Technology for transgender healthcare: Access, precarity & community care

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1. Introduction

In August 2022 facilities that provide pediatric and adolescent gender-affirming healthcare for transgender youth, like the Boston Children’s Hospital (Latifi, 2022), and the Children’s National Hospital in Washington D.C. (Monteil, 2022), received bomb threats and other threats of violence. Relatedly, during a live broadcast, Fox News’s Tucker Carlson showed names and faces of the board of directors for the Vanderbilt Medical Center, another healthcare center offering gender-affirming care to trans adolescents at the time, and claimed they were criminals deserving of the bomb threats they and other healthcare facilities were receiving. Large facilities like these present easy targets for detractors because providers at these facilities who work with trans youth advertise their services, and may even appear in mainstream media discussing trans healthcare and medicine.

Other grassroots anti-trans efforts have taken a modern and decidedly technological turn by co-opting a trans-created and trans-affirming online resource to instead target gender-affirming healthcare providers. Amidst the analog threats and a veritable legislative onslaught against trans medicine, a self-proclaimed gender critical group called Women’s Liberation Front compiled a centralized list dubbed the “Gender Mapping Project” on Google MyMaps documenting the locations of thousands of facilities that serve trans and gender diverse people (citation of them article, Factora, 2022). While the map itself has since been taken down by Google for violating its policies (Factora, 2022), the information still exists elsewhere online. This is because Alix Aharon, the creator of the Gender Mapping Project, pulled nearly all of the data on healthcare facilities providing gender-affirming healthcare from a trans-created resource: Erin Reed’s Informed Consent HRT Map. Perhaps what is most interesting about this incident is that the same technology and the same information can be used for opposing aims. Aharon’s version, the Gender Mapping Project, aimed to surveil providers of trans healthcare, condemn their clinical practices, and (in geopolitical and sociolegal contexts where gender-affirming care has been under legislative attack if not outright outlawed) criminalize them. In contrast, Reed’s map was created specifically to help trans people find knowledgeable providers, as we will show in the results of our interviews with her and other creators of trans technology for healthcare access.

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be used to such different effects; the anti-trans mis-use of the trans health resource that Reed compiled highlights the precarity inherent in trans health technologies – especially in the current anti-trans political environment. Questions about how technology operates in the hands of different actors, especially in the case of trans medicine and healthcare serve, in part, as the impetus for this article. In this way, we contribute to this special issue on transgender medicine by illustrating how creators of trans technology bolster trans healthcare by increasing access to vital health information and knowledgeable and affirming providers. As we outline in what follows, research on how trans people source information related to trans healthcare and medicine remains scarce, but insightful. We know perhaps even less about how that information is compiled and becomes available to access in the first place. Thus, our article focuses on a data set featuring interviews with creators of technologies that were designed to proliferate access to both gender-affirming healthcare services and information on trans medicine, and to combat the precarity trans communities face in finding trans health information both online and in person. We begin by defining trans technology, then characterize how trans health information and healthcare access informs our analysis of interview data with creators of trans health technologies.

In the context of social media blogging on Tumblr, trans technology has been defined as something that “must foreground and make real the ability to change over time, from one identity and gender to another,” (Haimson et al., 2021). Haimson et al. (2021) argue, following Jules Gill-Peterson (2014), that sex-linked hormones themselves, like exogenous estrogen or testosterone, operate as trans technologies, along with digital technologies like social media sites that enable a fluid narration of oneself as one’s identity forms and reshapes over time. Following further lines of inquiry within transgender studies on technology, notably Cassius Adair’s (2019) work on drivers licenses and Toby Beauchamp’s (2019) work on body scanners and biometrics, it is clear that technology can be a means of self-actualization or gender affirmation, or it can be a means of distributing violence and exercising state power and control. This spectrum of belief about technology represented in the academic literature within trans studies likely reflects the attitudes toward technology among trans people more broadly. Rather than prioritizing an understanding of technology as necessarily a means of administering violence, or as a limitless tool that can unlock a utopic future of gender self-determination, we insist on the ambivalence. We underscore the relationship between creator, the technology they create, and the user or audience for such tools as one in which ascribing values like ‘good’ or ‘bad’ to any of the three would only flatten the complexity, even though there are instances, like the Gender Mapping Project, that are best described as ill-intentioned. Put another way, creators have intentions in building technologies, and users have their own separate intentions in using said technology that may or may not align, and beyond these two actors there is the possibility that the technology has the capacity to use or be used differently from either the creator’s or the user’s intentions and motivations (Suchman, 2007). While our empirical data in this article focuses on creators of trans technology and their goals in proliferating access to trans healthcare and information about transgender medicine, technologies like the ones discussed here can be, and sometimes are, used for less affirming or trans-positive aims, as evidenced by the vignette at the beginning of the article.

