

# Infrastructuring Care: How Trans and Non-Binary People Meet Health and Well-Being Needs through Technology

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## ABSTRACT

We present a cross-cultural diary study with 64 transgender (trans) and non-binary adults in Mexico, the U.S., and India, to understand experiences keeping track of and managing aspects of personal health and well-being. Based on a reflexive thematic analysis of diary data, we highlight sociotechnical interactions that shape how trans and non-binary people track and manage aspects of their health and well-being. Specifically, we surface the ways in which trans and non-binary people *infrastructure* forms of care, by assembling together elements of informal social ecologies, formalized knowledge sources, and self-reflective media. We examine the forms of *precarity* that interact with care infrastructure and shape management of health and well-being, including management of gender identity transitions. We discuss the ways in which our findings extend knowledge at the intersection of technology and marginalized health needs, and conclude by arguing for the importance of a research agenda to move toward TGNB-inclusive design.

## CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**;

## KEYWORDS

gender, trans and non-binary health, personal informatics, marginalized health, infrastructuring, algorithmic harms, technology harms

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## 1 INTRODUCTION

Transgender and non-binary people encounter significant challenges in their everyday lives, ranging from myriad forms of discrimination to a lack of access to vital resources [7, 77]. A particular concern for trans and non-binary people is their personal health [45, 82]. Research has found that a range of technologies are ineffective at best, and often harmful, for trans and non-binary people, particularly if they were not represented in design decisions shaping the technology, or in the data used to develop and evaluate its algorithms or models [4, 86, 89]. Research at the specific intersection of gender transition and personal health and well-being is needed, as prior work has identified that gender transitions are often characterized by complex physical and mental health experiences, yet many of these experiences can be rendered invisible if not explicitly sought out through reflective study methods [48]. Unfortunately, current digital health experiences can also miscalculate health metrics for trans and non-binary people, robbing them of the benefits of these technologies, and instead furthering the potential for harm [2].

In this paper, we describe findings from a mobile diary study with 64 participants who identify as transgender and/or non-binary adults, located in Mexico ( $n = 24$ ), the U.S. ( $n = 22$ ), and India ( $n = 18$ ). Rather than focus on experiences associated with a single type of health technology, care interaction, or health or well-being goal, this paper aims to identify broader phenomena that surround and underpin trans and non-binary adults' experiences with sociotechnical systems of care. Our research questions include:

- (1) What sociotechnical experiences shape trans and non-binary adults' use of technology to meet health and well-being needs?
- (2) What sociotechnical conditions characterize the experiences of trans and non-binary adults as they track and manage aspects of their health and well-being?

We draw on a reflexive thematic analysis of participants' responses to diary prompts, including open-format text and audio responses, photos, and videos, to make the following research contributions:

- (1) A descriptive, cross-cultural account of transgender and non-binary people's interactions with sociotechnical systems, to track and manage aspects of their health and well-being, in

three countries. We focus on two overarching findings: how transgender and non-binary adults *infrastructure* forms of care with currently available technologies, and the specific conditions of *precarity* that these care infrastructures are subject to.

- (2) An analysis of the specific ways in which transgender and non-binary adults infrastructure forms of care: assembling together elements of informal social ecologies, formalized knowledge sources, and self-reflective media.
- (3) An examination of the conditions of sociotechnical precarity that shape current experiences of health and well-being management, and a discussion of the ways in which they can impact gender identity transitions and pervade infrastructures of care for marginalized health needs.

Our analysis of the ways in which participants infrastructure care finds that they *connect to self-reflective infrastructure* using a variety of self-tracking technologies. They *infrastructure futures* for themselves and others, often on social media, through motivating stories, planning and documenting medical needs, and witnessing and sharing gender transitions over time. While prior research has discussed how social media facilitates trans identity exploration and drawing from similar people’s experiences [43, 46], we extend this work by focusing on how people use technology as infrastructure to envision and plan trans futures for themselves, and to provide visions of trans futures for others. Finally, we describe the myriad ways in which participants *infrastructure around marginalization* in pursuing their health and well-being needs.

Participants’ diary responses also point to specific conditions of precarity that influence how infrastructures are assembled and experienced, which we term: *information precarity*, *informatics precarity*, and *access precarity*. After introducing these interlocking conditions, we conclude with a discussion of the areas of work that our findings extend, arguing for the need for sociotechnical systems to account for the ways in which precarity can pervade care infrastructures for people with marginalized health needs.

## 2 BACKGROUND

In this section we introduce terminology used in this paper, and situate our study design, findings, and discussion with respect to the social and political contexts that surround and influence the health and well-being of trans and non-binary people, in each of the three countries we studied.

### 2.1 Terminology

We use the acronym TGNB to represent transgender, gender-diverse, genderfluid, and non-binary identities—as well as movement or fluidity between or across them. Further, in India, there are local categories such as *hijra* that overlap with TGNB categories, as we explain below. We do not intend to erase the differences in these identity categories, nor their social implications, but use the term TGNB for consistency in this paper, to be inclusive of all whose self-conception of their gender is different from that assigned at birth, or encompasses that assigned at birth, but is not limited to a binary gender assignment, or who reject binary gender norms.

We use the term *marginalized* in relationship to TGNB people throughout this paper, to acknowledge the variety of structural

inequities and forms of exclusion they experience (including those we summarize for each country, below). In doing so, we echo the view that marginalization represents “a failing of society, rather than a failing of any individual person” [66].

