Bridging Trans Community Knowledge with Verified Information: Design Considerations for Patient-Surgeon Digital Communication Platforms for Gender-Affirming Surgery

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Abstract

For trans people seeking gender-affirming surgery, there are barriers to accessing trustworthy information about procedures, surgeons, and the postoperative process. Trans-led online information sharing communities are essential tools for trans people seeking surgery, however, they rely on community knowledge that may not always be accessible, complete, or accurate. To understand how an online communication platform might support both surgeons and trans people seeking surgery, we conducted asynchronous online focus groups with 14 participants (ten trans community members and four gender-affirming surgeons). We found that gender-affirming surgeons and trans community members hold *values in tension* surrounding information sharing, risk, and reputation, while sharing *values in alignment* such as shared desires for information accuracy, transparency, and communication efficiency to support the surgical process. We contribute design implications for future online information sharing platforms that balance the needs of both trans patients and gender-affirming surgeons, including surgeon-verified information, surgeon anonymity, credential verification, searchable FAQs, and integrated community knowledge.

CCS Concepts

• **Human-centered computing → Empirical studies in HCI**; **Empirical studies in collaborative and social computing**; • **Social and professional topics → Health information exchanges**; **Gender**.

Keywords

transgender, gender-affirming surgery, online platform design, online discussion, patient-surgeon communication, LGBTQ+

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1 Introduction

Gender-affirming surgery (GAS) is an essential form of health care for many trans and nonbinary people[1] [2]. However, there are substantial barriers to actually obtaining this care in practice, such as cost, geographic distance, inadequate insurance coverage, and a scarcity of competent providers [61, 73]. These challenges are exacerbated by limited access to accurate information verified by medical professionals online [6]. As a result, trans people seeking surgery rely on community-based information from online networks to learn

[1] For the remainder of this paper, we use "trans" to refer to people whose gender is different than that assigned at birth, including nonbinary trans people.

[2] It is important to note that medical and surgical aspects of trans experiences are only *one* of many vital areas; others include social, legal, and psychological realms [63]. Each trans person chooses which aspects of transition they wish to pursue, and some do not undergo medical transition at all. While research on trans surgery is needed, an over-focus on medical and surgical gender transition experiences sometimes overshadows the everyday experiences of transness and other ways people enact their trans identities [62]

about preoperative requirements, surgeons' reputations, recovery experiences, and financial/insurance considerations [6, 17]. These community-driven online spaces are essential resources, but also have limitations. They are not accessible to all, can vary in accuracy, and importantly, place the burden of maintaining these information sharing systems on trans community members [6, 17].

Prior work indicates that surgeons have limited participation in online discussions about GAS, due to concerns about time/burden, legality, and risk to professional reputation [20, 47]. The lack of surgeon-verified information online can contribute to misinformation, which could lead to harms and exacerbate existing inequities for trans patients who lack access to supportive or knowledgeable peers. Research on surgical communication has investigated shared decision making, telehealth, and patient-provider communication more generally [12, 21, 59], but these insights have not extended to the context of GAS.

To address this gap, we ask the following research questions: **RQ1:** What values, risks, and constraints shape how trans patients and gender-affirming surgeons engage in online information exchange about GAS? **RQ2:** How can digital platforms be designed to balance these values, risks, and constraints to support information access and accuracy via patient-surgeon communication?

To understand more about how trans patients and gender-affirming surgeons navigate online information networks and how a future digital platform could better enable them to exchange information online, we conducted asynchronous focus groups with gender-affirming surgeons (n = 4) and trans community members (n = 10). Through these discussions, we identify values in tension and values in alignment across these two groups. We found that the absence of verified information by surgeons causes the burden of information sharing to fall on trans communities, while surgeons face risks such as liability concerns and risk to their professional reputation. Based on our findings, we propose design implications for future platforms that support both groups' needs and values, such as surgeon anonymity, verification of physicians' credentials, legal disclaimers, and integrated community knowledge.

With this work, we extend prior research on online information seeking and patient-surgeon communication in the context of gender-affirming care, as well as trans and queer HCI, to make several contributions. First, we contribute an empirical understanding of the values that trans patients and gender-affirming surgeons bring to the table when these two disparate groups attempt to communicate online: some values in tension, and some in alignment. Further, we contribute design suggestions for online systems to facilitate patient-surgeon communication in ways that can increase information access and accuracy, thus improving decision-making and healthcare practices for a particularly vulnerable group.

2 Related Work

2.1 Barriers to accessing gender-affirming surgery

Accessing GAS is an incredibly difficult process for trans individuals. A systematic review found that major barriers to accessing GAS include affordability and accessibility, and that accessing care involves substantial racial disparities [28]. Financial barriers such as cost, insurance coverage, and difficulty finding in-network providers pose major barriers to receiving care [58]. Trans and nonbinary patients are more likely to lack health insurance compared to cisgender patients [32], further limiting access to surgery. Geographic accessibility is another major barrier to receiving GAS, with many regions lacking surgeons with the necessary expertise [45]. Trans patients are often forced to travel long distances for consultations and procedures, with one study finding the median distance traveled for gender-affirming surgical care was 191 miles [45]. Geographic disparities are compounded by the racial disparities in healthcare that trans people of color face [28, 60]. Prior work shows that eligible Black and Hispanic trans folks have significantly lower odds for receiving top and bottom surgeries compared to their white counterparts [60]. Racial disparities also impact postoperative outcomes and complications: Black trans patients have higher odds of returning to the operating room, being readmitted within one month of GAS, and developing infection near surgical incision sites [84]. Existing literature rarely examines how trans patients and gender-affirming surgeons understand, negotiate, and value online information sharing spaces that increasingly mediate access to care. Our study addresses this gap by examining the perspectives of both trans community members and surgeons, foregrounding how tensions and alignments around information accuracy, risk, and reputation influence the design of online platforms intended to support the gender-affirming surgical process.