Our contribution in this paper is to ground the ongoing discussions of trans technology with empirical data gathered from creators of technologies designed explicitly for trans people; in this way we contribute to transgender theory while also heeding Billard et al.’s (2022) call for an applied transgender studies. Thus, we apply a more practical definition of trans technology because we focus on a subset of trans technologies whose creators specifically sought to increase trans people’s access to healthcare and health information, rather than on social technologies like social media or body-changing technologies like hormones. Given this focus, we adopt another definition wherein trans technology helps to address the needs and challenges faced by transgender people (Haimson et al., 2020), and in our case that challenge is finding competent providers of trans-specific healthcare and health information. In this way we also expand on existing work at this nexus of science and technology studies and transgender studies that considers how objects, both analog and digital are used or accessed by trans people to instead understand how and why trans people create technologies to address problems their communities face.

Our adapted definition of trans technologies also eschews the often sharp contradictions between how medical sociology might theorize technology when compared to how technology figures in science and technology studies. More specifically, following Henwood and Marent (2019) and their reading of the treatment of technology strictly as a tool within medical sociology, we suggest that this definition of trans technology aligns more with science and technology studies and a more 21st century formulation of technologies as agents themselves. Indeed, our definition of trans tech can also be understood in an emerging vein of studies work that seeks to unpack the rhetorical and discursive labor that science, technology, and medicine do to confer authority and expertise (Shuster, 2021), and what trans studies might want from science discursively and epistemically (Everhart, 2022). This distinction is important to an understanding of trans technology because what makes the technology trans is not the identity of its creator, but its myriad uses, both potential and actual, that necessarily exceed the scope of the design. Our earlier vignette illustrating how Reed’s technology designed to proliferate access to trans healthcare was taken up by anti-trans actors and reimagined as a tool for monitoring, or perhaps even threatening and harming, healthcare providers serves as a sobering reminder that technologies are not merely tools wielded by their creators. Rather, technology generally, from the vantage point of actor network theory and other perspectives from science and technology studies (Latour, 2007), also acts upon the user. While our focus in this article is on creators of trans technology, it is important to underscore that digital technologies like those created by participants in our study are not always used for their intended purpose or by their intended user-base. Our goal in this article, then, is to analyze trans technology creators’ design experiences, motivations, and intentions, to complement existing work on trans users of health technologies and expand our understanding of what makes a technology trans.

How trans people, and indeed the LGBTQ+ population more broadly, access relevant health information has been understudied. Martinez and Tang have published a first of its kind literature review on LGBT people’s experiences with using health technology and their unaddressed needs (Martinez and Tang, 2020). However, their interventions are largely limited to an expansion of categories for including LGBT people in ways that are affirming, rather than stigmatizing, and to the implications their findings have on data collection and the electronic health record (ibid). Existing research focused on health information seeking behavior and transgender people has demonstrated that trans people may experience a unique interplay of barriers and facilitators to seeking out and finding accurate health information (Augustaitis et al., 2021). In a series of online focus groups, Augustaitis et al. (2021) found that trans information seekers included the capacity to both asynchronously access information and to synchronously interact with others online, the availability of groups for these kinds of connection, and the options to keep groups and user-generated sites and platforms private to those who were seeking similar information. Barriers, however, included ubiquitous misinformation, hate speech, and ongoing censorship issues related to algorithmic and other automated biases against gender and sexual minorities (Augustaitis et al., 2021). Skeen et al. (2021) have also explored how trans people’s health information and healthcare needs have been researched in the mHealth space, often without input from trans communities or with financial backing from venture capital firms hoping to capitalize on a growing healthcare market (Skeen and Cain, 2022). In a distinct, but related area of work, Wong et al. (2022) conducted a systematic review of information and communication technology-based interventions on trans
people’s health and found that 62% of these interventions were focused on HIV alone. While this area of research is paramount, their findings also point to a focus in the literature, and the funding landscape, on HIV-related interventions at the expense of other vital aspects of trans people’s health, including transition-related and gender-affirming care.

In this paper we seek to highlight how creators of trans technologies for trans health conceptualize their work and its role in aiding the communities the technology reaches to seek gender-affirming care and gender-affirming health information. Rather than focus on how trans people seek this information, or the larger political economic context in which technology-driven interventions have occurred, we turn to the creators of technology to hear from them, in their own words, about their goals for the tech they create and the motivations they have for making them available to trans people. Improving trans healthcare and medicine is meaningless if we do not also ensure that trans people who need that healthcare can both find out about it and access it, and trans technology creators like Reed are working to help bridge these information and access gaps.

This paper fills gaps in the existing literature by qualitatively exploring how digital technologies have been created with the intention of helping trans people find information on gender transition-related care and gender-affirming healthcare providers. Through analyzing interviews with designers of trans technologies, this work seeks to explore what motivates creators to make technology for trans healthcare access, and how these technologists conceptualize the impact their work has on the communities for whom they were designed. More specifically, we found two novel themes that advance our understanding of the challenges trans people face in finding health information and trans-specific health services by focusing on creators rather than users of trans technologies. First, each of the creators we spoke with shared a similar goal of proliferating access to gender-affirming healthcare and health information, but took different approaches to creating their technologies to achieve this goal. Second, these creators experienced precarity in both online and in person trans communities that is reflected in the precarity of internet-based digital technologies like the ones they create. Trans tech creators’ shared goal of increasing access to care and information, as well as their shared experience of both community and technology itself as precarious, illustrates the lengths that trans people must go to care for one another, especially in the absence of support from outside trans communities.

