteria 8: Aesthetic and minimalist design Dialogues should not contain information which is irrelevant or rarely needed.

Aesthetically appealing, clean minimalist layout across site. Images and information on leadership page could be more standardized. Additionally, the site is word heavy with very little visual contrast. More pictures and video could provide balance.

- Criteria 9: Help users recognize, diagnose, and recover from errors Expressed in plain language (no codes). Precisely indicate the problem.

No redirect/error message from broken links. Additionally, some pages of the site were missing a menu, so users have to use the back button to navigate back.

- Criteria 10: Help and documentation, even though it is better if the system can be used without documentation, it may be necessary to provide help and documentation.

The “What We Offer” tab had no helper content for providers to get additional training.

User interviews

Throughout October, I conducted 8 user interviews with transgender people living in Michigan to learn more about their health information needs and pain points. The questions asked can be found in the appendix section of the paper.

Internet usage and device questions

All interview respondents reported regularly using the internet throughout the day for personal and professional reasons. “I use the internet for work and social stuff” said Aaron, a recent college graduate (Aaron, October 30, 2019). Though all interviewees used the internet on a daily basis, access to the internet was difficult for two people. “Internet service is pretty terrible out here. I have to wait until I get to the city if I want to do much” said Petunia, an Animal Scientist living in central Michigan (Petunia, interview, October 28, 2019). While geography was not an issue for Ebony, a community organizer living in east Detroit, cost was prohibitive. During our interview Ebony disclosed that she used her phone to access the internet due to the cost of WIFI service. Exclaiming, “I didn’t think about it before. But, WIFI at home is a real blessing. So, my phone is how I get stuff” (Ebony, interview, October 15, 2019).

Current Transgender Health information

When asked where they received health information, there was significant overlap in responses. All interviewees identified a doctor or nurse practitioner as their primary source of medical information. When asked how they found this resource, interviewees identified community recommendations or internet search engine queries. Tiffani, a restaurant manager in Southeast Michigan said, “I asked the community who they go to.” (Tiffani, interview, October 29, 2019). Nathan, a transgender man living in Detroit said, “I start with activists or people who have been out for a long time. I feel like they know who to trust and go to” (Nathan, interview, October 22, 2019).

In addition to a health provider, interviewees identified online message boards and social media sites as their second source of gender related health information. Social media platforms like Twitter and Instagram were popular, however sites that allowed users to have more dialogue and long form conversations were the most popular. Websites and applications like Reddit, Tumblr, and Discord were the most popular with interviewees. “Tumblr and Facebook groups are super helpful” said Aaron (Aaron, October 30, 2019), while Petunia stated that due to her geographic isolation, she’d “have no idea how to find a doctor or even other people if it weren’t for Facebook Groups” (Petunia, interview, October 28, 2019). In addition to blogs, two respondents mentioned Susan’s Place, a blog and website for older transgender women as a resource.

When asked how their current medical information could be improved, respondents had a diversity of answers. Amber, a data scientist in Detroit and Petunia both expressed concerns about the lack of medical information for older adults. “Sometimes it really feels like a guessing game. The research just is not out there” (Amber, interview, October 24, 2019). Despite age, none of the interviewees felt there was a comprehensive place where they could get information. However, all interviewees said they used the internet to researched health information extensively. “Sometimes I have to educate my doctor” said (Nathan, interview, October 22, 2019). While Amber stated, “My doctor is fine, but I have to make sure I’m vigilant because of my [chronic health condition]. So, I read, a lot” (Amber, interview, October 24, 2019).

Medical Information and Trust

Due to the high level of mistreatment and discrimination experienced by transgender people in a medical setting, a portion of the questions were focused on how people find and discern trustworthy medical information and providers. All 8 of the interview responses said community recommendations weighed heavily on their choice of providers. Similar to responses about finding medical providers, health information was crowd sources and input from the community was an imperative.

The importance of community input and trust translated to digital spaces for interviewees as well. Interviewees who gathered health information from social media used each platform’s “Like” feature and comments to discern if information was accurate. For example, a tweet about surgery side effect that received several likes, meant the comment was most likely accurate. By

using the platform's like feature, users communicated a shared experience that demonstrated the information being shares was correct. "If I see a post on reddit with a lot of up votes. Or like, if someone answers a question, and it has 45 likes, it means it resonates with a lot of people. So, I trust that" said Aaron (Aaron, October 30, 2019). "Our community is quick to tell you if something is wrong. So, if people like something, it is an easy way to say they have either experienced it or know someone who has" said Ebony (Ebony, interview, October 15, 2019). Through word of mouth or social media interaction, users were able to crowd source health information that may be missing from transgender health research.