2.2 Surgeon-patient communication

Surgical research has long examined how patient-provider communication has an impact on preoperative and postoperative care [79]. Strong communication practices have a critical role in aiding patients to make informed medical decisions [13, 29]. A surgical journey must involve shared decision making and an ongoing process of determining and incorporating patient goals and preferences [9, 72, 85]. Prior work found that shared decision making significantly reduced decision regret among surgical patients [57, 59]. Communication is also an essential part of the post-surgery process, where higher levels of engagement between surgeons and patients is associated with improved clinical outcomes, better symptom management, and improved recovery outcomes [2]. Existing literature has explored the role of telemedicine and patient portal platforms in patient surgeon communication [5, 8]. These tools have been shown to improve access to surgical care, especially for patients who face geographic or logistic barriers [21]. Studies also show that telemedicine and asynchronous portal messaging have equal if not improved patient satisfaction compared to standard, in person care [12, 88]. Yet these platforms may have potential to increase surgeon burnout, due to the increased availability and communication burden placed on practitioners [20, 47]. Our work expands on this prior work by examining surgeon-patient communication in a novel context, GAS, and by considering how a digital system may help to facilitate information exchange.

2.3 Online information-seeking and communication in gender-affirming surgery

The current landscape of online resources sharing information about GAS relies on community knowledge from trans people sharing their experiences. Trans people seeking GAS face real risks of

provider mistreatment and poor medical outcomes [10, 44, 87], and community information networks and peer information sharing can serve a protective function, helping trans people learn from others' experiences with specific surgeons and procedures and identify trustworthy providers [6, 17, 31]. Platforms such as Reddit, Discord, Facebook, and trans-specific sites like TransBucket and ModClub are useful resources for trans people seeking surgery to research preoperative requirements and surgical results, caution against risky surgeons, and find advice on navigating the surgical process and surgical recovery aids [6, 17, 18]. While this wealth of community knowledge is invaluable, patients and clinicians provide different kinds of expertise [41, 68], and online communities typically do not include clinicians and their much-needed advice [43]. Trans patients express desire to communicate with gender-affirming surgeons online to receive factual information from them directly [6, 18, 52]. Surgeons have much more potential to disseminate accurate information about surgery compared to their trans patients, as surgeons have expertise and knowledge that patients may not. Online communication platforms may improve efficient, accessible, and accurate communication between gender-affirming surgeons and trans people seeking GAS [52].

However, gender-affirming surgeons have shown less engagement and interest in online communication with patients compared to surgeons more generally [11, 54]. On social media, over two thirds of gender-affirming content centers patient experiences [75], with limited information about GAS from surgeons themselves. One study examined gender-affirming surgeon's potential interest in using social media to communicate with trans patients about GAS [52]. An online communication platform could improve patient education and enhance patient care, however, 67% of surgeons did not believe a new platform would be necessary due to potential negative implications [52]. These implications include risks to patients (e.g., misinformation, liability, and platform use in emergency situations) and risks to surgeons (e.g., the additional burden that the platform would place on their already-limited time, changes to surgeon culture, and safety concerns related to online harassment) [52]. We extend this prior work by putting trans patients and gender-affirming surgeons into communication with each other to help us understand how online communication may enable improved information access while considering the inherent risks and barriers.

2.4 Trans and queer DIS and HCI

In recent years, a growing body of work in DIS and other HCI venues has focused on trans and queer HCI – that is, research examining how technologies can be designed to include, support, or even prioritize trans and queer identities [80]. This work aligns with what Dombrowski et al. [27] describe as social justice–oriented HCI, which emphasizes HCI's responsibility to consider how technologies can advance social justice goals.

DIS and HCI researchers have explored how to design technologies specifically for trans and queer people [34, 37], including through design workshops that invite participants to imagine how technologies might enable expansive and affirming futures for trans and queer lives [35, 40, 78]. Researchers and community members have envisioned technological systems that support people to explore their trans and queer identities [15, 46]. Some researchers have held workshops with tangible artifacts to examine how queer archives can support identity exploration and information activism [67], as well as to explore queerness through tangible interactions [65, 66].

A substantial body of research has also documented how existing technologies often fail to adequately account for trans and queer identities, and how systems might be reimagined to better support these populations. Spiel's autoethnographic work [76], for example, demonstrates how nonbinary genders are frequently rendered illegible by technological infrastructures that presume binary and static identities. Related work has examined the tensions involved in navigating and presenting trans and queer identities online [23, 25, 26, 33, 69], including privacy concerns [49] and inequities in content moderation [55, 56, 71, 81, 82]. Researchers have further shown how dating apps' affordances and databases can constrain trans and queer people's agency over self-presentation, particularly through algorithmic features, and limit their ability to connect with others [4, 86], especially for people with multiple marginalized identities [24]. Additional design inquiries have explored the relationship between queerness and voice technologies [48].

With the recent rise of AI technologies, new lines of HCI research have examined how trans and queer identities interact with AI systems [36, 70], as well as how trans and queer people might resist [83] or obfuscate [7] such systems. Further work has envisioned new ways of visualizing gender and queerness, highlighting tensions that arise when queerness becomes datafied and quantified [74].

Despite this substantial body of research, relatively little DIS and HCI work has focused specifically on the intersection of technology with trans health and the medical dimensions of gender transition. Notable exceptions include Augustaitis et al.'s [6] study of trans health information seeking online, and Chuanromanee et al.'s work examining how trans people use technology to connect with similar others, research transition-related information, and navigate gender dysphoria [18], as well as their study of how trans people track their gender transitions [19]. Building on this prior work, and on the broader literature in trans and queer HCI outlined above, we examine how technological systems might support digital communication between patients and surgeons in the context of GAS.