2. Methods

2.1. Data collection

Between July 2021 to June 2022, we conducted qualitative interviews with creators of trans technologies (N = 115). This paper draws upon a subsample of that data (n = 15), the creation of which we discuss below. We began recruitment using criterion sampling (Maxwell, 2013), whereby participants were selected and invited to participate in an interview based on meeting the criteria of being a creator, designer, or developer of some kind of trans technology. We developed our list of trans technology creators by carefully observing the trans technology landscape for several years and by searching for relevant keywords on Google and in app stores. Then, we used snowball sampling once interviews began by asking early stage participants to recommend other creators of trans technologies. Potential participants were contacted via social media or email with an invitation to a semi-structured interview with the research team via Zoom. We asked participants about the origin and design process of their trans tech, and also asked them to define trans technology in their own words. Beyond this basic structure, each interview shifted focus based on salient topics as they emerged. All interviews were conducted in English. Each participant was compensated $100 for participating either by check or gift card. This study was reviewed and deemed exempt from oversight by our institution’s review board.

2.2. Data analysis

We conducted interviews virtually and audio-recorded them. These recordings were transcribed prior to data analysis, which took place alongside data collection. As we collected more data, we iteratively adapted the interview guide reflecting on what was gleaned from ongoing analyses. We began by open coding (Corbin and Strauss, 2015), and began to organize codes based on major themes. We iteratively coded as we developed themes, refining them as we continued to collect data. In this article, we focus on a subset of the data involving health-focused technologies. While the full dataset is part of a larger study (n = 115) (citation anonymized for review), the subset of the data we use in this article (n = 15) features interviews with creators of health resource technologies, which we define as products designed to enable trans people to access gender-affirming healthcare, and health information related to gender-affirming care. The remaining interview data (n = 100) featured creators of trans technologies that did not focus on health and thus were excluded to focus explicitly on the nexus between technology and health. Within this subset, we draw largely upon codes related to the goals of the technology, whether and how trans communities were involved in the technology’s design, how trans technologies facilitate access to healthcare and resources, and, to some extent, how interviewees defined trans technology.

Interviews were conducted by a diverse research team at various career stages based on a semi-structured guide. Some scholars in qualitative health research with trans communities have argued that data from interviews and focus groups with trans people are richer when those collecting the data are also trans (Everhart et al., 2022; Rosenberg and Tilley, 2021). The interview guide and more details on methods of data collection have been published elsewhere (citation censored for submission). One author conducted initial open coding, and another author conducted axial coding to draw out themes based on those initial codes within interviews about health resource technologies. We then identified the core themes, which are featured in the results section, in response to our research question.

The authorship team assembled for this article is made up of both cis and trans people, each of whom are white, and each of whom has significant experience and expertise in both qualitative research and research on and with trans communities. Following Boveda and Annamma’s (2023) recent work on positionalit, we share our embodied identities and our experiences at the intersections of those identities and the relevant scientific literature as a means of “contextualizing methodology.” We maintain that our positionalit, that is as a complex interplay of our embodied identities, lived experiences, and relevant expertise, influences our interpretation of the data.

Participants in the subsample were 40% nonbinary, 27% trans women, 27% trans men, and 7% cis women. An overwhelming majority of participants were white only (73%), and 13% were Asian, 7% were Black, and 7% were multiracial (Latinx, Indigenous, and white). Ages ranged from 25 to 43, with an average of 35 (standard deviation = 5). All participants except one were located in the US, with one in the UK. Each of the creators featured in this article consented to having both their technologies named and their names used, and expressed a preference for being identified rather than anonymous. These demographics reflect our knowledge of trans technologies based on a predominantly monolingual Anglophone and US-based network of technologists, and also highlight how our positionalities as White researchers may have negatively impacted our sample’s diversity during the recruitment process. This means that our understanding of creators who are Black,
Indigenous, people of color, or otherwise exposed to structural racism is limited based on the skew in this sample toward white trans technology creators. At the same time, we focus in this article on a subset of technologists who are mostly themselves trans or nonbinary. In this way, we present findings that are informed by both first hand experiential knowledge of accessing healthcare and health information, as well as an embeddedness in trans communities that cis creators of trans technologies may have lacked. Throughout the results, we identify respondents the first time they are introduced by their ethnic racial and gender identities as reported to us during interviews.

3. Results

Results are presented in two parts. First, we explore how technologies for accessing health information and services take different design processes, but share similar goals of proliferating access to trans healthcare and related health information. Second, we discuss how technologists combat precarity faced by trans communities generally and the precarious nature of internet-based technologies by filling the gaps in community knowledge around where to access gender affirming care and information.