In addition to community input, presentation of information was a hallmark of trustworthiness. Ebony, Amber, and Petunia expressed that dated content, including research, pictures, and event information made websites they had visited feel untrustworthy. "I cannot tell you how many pages I've been on and they haven't updated the info. Most of the time, I wonder if they are even still operating" said Amber (Amber, interview, October 24, 2019). "If your research is from like the 90's, I don't trust it. It ain't perfect, but we've come far. As far as the information side of things" said Ebony (Ebony, interview, October 15, 2019).

Product Opportunity Questions

Only 3 of the interview respondents had spent time on Transcend the Binary's website, so the last segment of user interviews was dedicated to learning more about product opportunities and getting feedback on the current site. When asked about the current website, interviewees said the site looked professional and trustworthy- but lacked substance. Two interviewees, Amber and Tiffani said they found the information outdated. Amber said, "This has event information from 2016 and we are almost through 2019", (Amber, interview October 24, 2019). Aaron did not notice the dated information but commented that the website "looked like a website for an app that hasn't launched yet", due to the site's misuse of "icons that looked like they could be buttons" (Aaron, interview October 30, 2019).

All interviewees commented on the website aesthetic appearance. Using words like, "clean" or "professional" to describe the site's appearance. However, no participants could identify the organization's mission and goals despite spending several minutes on the landing page and internal pages. "I don't really know what y'all do" said Ebony (Ebony, interview,

August 15, 2019). While Nathan said, “I know they help the community, but I can’t really articulate all they do looking at the page” (Nathan, interview, October 22, 2019).

When asked what information they would like to see on a transgender health website interviewee had a diversity of needs and desires. Amber and Petunia said they would like to see more information about aging (Petunia, interview, October 28, 2019) (Amber, interview October 24, 2019). Additionally, both women wanted more access to transgender related research. “I’d like to see more actual research” (Petunia, interview, October 28, 2019). Several interviewees wanted a calendar of local and statewide events, all 8 interviewees wanted a posted list of trusted health care providers. “Why be gatekeepers? Don’t make people contact you for a list of doctors. If you have that information, share it.” (Petunia interview, October 28, 2019). “A list of doctors and therapist would be great”, said Nathan (Nathan, interview, October 22, 2019). “I just came out a few months ago, so a list of good therapists or like a surgeon when I’m ready” said Andrea, a food service employee from suburban Detroit (Andre, interview, October 5, 2019).

The user interviews conducted illuminated several things about how transgender people access health information, and what their information needs may be. First, community input is important. Those interviewed overwhelmingly trusted the opinions and advice of others within the community, in physical and digital spaces. This aligns with research conducted by Beirl, and Haimson respectively, that suggested online communities serve as health information platforms for sexual and gender minorities. While all users interviewed said they did seek out and trust medical providers, they also gave the same weight to information from those within the community. Second, those interviewed said they were skeptical of outdated or poorly designed information. This echoed work from Norman about the need for consistency in fulfilling user expectations. Furthermore, user interview responses suggest transgender people often conduct their own health research. This reinforces Karami’s claim that transgender people actively use the internet to find health research and resources.

Competitor Analysis

The websites that I analyzed were a mix of transgender health clinical providers and resource aggregators. They included RAD Remedy, University of California, San Francisco’s Center of Excellence for Transgender Health, University of California, San Francisco’s Transgender Care Clinic, the Fenway Clinic, and MyTransHealth.

RAD Remedy

A search engine that allows people to search and add a list of health care providers. The main goal and features of the website is centered around finding a provider or adding a provider. Provider pages included information about their specialty, location, and a section for user to leave a review. Additionally, the website had a small health zine (short for magazine) library. Search results were not specific to a city, and the website has a professional look and feel.

University of California, San Francisco's Center of Excellence for Transgender Health

University of California, San Francisco's Center of Excellence for Transgender Health was suggested by several healthcare providers as the premiere destination for providers seeking research articles and information about transgender health. The website, geared toward clinicians and researchers, features a search engine for transgender health publications, white papers about demographic health, treatment information, and training opportunities for health professionals. Though informative, the website had large text blocks and few pictures.