3 Methods

3.1 Eligibility

Participants from the trans community had to be over the age of 18 and had received or were considering GAS. Surgeons had to be recognized as a member of the World Professional Association for Transgender Health (WPATH) or listed on a popular trans health directory (transhealthcare.org). All individuals had to be proficient in written English to participate.

3.2 Recruitment

The study's 14 participants (4 surgeons and 10 trans community members) were recruited via different approaches. For trans community members, we circulated online advertisements in our local

trans communities and with community partners, and in trans online communities on sites including Discord, Instagram, and Facebook. Potential participants filled out a screening survey to ensure eligibility. We selected participants from the screening survey responses to ensure diversity of experience in gender, race/ethnicity, age, and type of surgery sought or undergone. To recruit surgeons, we contacted potential participants from a list of gender-affirming surgeons who had participated in a previous study on this topic and expressed interest in participating in a follow-up focus group. Those surgeons had been identified from two publicly available sources: the WPATH member directory and transhealth.org and contacted directly by email. This study was reviewed by our institution's Institutional Review Board and found to be exempt from oversight. Regardless, we used standard informed consent procedures with all participants.

3.3 Participant demographics

Of the ten trans participants, six had had GAS. Of these six, one was 0-6 months post-surgery, three were 1-3 years post-surgery, and two were 5-10 years post-surgery. Five of the participants were trans men, three were non-binary, and three were trans women (some participants identified as nonbinary and trans, and thus were counted in two categories). Five participants were white (with two of these participants self-identifying as Jewish), two were Latinx, two were Black, and one was Asian. Finally, four participants indicated that they were disabled.

Of the four surgeon participants, two had been in practice for 6-10 years and two for less than five years. Two specialized in Obstetrics and Gynecology, one in Plastic Surgery, and one in Urology. They performed a wide range of gender-affirming procedures, including breast augmentation, hysterectomy, mastectomy, metoidioplasty, orchiectomy, phalloplasty, vaginectomy, and vaginoplasty. Three of the surgeon participants were men and one was a woman. Two were white and two were Asian. All practiced in the US.

3.4 Asynchronous online focus groups

Asynchronous online focus groups have a long history of success in HCI studies, as evidenced by a number of studies [6, 17, 22, 50, 51, 53, 89]. We conducted a 5-day asynchronous online focus group, following best practices from Reisner et al. [64], with questions posted in the morning and afternoons each day. We designed prompts to address our research questions, and these prompts were reviewed by a multidisciplinary team which included gender-affirming clinicians and academics of varying genders (over half of whom were trans and/or nonbinary) and seniority. We held the asynchronous focus groups on a Discord server that we designed with three unique channels: one with trans community members only, one with surgeons only, and one with all participants. We provided participants with both written and video instructions on how to create an anonymous Discord account and participate in the channels. Several authors acted as moderators in each channel, using their real name and photo. Moderators were chosen to closely align with the identities of the participants in the channels (e.g., a surgical resident was the moderator for the Surgeon channel). Moderators released prompts in the morning and afternoon of each study day and asked follow up questions as needed, and also monitored the channels for potential inappropriate or harmful interactions (of which there were none).

3.5 Data analysis

We first collected all text from the Discord server, anonymizing all participant content. We used an inductive, bottom-up approach drawing from reflexive thematic analysis [14] to analyze the data, identifying codes and themes directly from participant responses. The first author conducted the initial open coding of the dataset, developing an intial codeset of 69 codes across six broader themes. These preliminary codes were iteratively refined through discussions with the second and fourth author, resulting in a finalized codebook which consisted of 33 codes that spanned seven themes: surgery experience, transphobia, online affordances, trans community, surgery considerations, intersectional identities, and surgeon considerations. The first and second author then independently applied the finalized codebook to the dataset. We discussed discrepancies in coding in consensus meetings among the first, second, and fourth authors until we reached agreement. This process ensured that our interpretations accurately reflected the data and minimized individual bias from the authors. Drawing from the codes and themes in our finalized codebook, we collaboratively grouping related ideas and patterns across trans community members, surgeons, and participants overall to arrive at the values in tension and values in alignment that we describe in this paper.

3.6 Positionality

Our research team spans both sides of the patient-surgeon relationship this study examines: the majority of us are trans and/or nonbinary and three of us are medical doctors, one of whom is a gender-affirming surgeon and one of whom is in training to become one. We come from a wide range of academic disciplines including computing/HCI and several areas of medicine. Some of us have experienced GAS ourselves, some of us have performed it, and some have played both roles. These aspects of our identities and experiences make us especially well-suited to interact with this study's participants and analyze data about trans surgery. In using reflexive thematic analysis [14], we actively considered our own identities and histories. Aligning with standpoint theory [38], our range of positionalities, which are in some ways similar to participants and in some ways different, has strengthened our research.

4 Results

Based on our focus groups of gender-affirming surgeons and trans community members, our data analysis revealed overarching themes that we organized into two broad categories: Values in Tension between surgeons and trans patients, and Values in Alignment between the two groups.

4.1 Values in tension

While both trans participants and surgeons expressed shared values of safety and quality of care, they expressed differing experiences in online information sharing platforms. This section details how varying risk levels and access to information affect tension between these groups around trust and reputation in sharing information online.

4.1.1 Information sharing and reputation. To choose a surgeon that may be the best available fit for them, trans community members rely on other people sharing information about their surgery experiences. In part, this phenomenon is due to the true variation in surgeon skill and training, as there are limited standards/best practices in the field. However, since information about surgical procedures and surgeons are often inaccessible, the onus is currently on the community to determine who can be trusted to provide safe, reliable results. Relying on these reviews from trans community members is necessary to navigate the surgical process and protect prospective patients from harmful outcomes and complications.