3.1. Differential processes, common goal

Our sample of trans technologists shared a goal of proliferating access to gender-affirming healthcare and health information. This shared goal resulted in similar end products, which often included geographic information, or took the form of web-based maps that enabled users to find nearby healthcare facilities that provided the kind of care they sought. One of them was created by Riley Johnson, a White transmasculine person, at Trans*H4CK in 2014, a hackathon that focused on trans issues and trans people. Johnson often met other trans people who were seeking doctors or other clinicians and having trouble finding reliable information about providers. Even though Johnson knew providers to informally refer people to, in their words, “we didn’t have a mechanism to centralize that information,” and “there were points where the information that we did have was out of date.” What started as a challenge for those working in trans health within Chicago, where Johnson was living at the time, became Referral Aggregator Database (RAD) Remedy. While RAD Remedy is now defunct, when it was operational it included not only a location-enabled referral resource that could locate providers based on where users told it to search, but also a review system. Johnson said that even in the early stages “we felt like it was important to have a review system once we got it into fruition. To have a review system that would … be able to provide maximum information to the end user so that they could make their own choices.” This was important because, in Johnson’s words, “we felt that folks are the experts of their lives and what their needs are.” This combination of location-enabled care seeking and an informal vetting process through the user-driven review system made RAD Remedy a first-of-its-kind technology for proliferating access to gender-affirming care for trans people. In fact, at its height it had grown far beyond the Chicago area to include information on facilities and providers in Canada, Mexico and other countries outside the US as well as reviews for a majority of the facilities. What began as a more localized resource in Chicago grew to an international database and a living technology that made vital health information accessible to many who may have not found it otherwise. It may be that the technology grew so substantially in part because Johnson and his collaborators emphasized the review system and user interaction with the technology, using crowdsourcing among trans communities to expand community knowledge about healthcare providers. Creating an almost open-ended resource that grew as more people shared their experiences with providers or submitted information on new facilities made RAD Remedy unique even among multiple iterations of similar databases.

The review system that made RAD Remedy a pioneering technology was something that other technologists arrived at independently. For example, Taylor Chiang, a Chinese-Filipino non-binary person and medical student, created TranZap, an application for reviewing primary care physicians for their knowledge of trans populations and ability to work with trans clientele. In developing the initial idea, Chiang recounts “what it came down to is that folks really wanted a way to find physicians, not necessarily endocrinologists or plastic surgeons, but just primary care everyday physicians” who could work in culturally competent ways with trans clientele, or in Chiang’s words “just someone who understands maybe the nuance of what the trans experience is.” In asking around through his social networks, Chiang discovered that other trans people often find providers through word of mouth, so they wondered “what if I took the word of mouth out of it?” What if I created some sort of system, some sort of app, that would be able to house this information and people could share their experience in that way, they could get a little bit more information on physicians of any specialty.” This process led to TranZap’s main functions which are to review clinicians the user has seen, and to use the database of reviews and information to find healthcare providers that have been vetted by other trans people. Rather than an attempt at a comprehensive database of all providers, Chiang’s process iterates through different health systems, beginning with the health system in which they were a medical student. In this way it relies more on users to populate the database with providers they’ve seen and reviews of the care they received, instead of an attempt to build out a database of all possible providers sans reviews like other technologies for finding healthcare providers who work with trans clientele.

While Johnson and Chiang enabled users to dictate what kinds of information was pertinent to share about providers, other creators defined specific parameters of what kinds of facilities or providers should be included in their technologies. For example, another technology, an Informed Consent HRT Map created by Erin Reed, a White trans woman, was designed to be a public-facing resource for trans people to find healthcare facilities where providers use an informed consent model for providing gender-affirming hormone therapy. This ethos of only including facilities that use an informed consent model made the Informed Consent HRT Map unique among other similar technologies. Reed’s goal was not necessarily a comprehensive database, but one that promoted only those providers and healthcare facilities that took the most low barrier approach to providing gender-affirming care. In addition, the interface for this resource was key to its design and usability, even though the information contained within it can be found elsewhere. Reed emphasized: “it’s a simple map; people know how to use Google Maps. People have looked at Google Maps before and they click on a pin. So it’s really intuitive.” To create this map, Reed relied on other online trans health resources.

In detailing her process for the map’s creation, it became evident that Reed’s own experiences had influenced her decision to limit the resource to informed consent clinics. She recounted her own process of accessing gender-affirming care for the first time, saying she “drove 3 h to [her] first hormone therapy appointment” after having “found [her] place through … one of the transgender subreddits.” Despite naming that her own personal experience of accessing care inspired her to create the Informed Consent Map, her motivation for creating the technology echoed Johnson of RAD Remedy’s in that she “wanted to give something back because [the trans community] helped [her] out.” And while Reed’s map did not include a review system, she did end up relying on volunteered geographic information (VGI) to build out the map upon

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2 Informed consent for gender-affirming hormone therapy in this context means that clinicians do not require a referral from a mental health clinician with an attendant diagnosis of gender dysphoria in order to begin or continue care. Healthcare in clinics is often provided via verbal informed consent, meaning no written attestation of consent is required, and gender-affirming hormone therapy has historically required coordination between mental health clinicians and somatic health clinicians.
releasing it. In her words, “at this point it’s more crowdsourced than not,” even though “initially, it wasn’t crowdsourced at all.” She hypothesizes that “the map needed to be seeded with a large number of places so that people could realize how important the map was, and how important a resource it can be, before they wanted to add to it.” Now, even though she created it, she sees it as “more of a trans community resource. And I like it that way.” Reed’s design process was unique in that it was carried out by her alone, but informed by information shared with her through her community connections. There are some unique aspects of the technology Reed created, especially its simplicity and its ethos of only sharing informed consent clinics. Yet the resulting technology looks and feels quite similar to others like it that share the goal of helping trans people access healthcare.