University of California, San Francisco's Transgender Care

The website dedicated to University of California, San Francisco's clinical transgender care practice is informative and simple. The site's mission is to help users learn more about treatment and find a provider. It features several PDF resources about medical transition in multiple languages. Similar to the UCSF's Center of Excellence for Transgender Health, the Transgender Care clinical site had no pictures and was mainly text based.

The Fenway Clinic

Another premiere research and clinical care provider, Fenway Health offered resources to patients and providers. The website consists of two parts; the clinical treatment focused Fenway Clinic, and the research focused Fenway Institute. Within the clinical site was a page dedicated to transgender treatment and care. Though the section was small, it had a lot of resources that include links to webinars for provider education, pre-appointment forms, a comprehensive list of community organizations, pamphlets and bilingual health education resources. Though the information was useful, the page is full of PDF links, making it inaccessible to anyone using a screen reader. Additionally, most of the page's information was kept in an accordion style menu. The information was so rich, each section could be its own page. However, this key information was kept in small sections, focusing users to click through each section of the accordion.

MyTransHealth

Designed by a team of transgender software engineers and designers, MyTransHealth is a search driven website. The website was clean, professionally designed, and had an overall positive user experience. Users were asked about their location and service needed, then are presented with search results. Results display the provider name, contact info, and area of practice. The areas of practice range from massage therapists to doctors and non-traditional medicine. Though it was well designed and easy to use, the website did have challenges. First, users can only access the search feature from the homepage. Second, information can be submitted by the public, but there is no information about how the providers are vetted. Additionally, the website information provided was limited to major cities like New York and San Francisco. However, this is not communicated to users until they searched for resources in their area.

The competitor analysis was fruitful for two reasons. First, it gave me key insight into the current state of transgender online health and education resources. This helped create an information architecture that users recognized and could associate with trusted health providers. Moreover, an analysis of competitors revealed several themes that reinforce the information needs outlined in literature and user interviews. For example, each website had a clear connection to the transgender community. This communicates trust, and credibility. Additionally, each site included holistic resources. Recognizing the level of discrimination faced by transgender people, each website had links to housing and legal resources.

Ethnographic Research/Contextual Inquiry

To better understand how the website fits into the user journey, I conducted an ethnographic study. This informed me of the complete user journey, and how the website helps users meet their goals. Currently, all clients must send the organization an email through a web form in order to begin services. After the form is received, clients are emailed a two-page PDF and asked for suggested times to meet with a health advocate online or via phone. During the first meeting, the patient is given a needs assessment. After the initial meeting with a health advocate, the client receives an email to meet with a clinical provider.

After my intake experience, I incorporated my notes into the site redesign strategy and recommendation. Currently, the website is used to begin the relationship with clients. However, clients do not return to the website after they begin the intake process. After learning more about the customer journey, I looked for ways the website could help Transcend better serve the community throughout their transition.

After conducting research, I found key themes that could be integrated into the site's design. First, trust and credibility through relationships are paramount. User interviews and the competitor analysis demonstrated the importance of trust through a connection to the transgender community and established medical providers. Each site had a clear connection to the transgender community and communicated this through visual and written content. This, in combination with information from established medical providers, built trust and credibility.

Additionally, access to resources was a recurring theme. Each competitor site had a list of resources, often holistic in scope. This included research and referrals to local agencies. The need for holistic resources was reinforced in user interviews. All interviewees said they would expect to see a list of resources and providers on a community health website. Finally, up to date and modern looking websites were important. Users interviewed and the competitor analysis demonstrated that outdated information or poor web design failed to garner trust.