Participants perceived a large range of variation in gender-affirming surgeons' training. For example, P3 stated,

> *I would like surgeons to make a portfolio of their results available online (with the consent of patients of course) showing a range of techniques (at least, for top surgery there's several), body types (especially in regards to weight), and racial backgrounds of patients. I also wish surgeons would make information about their training, how many procedures they've performed, and their complication rates more readily available.*

In wishing for surgeons to provide portfolios of their results, this participant implies that surgeons have a broad range of experience and training, which in turn leads to a wide range of surgical results. Patients have access to a limited subset of examples, which makes it difficult to choose a surgeon – particularly for trans patients who are racial minorities or with non-normative body sizes.

The shared patients-surgeons channel provided a concrete example of how trans participants directly engaged surgeons to interrogate uncertainty in clinical decision-making. For instance, one trans participant, P3, asked:

> *I'd like to ask surgeons how they make decisions about things they require of patients when there is not a clear consensus (for example, a lot of surgeons require transmasc patients on testosterone to stop taking T a few weeks prior to surgery, even though a lot of others don't and there doesn't seem to be a clear medical reason to do that—how do you decide?) I'm also curious, considering how much transphobia is in the medical industry and how often research has an underlying transphobic intent behind it, how do you find reliable information about these procedures?*

A surgeon (S2) responded:

> *For me as a gynecologist doing gender-affirming hysterectomies and sterilizations/gonadectomy, I don't require my non-binary folks to be on T or for my trans masculine folks to stop T. The first thing I always do after initial introductions when meeting a patient is literally ask them "what brings you in, tell me your story, what can I do for you, I'm just gonna listen" and we go from there after the patient having some uninterrupted time to tell me about themselves.*

This interaction shows how trans participants used the shared space with surgeons not only to seek information, but to critically examine how surgical knowledge is produced and applied. In response to similar questions in the shared channel, surgeons emphasized the challenges of operating in areas with limited or evolving evidence, often pointing to clinical judgment, emerging guidelines, and peer practices.

By relying on other trans people to share their experiences interacting with different surgery clinics and surgeons, trans individuals can learn about providers' reputations. They can then use this research to gauge their interest in and comfort level with a prospective surgeon, and potentially prevent experiencing harms such as transphobia and unwanted results. P8 detailed the potential harm they wished to avoid, saying,

> *There are a lot of stories in trans spaces and internet forums about surgeons who have acted in truly ethically abominable ways toward their patients — leaving their bodies horrifically disfigured after severely botched surgeries and then refusing to perform revisions, doing entirely different surgeries than their patients paid for, . . . having their interns perform the surgeries after promising their patients they'd be performing the surgeries themselves. The list goes on and on.*

This quote details the severe harms that trans people could potentially face when seeking out GAS, and that community networks are a primary source of information they use to avoid harm. P8 elaborated, saying,

> *The result is a whisper network among trans people, who tell each other whom to avoid, but unfortunately not every trans person has access to the same intracommunity knowledge, so these surgeons continue to profit from ruining people's lives in broad daylight.*

Yet because many trans patients do not share information about which surgeons to avoid, this lifesaving information is often unavailable and incomplete. These cautionary narratives sometimes caused participants to take pause in seeking care. P8 detailed their apprehension about seeking GAS, which they postponed in part due to medical mistrust:

> *I'd like to get FFS [facial feminization surgery] and vaginoplasty someday, but I'm on Medicaid and I hear horror stories about all of the surgeons in my state who are covered by my insurance — horrifically disfigured bodies, caved in facial bones, people left suicidally depressed by their results with surgeons' offices that stop returning calls or offering revisions.*

Finding a gender-affirming surgeon is already incredibly costly and resource intensive, and insurance restrictions exacerbate this challenge by limiting the range of available options, causing further scarcity. Negative online reviews can help trans patients avoid harm, but this also impacts access to care: although there may be a surgeon available, trans patients cannot be sure that they are a safe choice.

The gender-affirming surgeons in our study were acutely aware of the negative information patients posted online, and worried about how this information would impact their reputations. Some surgeons acknowledged how exchanging this information could be helpful for patients. Most emphasized that their reputation directly

affects their practice and, consequently, their income. In our online focus groups, they attempted to address some of the negative reviews they had received. Surgeon participants were particularly focused on mitigating unfavorable feedback related to adverse outcomes.

Some surgeons acknowledge the importance of online communication among trans community members, as S1 stated, *"When I talk with patients, it seems like a lot of the info they have comes from experiences of the community and friends' personal experience. Often this is really helpful for giving them a sense of what to expect."* This illustrates that patient reviews are important for educating those seeking surgeries, and that trans community information networks are so pervasive that surgeons themselves are aware of them. In a conversation about a hypothetical online system where trans people could remain anonymous yet surgeons were identifiable/credentialed, S3 shared,

> *I feel that that could never be a space for me to voice my concerns [when] one population has complete anonymity and the other has the total opposite. I cannot share stories about patients who post defamatory comments online that change the trajectory of people's practices and careers. The angry patient... accused one of my colleagues of gatekeeping and being transphobic because they wouldn't operate on someone with a hemoglobin A1c of 14. That posting a comment like that about a surgeon on a community forum, especially without context, will dissuade others from seeking care from that surgeon, even though that was the safer decision than to operate.*

Surgeons like this one seemed frustrated with the idea that patients have the ability to greatly impact surgeons' reputations, even when surgeons are making clinical decisions meant to prioritize safety and minimize risk. S1 further detailed how online patient reviews can impact clinical decision making, saying,

> *If a patient has a negative outcome or complication that's perhaps outside of our control, they will sometimes take to the blogs to write about what they perceive to be the bad care they received and encourage others to seek care elsewhere. As a result, I see surgeons putting in more pre-op requirements for surgery, maybe not as a direct result, sometimes (not always) in an absence of data, in order to ensure that they have good surgical outcomes and decrease their complication rates - things like BMI limits, smoking cessation, no prior history of abdominal surgery, etc. Other types of non-gender surgeries don't always have these types of restrictions and I often think about why that is.*

This surgeon posits that the cause of sometimes excessive preoperative surgical requirements may be to avoid harm to surgeons' reputations, rather than rooted in scientific evidence or prior research. Importantly, this implies that some surgeons may be more concerned with protecting their reputations by avoiding complications rather than with timely access to gender-affirming surgical care, which can then impact which patients are able to receive surgery.