One key regional resource, the Trans in the South guide, was important for both Erin’s Informed Consent Map and other databases (Everhart et al., 2022). The Trans in the South guide, in one of its creators Ivy Hill’s, a White genderqueer person, words, “is a resource guide that connects folks with service providers, primarily medical care providers, but also legal resources across 13 Southern states,” which they also noted “was really born out of a workshop that we did at the conference called LGBT in the South years ago.” In the interview, Ivy traced the process from a “really unwieldy PDF” to a community-driven, interactive web map as one that involved multiple iterations and ongoing feedback from end users. Ultimately, the guide’s goal, according to Hill, was to help “trans folks who live in the rural South, who aren’t really connected with community and who are trying to find someone who will treat them.” Hill hopes “that it’s removed some of those barriers for folks.” For Hill, the necessity of a regionally-specific resource was about the specific barriers that trans people living in the South face in trying to access care. When asked about whether the resource deserts that appear in the map are because of a lack of providers, or a lack of connection to the people in those communities, Hill took personal responsibility, stating, “I think for the vast majority of it, it’s that I have not yet tapped into community in those locations, that it’s more difficult to find community here and just, I personally don’t already have networks there.” They also claimed that:

There are providers who want to treat trans folks in every town in the South. And they may not feel empowered to, they may not feel like they have enough education or whatever around specifically trans needs, but I do think that in almost every town, if not every town across the South, there are providers who want to treat trans people with dignity and respect. So even in those areas, the resources are harder to find, but I do think that they exist and it’s just the work of connecting the dots.

Hill’s personal perspective on the landscape of healthcare providers reflects their commitment to a community-driven design process. Taken a step further, Hill sees Trans in the South as perhaps an incomplete or imperfect technology because not all of the data have been connected between trans people seeking care and existing or potential providers. In this way, their design process looks different from other technologists and creators we interviewed, but their goal was the same. That commitment was echoed in their definition of trans technology, which they conceptualized as “like a tool, what tools are out there to find a community and then all the resources and stuff that come with being connected with other trans people.”

Another more regional resource, the provider directory created and hosted by the TGRCNM’s Provider Directory, and Gender Infinity’s Resource Locator - share a similar goal: proliferating access to transgender healthcare. However, they all take different forms in terms of the parameters they use to define which facilities or providers to include, who the end user should be, what interface to use, and even the creators’ motivations for creating the technology. In fact, Johnson of RAD Remedy noted in their interview that they were aware of other similar technologies and resources and that “all of these projects had different incarnations and different philosophies behind them.”

3.2. Precarity and filling the gaps

The creators of trans health technologies emphasized how easily resources and knowledge are lost or forgotten. For example, Keaton Kash, a White trans man and creator of transition resource and photo-sharing website ModClub/ClubFTM said in our interview with him that TransBucket, the only other site designed for trans people to upload results from their gender-affirming surgeries, had not been functioning for some time when he began ModClub. He went on to say “people are trading … particularly lower surgery results, like prohibition and contraband,” such that “… it puts the onus on the people who have surgery to have to continually hand out their private pictures to all the brand-new people through [direct messages].” In this way, Kash positioned ModClub as an alternative to sites like TransBucket, another
community-led effort to curate vital health information via user-shared pictures of surgery results. In his words, “first and foremost, we need a second place to upload surgery results … we need more than one resource; we don’t want all our eggs in one basket. One site goes down and then there’s our entire legacy.” The precarious nature of these kinds of digital spaces that can serve both as archives of information and vital spaces for connection across time and distance was something that Kash underscored throughout his interview. He noted that when he started his transition in 2006 “back then, basically all we had for research and community was Yahoo groups … but all those Yahoo groups have been wiped away.” While these kinds of groups and spaces for connection and trans health knowledge sharing do still exist in new iterations, according to Kash “they still seem scattered.” Kash, then, sees his technology as one part of a larger information infrastructure that can provide trans people with vital health information in ways that also necessarily produce community spaces for connection. He is intimately aware that he is recreating an existing technology, or at least a very similar one, but suggests that this new iteration is necessary precisely because of the overlapping precarity of the internet and of trans communities and resources on it.