Chapter 5: Recommendations

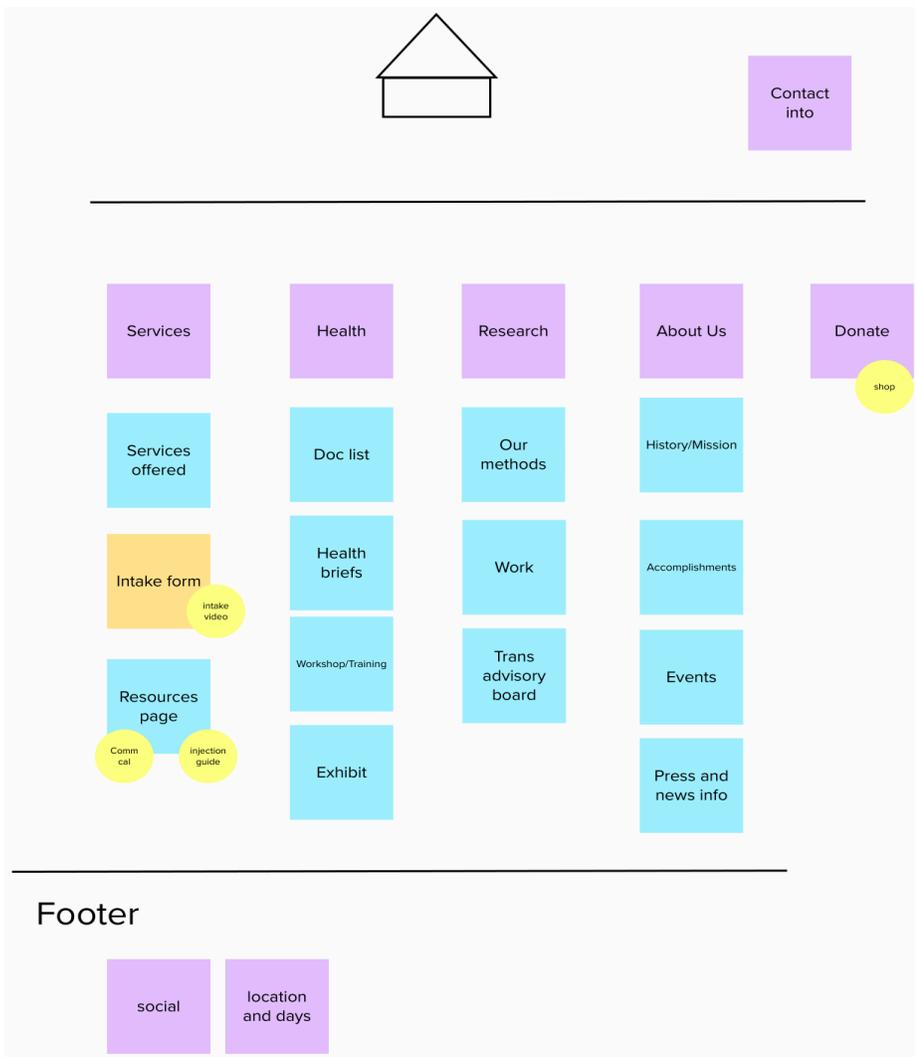
After extensive user research, recommendations and a site architecture were drafted.

The website's high-level needs included:

1. Content that explicitly states the organization's mission
2. Strong calls to action that lead users to their desired areas of the site
3. Contact information
4. Shortening the intake process and removing extra steps
5. A community calendar
6. More pictures, especially of transgender people
7. Information about trainings and professional opportunities that could be used as a revenue

Site Map

After research, and ongoing meeting with the organization's leadership, a proposed site map was created. The information architecture of the site is focused on meeting user, organizational, and business goals. Themes uncovered through research including trust, credibility, holistic resources, and barrier free presentation of information were incorporated into the site's new design concept. In order to meet the need of the site's main demographics, I separated information into three main areas: resource for patients, resources for providers, and researchers. Below is a picture of the proposed site map, along with the rationale for each decision.



Home

Home, or the landing page will display information about the organization's mission statement and highlight the organization's free services. None of the users interviewed could identify the organization's mission. Thus, making the mission and cost-free services more explicit was important to user retention. Additionally, the home page would feature pictures and calls to action to produce a strong information scent, driving user to the site's main buckets: health services, training, or research. The organization's contact information will remain in the header, because it was viewed favorably by users during user interviews.

Services

The services tab will have a detailed list of services and links to the organization's intake page, resource page, and community calendar. The services offered page will be a full list of services offered by the organization including legal services, health navigation, and health services. The intake page in the services tab will have a short video about the intake process, and a web form for users to complete. This eliminates the need for users to download and send their forms. Due to the financial, geographic, and technical constraints facing the transgender community, eliminated extra steps and barriers may lead to a better user experience. The resources page will have a list of community, statewide, and national resources. The community calendar will be an ongoing calendar of transgender related community events. The calendar feature was included because 5 of the 8 users interviewed said they would like to see a list of transgender related events in their city.