While both the trans people and surgeons in our study described taking online reviews of gender-affirming surgeons seriously, the two groups experienced starkly different levels of risk in this process. For trans people, these online reviews helped them to navigate lifelong changes to their body, and can feel like the sole resource protecting them from harm, mistreatment, transphobia, and costly complications. Conversely, surgeons take these reviews seriously because they impact their professional livelihood and perceptions about their clinical judgment. This imbalance stems from a current online landscape in which sharing essential information about personal experiences with surgery falls almost unilaterally to trans individuals, rather than their surgeons.

4.2 Values in alignment

Despite their differing experiences, trans people and surgeons found aligned goals of improving information accuracy, information access, and efficiency of the surgical process. Both groups imagined a more streamlined, transparent, and trustworthy system for sharing communication and knowledge about GAS.

4.2.1 Information access and accuracy. Both surgeons and trans community members share the perspective that patients lack accessible, basic information about surgeries. Information such as cost, insurance coverage, and the types of procedures available are often difficult for trans patients to find and access. Further, both groups acknowledge the lack of existing research in GAS best practices and the broad variation in the information people receive. Ultimately, both groups desire trustworthy and surgeon-corroborated information resources.

Trans community members voiced a desire for more health information disseminated from verifiable sources such as medical professionals rather than only from community networks. With both types of information sources, they could learn from community members' experiences, but also be assured that the information they receive is accurate. Similarly, the gender-affirming surgeons in our study were concerned about GAS misinformation spreading online, and wanted to prevent harms this inaccurate information could cause for patients, as well as reputational harm to themselves and their practices.

Trans patients were curious about how surgeons make certain medical decisions, considering the limited existing research on GAS. For instance, P3 stated,

> *I'd like to ask surgeons how they make decisions about things they require of patients when there is not a clear consensus (for example, a lot of surgeons require transmasc patients on testosterone to stop taking T a few weeks prior to surgery, even though a lot of others don't and there doesn't seem to be a clear medical reason to do that - how do you decide?). I'm also curious, considering how much transphobia is in the medical industry and how often research has an underlying transphobic intent behind it, how do you find reliable information about these procedures? Do you do anything to try to listen to the ideas and lived experiences of trans people themselves?*

This participant shared how the lack of existing data surrounding gender-affirming surgeries causes variation in the information

they receive about preoperative requirements. S1 contributed their perspective on the subject in the shared channel, saying,

> *It's often a really difficult balance, because we are trying to make policies with little to no data. I think it's important for surgical practices to stay up to date on the literature out there and adjust policies as needed. We mostly do transfeminine surgery and previously had patients decrease their estrogen dose beforehand to decrease the risk of blood clots, but then new data came out and the WPATH SOC [World Professional Association for Transgender Health Standards of Care] changed their recommendations to no longer require that. In an absence of literature, sometimes talking with other practices and seeing what their policies are can be helpful to getting at least some sort of standard of care.*

This surgeon emphasized that it is a difficult endeavor to make clinical decisions in the absence of robust data and uniform standards. Both surgeons and trans participants would benefit from increased research surrounding GAS best practices, and surgeons seem to be committed to continuous learning and flexibility in their policies as new research and guidelines are released.

Surgeons in our study also highlighted the importance of accessible, accurate surgical information in preventing misinformation from spreading online. For example, S3 stated,

> *The most common example [of misinformation] is about the rates of nipple graft loss. Some patients have read many stories about others' experiences and I think dramatic complications (like nipple loss) get a disproportionate amount of attention in social media. Many patients come into their consultation undecided or hesitant about nipple grafts because they think the rate of loss is very high, when, at least at our institution, it is 0.1% or less. I just address it by asking them, risk aside, if they envision their chest with nipples and then going through the numbers for actual risk.*

This is an example of surgeons valuing and providing accurate information to patients to correct misinformation. Yet in this example, the surgeon described providing this accurate information in consultation appointments, which is helpful, but reaches a relatively small audience compared to online information. Further, some patients considering surgery may decide not to schedule a consultation with a surgeon due to an inflated fear of losing their nipples. Surgeons in our study seemed motivated to correct misinformation, both to improve quality of care and to maintain their reputation.

The scarcity of accessible, accurate information around surgical requirements and specific GAS surgery information impacts both surgeons and trans patients. However, surgeons have potential to counter misinformation by disseminating accurate information to trans patients seeking surgery, whether in-person or online.

4.2.2 Efficiency and reduction in bureaucracy. Both groups recognized that time is a valuable resource, both for patients and surgeons. Individuals seeking to obtain GAS often spend considerable hours on the phone trying to reach surgeon's offices, and months, or even years, awaiting appointments. Surgeons can only dedicate a limited number of hours each day to patient consultations, and trans participants were aware of this limitation. Ultimately, both groups determined whether to participate in online interactions based on the time required and the potential for saving time in healthcare interactions.

P3 detailed the time consuming process of pursuing GAS, saying,

> *The main barrier I've encountered [when] talking to surgeons is the way medical bureaucracy is structured. For example, in trying to get top surgery through [a local health system] I've had to call and follow up several times over several months to get the hospital staff to even set up a consultation, and there seems to be one receptionist in charge of all the gender-affirming care. They don't let you communicate with the surgeon in any way besides the consultation, and if you have follow up questions for the nursing staff or the administration you're more likely than not to be ignored.*

As it stands, it is quite difficult and time-consuming, and sometimes impossible, for patients to communicate directly with surgeons to receive basic surgical information. Direct consultations with surgeons are one of the only existing ways to access credible information, which makes choosing a surgeon and eventually scheduling a surgery an incredibly lengthy process that often takes years. As P8 described,

> *As it is, obtaining even basic information sometimes requires asking an assistant to wrangle a surgeon via email or even going to an in-person consult. It would be orders of magnitude easier to have a Q&A forum, like a Discord server, on which to ask those questions.*

Having a mechanism for online communications would make gathering accurate information much more efficient and greatly minimize the time patients spend trying to obtain basic surgical information.