This phenomenon in which new archives of information, or groups for trans communities to connect, crop up regularly was also named by Reed, the creator of the Informed Consent HRT Map. She mentioned “constantly I learn about new Facebook groups that are posting [the informed consent HRT map] in their locations,” and that “every now and then it kind of blows up a little bit.” However, since she updates her map of clinics and providers that offer an informed consent model for hormone therapy exclusively based on volunteered information, there is a semi-constant need to update her technology. She described periodically receiving a barrage of messages when the map has been shared widely anew, and then spends “maybe three or 4 h a week” of her free time updating the resource. Additionally, she stated plainly in her interview that “there’s never been any funding attached to it. [Updating the map] has always been in my spare time.” At the same time that this ongoing maintenance is clearly motivated by a desire to help other trans people access vital healthcare, the concentration of an information archive like this one in the hands of one person echoes the precarity mentioned by other technologists. And while Reed herself may not have conceptualized her work in building and maintaining the map as a precarious endeavor, she was aware of precarity in the larger trans health technological landscape. She noted, “It’s really interesting and kind of unfortunate, but it’s part of just the way I guess things work. Most of these technologies are by trans people. There’s very little provided in terms of trans technologies for trans people that aren’t done by trans people and usually done in a volunteer way.” In these ways, Reed sees her work as solving a problem, namely a lack of health information, that could not necessarily be solved by a single person because no one could have the depth and breadth of experiential knowledge needed to create a resource like hers.

Despite her design process being entirely solitary, Reed still relied on and continues to rely upon volunteered geographic information from trans community members. Even if her technology, a simple Google is to creating trans technologies, she replied, “extremely.” Reed went on to say,

I think that community is essential in trans technologies because it helps you identify blind spots and helps you make your technology better. It helps you learn how your technology is being used. And it lets you know that people are using it for the purposes that you wanted it to be used for, that it is helping people in the ways that you wanted to help them.

This perspective on her technology as a community-driven tool underscores the importance of the resource. While Reed may not anticipate precarity in the information infrastructure needed to proliferate access to gender-affirming care the way Kash of ModClub did, she does intuitively understand that the technology must continuously be maintained. She downplayed the ongoing labor of that maintenance, but this act of curating a resource like this could be seen as an expression of care for the community for whom she built the technology.

In regards to the anticipated precarity surrounding the TGRCNM Provider Directory, it was less about the digital infrastructure for accessing health information, and more about the lived realities of the people accessing services through TGRCNM. When prompted about whether the resource guide was his idea or the organization’s webmaster’s, Trimm is quick to say “no, that came from the organization itself based off of the needs of our participants.” In discussing their other programming which had moved online due to the COVID-19 pandemic, Trimm explicitly named the precarity of many trans people’s life circumstances when he said, “it is so much easier to have one thing, versus having every group has their own private Facebook group that this person is in charge of … that’s not sustainable long term, especially because a good majority of our facilitators are volunteers. Something changes in their life, and they can no longer facilitate, and they disappear off the face of the earth. Now we’re chasing down somebody with a password to give us access.” Trimm’s quote emphasizes the benefits of centralizing the labor of maintaining and sustaining these support groups, which fell under his purview as director of the organization. He understood his taking over as introducing a kind of sustainability, as a solution to the precarity of relying on volunteer labor to do the work of holding space for community connection and managing the support groups logistically.

While support groups moving online, and internet-based technologies for proliferating access to trans-affirming service providers were ubiquitous, the particular resource site iteration about which we spoke with Trimm illustrates that many of these technology creators are aware they may be reinventing the wheel, so to speak, yet still deem doing so necessary - primarily, in Trimm’s case, to create a resource site designed specifically for the local trans community that TGRCNM serves. As Trimm put it, “there really isn’t anything like [TGRCNM], and especially for this part of the country … Nothing like it. You know, once you leave Southern California, we are it. Until you get east of the Mississippi.” In this way, Trimm emphasized the necessity of localized resources because some regions may be left out of larger, nationalized efforts, or other regionalized efforts, to create resources like the TGRCNM’s provider directory.

Echoing this sentiment of regionality and precarity, Bantuelle of Gender Infinity Resource Locator recounted their experience of attending a conference in Texas where they introduced people to the Resource Locator technology. They noted that “the majority of [attendees] really did want to know if they were already in the database because they were providing some kind of service to the trans community,” and that “overall, they were just happy to see that it was there and that they were able to get their name out as somebody who was trans affirming.” This enthusiasm to be included also came up in our interview with Hill of Trans in the South, who stated, “basically as soon as the guide was published, which got to be this really unwieldy PDF, it was already out of date because as soon as we did the launch, people would write us and say, ‘Oh, we need to be included, we want to be included,’ and all that. And then it was a whole nother year before we would do updates for them.” That kind of enthusiasm from providers may be given the context of a trans-specific conference at which they tabled, made sense to Bantuelle because, as they put it, “there historically have been very minimal resources for [trans] people.” However, they were also careful to mention “I was very mindful of the fact that there are some pretty horrible people out there and really restricting the ability for anyone to do anything hateful with the website was a big focus of mine initially.”

Bantuelle’s desire to keep the Gender Infinity Resource Locator safe to use speaks to the anticipated precarity of trans technologies and the
This paper reveals two key insights. First, multiple technological reimportance of community-based design processes as a feminist and so
the map as well as in maintaining and expanding it through user-healthcare needs can be met with a single technology. While our creators
engage and things like that,” Bantuelle noted not only that other tech-
nologies like that already existed, but also that “I’d be very fearful of
what opening up any sort of trans resource to comments could do with
the horrific nature of the internet.” Bantuelle’s comments exemplify
the great emphasis that trans tech creators put on creating technology that
cares for its users, while at the same time increasing their access to care.