Health

The health tab will include content written by the organization's health team. This includes white papers and health briefs. Additionally, this tab will contain a link to a list of vetted health providers.

Research

The research tab will include a page about the organization's research methodologies, published research, and presentation briefs. Additionally, it will feature a link to the Michigan Trans Advisory Board, a Google group for Michigan based trans health researchers.

About Us

The "about us" tab is critical to establishing trust and credibility with patients and providers. User interviews and literature reviews reiterated the importance of transgender people as a resource and a way to verify quality care. Thus, more information about the history and leadership of the organization can build its credibility with transgender people seeking help. Moreover, including academic information and credentials of the organization's leadership will help build trust with medical providers looking for training or referral information. This tab will also include press and news information.

Donate

Finally, the donate tab will lead to a donation page and shop. Allowing users to donate to the organization outright or purchase a t-shirt, this will help with revenue streams, a desire communicated by the organization.

Chapter 6: Design Impacts and Implications

Literature on transgender health information seeking behavior suggested that the internet is a hub for information and community building. Thus, Transcend the Binary's new site map reflected these priorities. A list of trusted providers and a community calendar make key information findable, while the shortened intake process and easy to find contact information reduces barriers and increases transparency. Additionally, providers throughout the state of Michigan will be able to find and locate training opportunities to expand their knowledge of clinical practice.

A well-designed modern website that incorporated recommendations could lead to an increase in clients and revenue streams for Transcend the Binary, meeting their organizational and business goals.

Chapter 7: Next Steps

Due to concerns about the Health Insurance Portability and Accountability Act (HIPPA) health care providers were excluded from this study. Moving forward, I will recruit health care providers to test the site's architecture and content. The next steps in the project is to create a low fidelity prototype of a possible website. Working collaboratively with Transcend's communications team, I will test the proposed site navigation using a process known as "tree jacking". After tree jacking, the organization's content writers will develop the site content and the project will move to production.

References

- James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). *The Report of the 2015 U.S. Transgender Survey*. Washington, DC: National Center for Transgender Equality
- Baldwin, A. M., Dodge, B., Schick, V., Sanders, S. A., & Fortenberry, J. D. (2017). Sexual minority women's satisfaction with health care providers and state-level structural support: Investigating the impact of lesbian, gay, bisexual, and transgender nondiscrimination legislation. *Women's Health Issues, 27*(3), 271-278.
- Dowshen, N., Nguyen, G. T., Gilbert, K., Feiler, A., Margo, K. L., & Stroumsa, D. (2014). Improving Transgender Health Education for Future Doctors/First Responders. *American Journal of Public Health, 104*(7), e5-6.
- McPhail, D., Rountree-James, M., & Whetter, I. (2016). Addressing gaps in physician knowledge regarding transgender health and healthcare through medical education. *Canadian medical education journal, 7*(2), e70.
- Scheuerman, M. K., Branham, S. M., & Hamidi, F. (2018). Safe Spaces and Safe Places: Unpacking Technology-Mediated Experiences of Safety and Harm with Transgender People. *Proceedings of the ACM on Human-Computer Interaction, 2*(CSCW), 155.
- Karami, A., Webb, F., & Kitzie, V. L. (2018). Characterizing transgender health issues in twitter. *Proceedings of the Association for Information Science and Technology, 55*(1), 207-215.

- Hawkins, B. W., & Haimson, O. (2018, May). Building an online community of care: Tumblr use by transgender individuals. In Proceedings of the 4th Conference on Gender & IT (pp. 75-77). ACM.
- Beirl, D., Zeitlin, A., Chan, J., Loh, K. I. A., & Zhong, X. (2017, May). GotYourBack: An Internet of Toilets for the Trans* Community. In Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems (pp. 39-45). ACM.
- Vergara, F. (2018). Addressing Social Connectedness and Social Isolation among Older LGBTQ Adults through Software Design. California State University, Long Beach.
- Pang, P. C. I., Chang, S., Verspoor, K., & Pearce, J. (2016). Designing Health Websites Based on Users' Web-Based Information-Seeking Behaviors: A Mixed-Method Observational Study. *Journal of medical Internet research*, 18(6), e145.
- Pohjanen, A. M., & Kortelainen, T. A. M. (2016). Transgender information behaviour. *Journal of Documentation*, 72(1), 172-190.
- White, E. (2019, May 11). Trans-inclusive Design. Retrieved from <https://alistapart.com/article/trans-inclusive-design/>.
- Magee, J. C., Bigelow, L., DeHaan, S., & Mustanski, B. S. (2012). Sexual health information seeking online: a mixed-methods study among lesbian, gay, bisexual, and transgender young people. *Health Education & Behavior*, 39(3), 276-289.
- Singal, H., & Kohli, S. (2016, March). Intellectualizing TRUST for Medical Websites. In Proceedings of the Second International Conference on Information and Communication Technology for Competitive Strategies (p. 83). ACM.