Trans patients recognized that surgeons' time is limited; as P5 said,

> *I've not seen surgeons in online spaces. I don't really see them doing that, because when would it happen? Our medical system is set up in a way that people barely have time for patients, and surgeons have a life outside of their practice so I wouldn't expect people to be online after hours.*

While online communication between surgeons and prospective patients may be helpful, surgeons' busy schedules limit opportunities for direct and in-depth interactions.

Despite time constraints, both surgeons and trans participants in our study agreed that online communication platforms may provide a more efficient manner for disseminating information related to surgery. Interactions in the shared patients-surgeons channel also reflected this emphasis on efficiency. Trans participants primarily used the space to ask targeted, information-seeking questions that would otherwise require formal consultations, while surgeons provided concise, experience-based responses. This pattern suggests

that even limited, asynchronous engagement can meaningfully reduce informational barriers without requiring extensive additional time from surgeons. As P2 detailed,

> *I think that the availability of online communication would serve both surgeons and patients... Patients would have an easier time narrowing down a choice of surgeon and surgeons [being] more readily available for questions etc. online would be more appealing to patients looking to ask questions before committing to a choice... Therefore [surgeons would] get more patients (at least in theory).*

Participants viewed online communication about surgery as mutually beneficial in terms of increasing efficiency for both patients and surgeons. In terms of specific mechanisms for how communication might work on such a platform, S2 shared, *"[A] beneficial thing would be to have a page of common FAQs about each surgeon to maybe help cut down on some of the questions people might ask."* Another surgeon (S3) agreed, saying, *"I do think surgeon-specific FAQs would be helpful. A lot of patients are able to access surgeon-specific info through their own online networks and communities, but it would be more effective to have those available [directly from surgeons]."* Surgeon participants recognized the potential for online information dissemination to improve efficiency and save time spent on direct communication with patients. They also recognized that basic information specific to each surgeon is currently inaccessible to patients without direct communication. The types of online information sharing that both groups of participants would benefit from need not be complex; as P3 stated,

> *Personally I don't have a problem with not being able to talk individually to surgeons, so much as I often feel frustrated by how little basic information surgeons decide to put out about themselves and their procedures online - often as little as "yes I do top surgery and I accept x insurance."*

Increasing the amount of comprehensive and surgeon-specific surgical information online might not be a difficult endeavor, and would greatly benefit surgeons and patients alike by improving efficiency in the information-gathering process.

Interactions in the shared channel also demonstrated how both groups used this space for efficient information exchange across the patient-surgeon divide. Trans participants asked targeted, high-impact questions, such as those about surgical requirements or risks, that would otherwise require formal consultations. As one participant noted, having access to a forum like this would make it *"orders of magnitude easier"* to obtain basic information compared to coordinating through clinical staff or attending in-person consultations. Participants also noted that such spaces could expand access to those who face structural barriers to care, including cost, lack of insurance, or unsafe home environments, highlighting the role of anonymity and asynchronous communication in broadening access. These interactions suggest that shared online spaces may function less as sites of extended dialogue and more as efficient, low-barrier Q&A environments, enabling selective but meaningful exchanges that increase access to information while preserving surgeons' limited time.

5 Discussion

5.1 Values, risks, and constraints in online information exchange about gender-affirming surgery

Prior research on surgeon–patient communication has consistently shown that frequent, reciprocal communication between patients and providers improves care quality, patient satisfaction, and health outcomes [30, 79]. Despite these well-documented benefits, surgeon-patient communication remains largely confined to brief in-person medical appointments and asynchronous messaging through patient portals, where responses are often delayed or filtered through staff.

These constraints are especially consequential in the context of GAS, where patients often face long waitlists, limited access to affirming providers, and complex, high-stakes decision-making. Although surgeons are frequently hesitant to share medical information in public or semi-public online spaces [52], and are rarely incentivized by institutions to do so, our findings suggest that expanding digital patient-surgeon communication is necessary and crucial. Existing communication infrastructures reinforce power asymmetries between surgeons and trans patients. As medical sociology scholars have noted, clinicians occupy positions of epistemic authority while patients must often seek information independently, particularly online [39]. In GAS contexts, this imbalance is amplified: surgeons hold scarce, high-value knowledge while remaining relatively inaccessible, leaving trans patients with few viable alternatives for obtaining reliable information. While increased communication cannot eliminate these power differentials, greater access to accurate, surgeon-verified information can meaningfully reduce informational vulnerability and uncertainty.

5.1.1 Online information seeking for gender-affirming surgery. Prior work has shown that trans people frequently turn to online platforms to seek information about gender-affirming procedures, surgeons, risks, and postoperative recovery [6, 17]. Trans individuals rely heavily on online communities to compensate for gaps in formal healthcare systems, and information-seeking around gender-affirming care is shaped by mistrust of providers and uneven access to expertise [6, 17]. These community-driven spaces provide essential experiential knowledge and emotional support, particularly given the historical marginalization of trans people within medical institutions.

At the same time, such information is often anecdotal, difficult to verify, and based on highly individualized experiences ($n = 1$ accounts), making it challenging for patients to assess medical accuracy or relevance to their own bodies and circumstances. Our findings reinforce this tension: while trans communities have developed robust infrastructures for surgical information exchange, relying exclusively on peer-produced knowledge places an undue burden on patients to evaluate medical risk without authoritative input. We argue that community knowledge should not be understood as a substitute for professional medical information, but rather as something that could be complemented (rather than displaced) by surgeon participation in carefully designed online communication systems. Our work takes first steps toward understanding how such bridging information ecosystems might be designed.