4. Discussion

In this article, we have outlined how the creators of trans technology
interviewed in this study converged on a single goal of proliferating
access to healthcare and health resources for trans people, each in their
own unique way. Further, our findings show how creators of trans health
techs understand their technologies to be reiterating other technologies
as a means of combating the precarity of both internet-based technologies in general and trans communities online in partic-
ular. Importantly, our results suggest that community itself is an integral
part of both designing and using technologies for trans healthcare
access. For some of the technologies, trans community members them-
selves help to build out the resources through VGI, such as in Erin Reed’s
Informed Consent HRT Map, the Trans in the South resource guide, and
the now defunct RAD Remedy site. For others, trans people built com-
unity around using these resources, such as with ModClub which
began as a photo sharing resource for those who have had or were
seeking bottom surgery and became a virtual hub for the transmasculine
community. These results extend prior work that has argued for
the importance of community-based design processes as a feminist and so-
cial justice-based approach (Bardzell, 2010; Costanza-Chock, 2020;
Dombrowski et al., 2016; Haimson et al., 2020). Specifically, our results
illustrate that community involvement need not be limited to design
processes, but can also entail contributing to, building, and populating a
technology. Even further, community can be built up through the end
use of a technology, especially when the technology itself involves the
community for whom it was designed in these other myriad ways.

Taken together, the distinct but similar technologies we chronicle in
this paper reveal two key insights. First, multiple technological re-
ources for trans healthcare continue to be created because there is no
singular trans community whose collective health information and
healthcare needs can be met with a single technology. While our creators
often had knowledge of other similar technologies, trans communities, and
indeed the trans experience, are not monolithic. And the results
highlighted, the precarity of trans communities online and technologies
designed by and for them sometimes drives people to create such similar
technologies, even when they’re unfamiliar with their technical pre-
decessors. For example, by the time Reed began creating her resource for
accessing informed consent care, RAD Remedy, one of its predecessors,
was defunct. Highlighting the regionally specific concerns some of our
technologists cited, Hill of Trans in the South emphasized the particular
needs of trans communities in the South as an often overlooked region,
or one that is written off (by those without personal connections to
Southern trans communities) for its ostensibly conservative cultural and
political landscape. Reed of the Informed Consent Map underscored how
important Reddit and Twitter were for her own edification in creating
the map as well as in maintaining and expanding it through user-
volunteered information. And finally, Johnson of RAD Remedy re-
lected on their own experience as a young person in Western Illinois
where there were no local trans-friendly clinics when they began
seeking gender affirming care and how that experience shaped their
approach to building RAD Remedy. These were totally different ex-
periences geographically, with Reed’s map being born of the internet,
Johnson’s RAD Remedy beginning as a local Chicago resource, and
Hi’s, Trimm’s, and Bantuelle’s tech designed explicitly to fill regional
gaps. Yet these creators converged on similar products because of a
shared goal of proliferating access to care and information.

Second, these technologies underscore the complex interplay be-
tween online health information seeking and physical resource access.
None of these technologies were designed to provide knowledge about
trans medicine itself, such as by answering users’ concerns about medical conditions or the long term effects of exogenous hormones on
the body. Instead, they were designed to address a kind of health in-
formation need that may be taken for granted for any cis people whose
identities or health needs are not as medicalized or pathologized as trans
people’s: simply determining where care is available. Given that there
are so many different trans communities, it is astonishing that these
types of technologies can serve as resources both for trans patients
themselves and for those who care for trans people or who make re-
ferrals for trans people who may not have reliable and consistent access
to the internet. Each of the creators of these trans healthcare access
technologies shared stories of how they were contacted by providers or
those making referrals in their clinical practice, thus demonstrating a
dearth of formalized, authoritative repositories for information about
accessing trans healthcare - a knowledge gap that trans health tech-
nologies aims to fill.

At the same time that proliferating access to information and
healthcare itself should be celebrated, it is important to also consider
what it is that people seek to access. One of our respondent’s technolo-
gies, Reed’s Informed Consent HRT Map, specifically only includes
clinicians who are reported to use an informed consent model, meaning,
for her, one that does not require a mental health evaluation before
accessing care. However, even among clinicians there is no real
consensus on what constitutes ‘informed consent’ to trans medical care
(Blasdel et al., 2023). Additionally, Stef Shuster (2021) demonstrates
that scientific evidence is a double-edged sword in the context of trans
medicine, something that is often cited to uphold the legitimacy of trans
medicine, but also something used to shore up the expertise of clinicians
who often disagree. In the current moment where trans medicine and
healthcare are under constant legislative attack, critique of any kind can
be weaponized by anti-trans actors to cast aspersions on the legitimacy
of trans healthcare. Yet, it is vital to question the quality of care and
information to which trans people seek access. Our findings showcase
the ways in which the trans technology has and continues to be an
amorphous tool for survival and resistance, especially in a moment
where transness and trans people are under attack. In studying trans
technologies, we must consider the dangerous and precarious positions
in which trans people find themselves, and remember that this danger
and precarity is not felt evenly by all trans people in every geopolitical
and sociological context. And in studying trans medicine and healthcare,
we must also remember that not all care is created equal, and the
 technologies of gender-affirming medical care are themselves in need of
improvement. Plainly, improving access to trans healthcare and infor-
mation is only worth struggling for if the care and information itself is
worth seeking.