Bryant, A., Ramadurai, V. (2014). Collaborative Healthcare: Credibility and Navigation on the Internet. *User Experience Magazine*, 14(3).

Retrieved from <http://uxpamagazine.org/collaborative-healthcare/>

Norman, D. (2013). *The design of everyday things: Revised and expanded edition*. Basic books.

Weinschenk, S. (2011). *100 things Every Designer Needs to Know About People*. Pearson Education.

Stickdorn, M., Hormess, M. E., Lawrence, A., & Schneider, J. (2018). *This is service design doing: Applying service design thinking in the real world*. " O'Reilly Media, Inc."

Rubin, J., & Chisnell, D. (2008). *Handbook of usability testing: how to plan, design and conduct effective tests*. John Wiley & Sons.

Krug, S. (2010). *Web usability: rocket surgery made easy*. Pearson Deutschland GmbH.

Horton, S., & Quesenbery, W. (2014). *A web for everyone: Designing accessible user experiences*. Rosenfeld Media.

Appendix

Appendix A
Content Inventory

The spreadsheet document included:

- Unique Content ID
- Title
- URL
- File Format (HTML, PDF, DOC, TXT...)
- Author or Provider
- Physical location (in the content management system, on the server, etc.)
- Meta Description
- Meta Keywords
- Categories/ Tags
- Dates (created, revised, accessed)

Appendix B

Pre-Screening Questions

1. I am a member of the trans/gender diverse community.
 1. Yes
 2. No
2. First Name
3. Last Name
4. My Pronouns
5. My gender identity
6. Race/ethnicity
 1. African America/Black
 2. Native American/Indigenous
 3. White
 4. Biracial
 5. A race/ethnicity not listed
7. Do you live in Michigan?
8. Do you have one or more impairments/ disabilities?
9. If you feel comfortable, please elaborate on your impairment(s)/ disabilities?
10. The following apply to me:
 1. I am/have experienced homelessness or houselessness
 2. I've experienced discrimination for my sexual / attractional identity
 3. I've experienced discrimination for my race / ethnicity
 4. I've experienced discrimination for my gender expressions and presentation

5. I've experienced discrimination for my religious / cultural expression and presentation
6. I've had difficulties getting access to affirming care
11. Sexual Orientation
12. Date of birth
13. Annual household income
 1. >\$10,000
 2. \$10,000 to \$24,999
 3. \$25,000 to \$39,000
 4. \$40,000 to \$59,000
 5. \$60,000 to \$80,000
 6. \$80,000+
14. Contact me
 - In the morning
 - . In the afternoon
 - a. In the evening
15. You can text me
 1. Yes
 2. No
16. Email address

Appendix C

User Research Interview Questions

Intro questions:

- What does your typical day look like?
- When do you normally first use the Internet in a typical day?
- How do you typically access the internet?

Topic specific questions:

- Where do you currently get trans affirming health information?
 - ○ If interviewee say a service/website..
 - How did you hear about these other products or tools?
 - What about it do you like?
 - What do you think could be changed to make it better?
 - How can you tell when a service or resource is reliable/trustworthy?
- What are the biggest challenges when accessing trans affirming health information?
- Can you see yourself ever using a website for health information?
- In what context?

Product Opportunity Questions

- What do you think of this website? (meant to be asked at the homepage to gauge initial reaction)
- Why do you think someone would use this website?
- Can you see yourself ever using this website?
- Why do you think you can trust this website?
- How do you think this website is going to help you?
- Would you use this product today?

- What might keep people from using this website?
- Does this remind you of any other products or website?