5.1.2 Bridging trans HCI with health technologies. Within trans and queer HCI and design research, scholars have documented how trans people use technology to navigate identity development, embodiment, safety, and access to care, while also identifying the systemic exclusions that shape these experiences [34, 76, 77]. Technical systems routinely misrecognize trans identities [76], but trans people can create and participate in transgressive design practices that resist normative assumptions embedded in sociotechnical systems [34, 83]. Despite this growing body of trans HCI research, insights from trans-centered HCI are rarely applied to thinking about health technologies or clinical communication infrastructures.

Our study contributes to bridging this gap by considering what it would mean to bring surgeons into the online spaces that trans people already inhabit. Prior research has shown that trans communities frequently organize and exchange information on platforms like Reddit and Discord – systems not designed for clinical communication, but deeply embedded in trans digital life [17, 25] . While many current gender-affirming surgeons may feel uncomfortable engaging in such environments, future generations of surgeons, who are increasingly digital natives, may be more open to online, community-oriented forms of engagement. Further, as more trans people enter medicine and surgical specialties, the boundary between "surgeons" and "trans patients" may continue to blur, creating new opportunities for relational, trust-based communication models.

5.1.3 Divergent risks, shared goals. Our findings highlight both alignment and tension between trans community members and gender-affirming surgeons regarding online communication about GAS. Participants across both groups emphasized shared values around information accuracy, transparency, and the potential for improved efficiency in the surgical process. At the same time, tensions emerged around reputation, liability, and the risks of misinformation. Surgeons expressed concern that online platforms could expose them to reputational harm through negative reviews or misinterpretation of medical guidance, echoing prior work showing that surgeons rarely discuss GAS on social media and often view additional communication platforms as unnecessary [52].

Crucially, the risks faced by surgeons and trans patients are vastly different and not symmetrical. For trans people, inaccurate or inaccessible information can lead to physical harm, dysphoria, delayed care, or costly and irreversible complications [61, 73]. For surgeons, online engagement carries professional, legal, and reputational risks that may affect their ability to practice [52]. Designing systems that treat these risks as equivalent risks reproducing existing inequities rather than addressing them. Our findings extend prior work by unpacking the values, constraints, and power dynamics that underlie surgeons' reluctance toward online engagement, while also foregrounding the stakes for trans patients who must rely on online information to protect their health and well-being.

Taken together, these findings answer **RQ1** by articulating the values in alignment and in tension that shape how trans patients and gender-affirming surgeons engage in online information exchange about GAS. In the following section, we turn to **RQ2** and discuss design considerations for digital platforms that can better balance these competing needs while supporting access to accurate, trustworthy surgical information.

5.2 Design implications for gender-affirming surgery online patient-surgeon communication platforms

Increased online information exchange can bridge critical information gaps between trans patients and gender-affirming surgeons during the lengthy process of deciding about, planning for, undergoing, and recovering from surgery. Both groups recognize the potential for an online platform to optimize information exchange, as greater patient access to information can improve preoperative preparedness and reduce the prevalence of misinformation. An online communication platform connecting trans patients and surgeons would be novel due to physicians being involved in online discussions, since current online communities disproportionately rely on trans people sharing their experiences.

Yet for such a platform to be successful, surgeons would need to feel comfortable contributing their expertise, which would require limiting potential risk to their reputation and ability to operate. Platform design must align with prior research on clinician participation in online health communities, professional boundary maintenance, and risk mitigation in digital health platforms. For example, prior work has shown that anonymity can encourage participation in sensitive discussions [3], credential verification can increase trust in medical information without requiring personal disclosure [1], and disclaimers can help clarify the limits of online medical guidance [16]. Design affordances, then, must enable surgeons to share credible, accurate information about surgical requirements and processes while protecting them from potential risks to their reputations and ability to provide care. In what follows, we outline several design affordances that could support a mutually beneficial online platform for communication between trans patients and gender-affirming surgeons. These design directions aim to balance information access and accuracy with surgeons' concerns about risk, liability, and professional reputation.

5.2.1 Anonymity, credential verification, and legal safeguards. Surgeon participants emphasized the importance of reducing professional and legal risk while maintaining trust and accountability for patients. Platform features that could support this balance include surgeon anonymity, verification of physicians' credentials without disclosing personally identifiable information, and clear legal disclaimers indicating that platform content does not replace individualized medical advice. Together, these features could enable surgeons to contribute accurate information while mitigating concerns about liability, misinterpretation, and reputational harm. Yet tensions exist here, namely that patients may be less likely to trust surgeon information that is provided anonymously, even if it is verified. Further, while we expect that most surgeons will act responsibly, separating surgeons from their reputations may decrease the incentive for them to provide high-quality information. Questions also arise about accountability in cases when surgeon-provided medical information is anonymous but turns out to be inaccurate; to maintain accountability, the platform could keep a private record linking surgeons to the anonymous information they

provide. Regarding verification and legal disclaimers, the platform must take great care not to privilege Western knowledge or perpetuate gatekeeping, especially since many prominent trans surgeons operate in non-Western contexts (e.g., Southeast Asia and Latin America). Those in charge of verification must share values with the trans patients and surgeons using the site, which, as our findings show, are not always aligned.

5.2.2 Surgeon-maintained frequently asked questions. Based on our data, it is clear that effective technological interventions need not be resource-intensive or complex. Simple solutions, such as surgeon- or practice-maintained Frequently Asked Questions (FAQ) pages, could clarify common points of confusion related to surgical procedures, eligibility criteria, insurance coverage, and postoperative expectations. Importantly, such information should be tailored to a specific surgeon's practice, as this information will vary greatly across surgeons. Providing these categories of information about multiple surgeons in a centralized online platform would reduce repetitive inquiries for surgeons (thus improving efficiency) while increasing access to reliable, consistent information for trans patients navigating the surgical process.