This theme of precarity was seen across each of the interviews, and
seen differently with each creator. While the technologies shared a goal
of proliferating access to healthcare for trans people, each technology’s
creator either referenced or was caught up in a kind of precarious virtual
geography. Kash of ModClub outright named the lack of sustainability
not just in virtual spaces, but in trans communities and the resources
built by and for them. This awareness may have been part of his moti-
vation to initially charge a fee for service and access to ModClub, as a
means of creating a kind of financial sustainability for what has clearly become a vital resource. For Reed, she sustains the entire resource she created on her own, dedicating a lot of her free time to taking submissions and building out the map so others can use it to access care. Yet she did not articulate any kind of apprehension about being the central node in an extensive network of people who have built up the resource, even though without her the Informed Consent HRT Map may collapse. Similarly, Trimm became the control center for the technologies maintained by the Transgender Resource Center of New Mexico when he became its director. His approach to combating the anticipated precarity surrounding trans communities and virtual spaces was to centralize knowledge needed to sustain it. Finally, Bantuelle worried about the potential harassment and violence trans people in the Southwest may face if the Gender Infinity Resource Locator began taking submissions without vetting, or if it became a social media platform open to the public. Given that they are based in Texas with its legislative attacks on transgender health and life, it makes sense that Bantuelle would anticipate precarity in these ways, even if they were differently articulated from the other creators with whom we spoke. Ultimately, this theme of precarity may explain why the creators we spoke to in this study created so many technologies that do similar things and share similar goals toward increasing trans access to healthcare resources.

Across each of the interviews, trans tech creators’ motivation to develop and maintain technology were guided by care. These findings echo Malatino’s (2020) description of “trans care” and how trans people often care for each other in specific and inventive ways, especially in contexts where medical providers and mainstream society neglect trans people’s unique needs. Malatino (2020) describes the long history of trans care in online mediums, including newsletters, listservs, and transition crowdfunding, that were used to build solidarity in response to medical barriers like diagnostic criteria and transition. For Reed, she sustains the entire resource she created on her own, dedicating a lot of her free time to taking submissions and building out the map so others can use it to access care. Yet she did not articulate any kind of apprehension about being the central node in an extensive network of people who have built up the resource, even though without her the Informed Consent HRT Map may collapse. Similarly, Trimm became the control center for the technologies maintained by the Transgender Resource Center of New Mexico when he became its director. His approach to combating the anticipated precarity surrounding trans communities and virtual spaces was to centralize knowledge needed to sustain it. Finally, Bantuelle worried about the potential harassment and violence trans people in the Southwest may face if the Gender Infinity Resource Locator began taking submissions without vetting, or if it became a social media platform open to the public. Given that they are based in Texas with its legislative attacks on transgender health and life, it makes sense that Bantuelle would anticipate precarity in these ways, even if they were differently articulated from the other creators with whom we spoke. Ultimately, this theme of precarity may explain why the creators we spoke to in this study created so many technologies that do similar things and share similar goals toward increasing trans access to healthcare resources.

Expanding upon Malatino (2020), interviewees in our study demonstrated trans care by connecting community members to trusted resources and reliable information about gender-affirming care in an age of rampant dis- and misinformation (Garofalo, 2023).

Future research into the centrality of technology in the process by which trans people identify providers, access care in the clinic, and share their experiences should consider how these aspects of healthcare seeking relate to existing literature on health information seeking behavior. For example, Greyson (2018) proposed a theory of information triangulation wherein information seekers gather opinions from multiple sources and weigh them against each other based on how much they trust the source, and this theory would likely be quite useful for studying how trans people source and use health information. At the same time that theoretical advancement like this is useful, health information scholars must expand their understanding of health information to include availability of care and services, and in this way could develop more nuanced understandings of health geography and health services research and move toward increasing trans access to healthcare resources. For example, health geographers have demonstrated that spatial distribution of healthcare facilities is not enough information to understand access (Planey et al., 2023), and that investment in travel to care, waiting in clinics to see providers, and researching health conditions or providers with relevant expertise should be considered as another social determinant of health (Planey et al., 2022). While our data were limited to creators of trans technology and we did not interview users themselves, it is patently clear from these interview data that who provides trans-affirming care, where that care is provided, and how competent specific providers are in working with trans clientele are missing pieces in the puzzle of health information seeking for trans populations. To that end, future research should also incorporate interviews with users alongside creators to gather a more holistic understanding of the role technology could play in proliferating access to healthcare for trans people.

CRediT authorship contribution statement

Avery R. Everhart: Conceptualization, Methodology, Writing – original draft, Writing – review & editing. Kristi E. Gamare: Writing – original draft, Writing – review & editing. Oliver L. Haimson: Funding acquisition, Methodology, Project administration, Resources, Supervision, Writing – original draft, Writing – review & editing.

Data availability

The data that has been used is confidential.

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