5.2.3 Tiered platform access and incentivized engagement. One way to incentivize surgeons to contribute to an online communication platform is a tiered platform structure, in which a free tier provides standardized, surgeon-verified information about available gender-affirming procedures, while a paid tier enables private messaging or individualized consultation [52]. Examples of tiered systems already exist in some health contexts, such as First Derm for dermatology and Maven Clinic for women's health, suggesting that a similar platform for trans health is feasible. A trans surgery tiered platform would increase baseline information access for trans people seeking surgery while offering financial compensation to surgeons who engage more directly. Tiered access may also improve efficiency for surgeons by reducing redundant consultations, ensuring that they meet with patients who are prepared for and knowledgeable about surgery, and streamlining preoperative communication, ultimately supporting more informed decision-making for patients. That is, patients who have already engaged with the standard information in the free tier will arrive at their consultations with a baseline level of knowledge that will enable surgeons to focus more on individualized care. Tensions exist, however, in any system that requires payment for care: those who cannot afford the second tier will be limited to standard information, while those with financial resources can receive individualized support.

5.2.4 Integrated community knowledge. Trans community knowledge is vital, and an online platform for patient-surgeon communication should foreground trans patients' experiential information alongside surgeon-generated information. The platform could provide a discussion forum for trans patients to share their experiences, ask questions of others who have had similar surgeries, and seek and provide support. A medical professional could read through and flag any content posted that may be misleading or false. In some cases, particularly when patients have had negative surgical experiences, patients' descriptions of their experiences with certain surgeons will not align with the surgeons' perspective. While in some instances such disagreements may reflect genuine differences in perspective, in others they may reflect real harms that surgeons are reluctant to acknowledge. A discussion forum could enable a conversation between the patient and surgeon; transparency around such disagreements would benefit prospective patients navigating their own decisions, and the discussion may even lead to a resolution of past grievances. Patient-generated information and discussion alongside surgeon-generated information will provide crucial integration of the different perspectives necessary for those pursuing surgery.

5.2.5 Searchability, moderation, and iterative updates. Additional design suggestions reflect values shared by both surgeons and trans community members, including information accessibility, accuracy, and timeliness. Searchable and well-indexed content can reduce the labor required for patients to locate relevant and trustworthy information, particularly for those who lack access to informal community networks. Moderation mechanisms can help limit the spread of misinformation while maintaining community trust, a challenge well documented in prior research on online health forums [42]. For instance, a trans-centered moderation approach – one that removes anti-trans content and users, positions trans people as moderators, and uses a collective and community governance framework [82] – may work well here. Finally, platforms should support continuous, iterative updates to ensure that information aligns with evolving standards of care, such as WPATH guidelines, and incorporates emerging surgical techniques rather than relying on outdated or anecdotal knowledge.

5.3 Limitations and future work

We recognize that our sample size, especially for gender-affirming surgeons, is relatively small. Surgeons are incredibly busy and well-paid, and thus do not respond to research incentives (e.g., monetary compensation) as readily as other groups. Our study required sustained engagement over five days, which is a lot to ask from these busy professionals whose main priority is in the operating room. That said, our sample size does align well with best practices for focus group studies about sensitive health topics [64]. Future research could include a larger, more diverse surgeon sample, including those resistant to online communication, to capture a wider range of perspectives and potential barriers to participating in an online platform with patients. Legal and institutional dimensions such as liability, malpractice concerns, hospital policies, and broader legal and policy constraints that may affect surgeon participation and warrant further investigation. Given that community information networks are not equally accessible to all trans people, future work should examine how platforms like the one proposed could better serve trans people of color, rural trans people, and those with limited digital skills or reading/writing proficiency.

Further, while we have identified shared values and tensions between gender-affirming surgeons and trans community members seeking surgery, it remains to be seen how online communication platforms would function in practice. Building and deploying a new system was beyond the scope of our study, though the focus groups on Discord, especially in the channel that included both trans patients and surgeons, did approximate a patient-surgeon communication platform. Future work should examine how different design affordances like varying levels of surgeon anonymity,

moderation, and credential verification shape trust, participation, and information accuracy and quality over time. Mixed-methods and longitudinal approaches could further complement and extend this work. An in situ study of a system in use would reveal how engagement with these platforms could influence patient decision-making, surgical outcomes, safety, and preparedness, especially for trans people who face compounded barriers to GAS due to race, geography, or insurance coverage. Research could also examine how an online patient-surgeon communication platform may impact existing trans community networks. Overall, future work can inform the development of equitable, sustainable online infrastructure that meaningfully supports access to gender-affirming care.

6 Conclusion

Accessing reliable and accurate information about GAS is a challenging, time consuming, and inequitable process for trans people seeking surgery. Our study highlights how the absence of information verified by surgeons causes the burden of information sharing to fall to trans communities. At the same time, surgeons face another set of risks such as liability concerns and risk to their professional reputations. Patients' and surgeons' concerns must both be carefully accounted for in the design of any future communication platform to connect the two groups. We found that both patients and surgeons share the desire for more accurate and accessible information on GAS, greater transparency around surgical requirements, and more efficient ways to navigate a complex and often time-sensitive surgical process. These shared values suggest that an online platform designed around the needs of both groups could bridge existing information gaps and improve the efficiency of the surgical process. We propose several design possibilities that could address the values of patients and surgeons, including surgeon verified information, searchable FAQs, surgeon anonymity, credential verification, and integrated community knowledge. These potential platform affordances seek to balance information transparency with safety for all parties. An online communication platform that accounts for the needs and experiences of trans patients *and* gender-affirming surgeons has the potential to greatly increase access to accurate information about GAS.

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