### 2.2 Mexico

Gender identity in Mexico, like other colonized nations, was influenced by the cultural norms of those who invaded and changed Indigenous societal structures [68, 84]. Resistance to colonization varied by region, and geography continues to shape post-colonial experiences of gender [105]. Mexico law has moved toward increased federal legal protection and gender recognition [18, 69] and has enshrined gender protections in the constitution that apply a human rights lens [83]; however, disconnections between the “law on the books” and the “law in action” cause many TGNB people to navigate ambivalent and difficult bureaucracy [67]. For example, federal laws that, in theory, allow anyone to legally change their name and sex on government documents [1, 39] and that prohibit employment discrimination [18, 69], are applied inconsistently across states. Selective applications of these laws create significant barriers to the ability of TGNB people to fully exercise their legal rights. Trans people in Mexico also face disproportionate violence and social discrimination [18, 69, 78] adversely impacting health and well-being [52], which is compounded by experiences of discrimination in accessing medical services [67], similar to non-gender people in other parts of the world [37, 70].

### 2.3 United States

In the U.S., formal health resources available to transgender people vary widely by state and locality. This is in part influenced by the uneven patchwork of laws and protections that have been written or have been interpreted to include TGNB people. TGNB people’s rights vary significantly by state [20]. In 2020, only 19 states and the District of Columbia had a broad range of protections to ensure equality for LGBTQ people, while 25 states had no additional protections or anti-LGBTQ laws [112]. This variability is reflected in how insurance companies offer uneven and sometimes inconsistent coverage for trans-related health care needs. Many health plans deny coverage to transgender people for certain health care services, with coverage varying widely by state and provider [38]. Health insurance companies are not allowed to limit preventive services based on sex assigned at birth, gender identity, or recorded gender, but this has not stopped insurance companies from denying trans-affirming care to transgender people [38].

Trans health inequities extend beyond insurance coverage, however. Even if a TGNB person has access to trans-affirming health care, they can face multiple barriers to receiving competent gender-affirming care, including difficulty finding competent care providers, discrimination, structural barriers, and financial barriers [104]. Consequently, many do not seek preventive care or may postpone routine care related to their overall health [33]. The cumulative effects of these structural inequalities and barriers to health care manifest in a variety of disparate mental and physical health outcomes for transgender people [40].

## 2.4 India

The terms “transgender” and “non-binary” are relatively recent ways of referring to gender identity in India. Historically there have been different terms used to refer to TGNB people, based on language and geography. For example, hijra has been historically recognized as the “third gender”, with many linguistic variations. Hijra is a social and cultural term that collectively refers to people in South Asia who do not subscribe to binary gender assignment, but rather “combine or move between them” [80]. Hijra cultural identity is complex, as “hijra” was also known as a hyper-visible category used in the colonial era [54].

More recently, there has been significant progress in recognizing rights of TGNB people in India, including hijra (see Shah [2015] for the ongoing legal history [94]). The most recent legislation in 2019 enshrined some protections and rights for TGNB people, but still fell short of the demands raised by impacted communities. Furthermore, TGNB communities are not monolithic, and these rights in practice are refracted through caste, urban–rural, and class divisions. As Mount [2020] shows, there has been effort by some middle class and upwardly mobile trans women to be seen as transgender, but not as hijra, because Hijras, who are perceived to be employed in menial jobs or begging, and a colonial category, are often stigmatized and excluded from mainstream society. In fact, the term is often colloquially used in derogatory and offensive ways with an intent to insult [75]. This treatment bears out in hijra experiences on social media platforms: though social media can support identity exploration and development for many TGNB people, hijra face stigmatization that impacts their disclosure and self-presentation practices, reducing the benefits they are able to experience on these platforms [80].

## 3 RELATED WORK

This paper, and the findings therein, engage primarily with everyday technologies used by TGNB people to meet health and well-being needs. In this section, we’ve synthesised literature from the disciplines most closely related to those technologies. Our goal is to provide context about how these technologies are used and describe pre-existing knowledge about harms related to their use. As we specifically studied people who keep track of aspects of their health and well-being, including through the use of technology, we review the personal health informatics literature in-depth, to complement our review of TGNB people’s experiences with technology more broadly. We also introduce and situate key concepts that our study findings build upon, including *infrastructure*, *infrastructuring* and *precarity*. The contributions of our study extend the work summarized in this Related Work section, and highlight the need for new and strengthened forms of care infrastructure, which includes a range of technologies, to meet TGNB people’s health and well-being management needs.

### 3.1 Technology-mediated Harms to TGNB People

While technology can be helpful and a means to access community, support, and resources for TGNB people [8, 45–47, 103], it can also bring about substantial harms. For instance, TGNB people often face barriers in representing their identities in sociotechnical

systems [99]. This may take the form of social media sites that make gender transition difficult [44], credit reporting technologies that view trans people as fraudulent [72], identity documentation systems that expect unchanging identities [53, 97], and systems like airport security in which scanning systems require binary gender categorization and often flag TGNB people as anomalies [27, 29]. Technologies for gig work and online dating often enact barriers that bar TGNB people or do not allow them to equitably use platforms [55, 108]. Additionally, algorithmic approaches to personal identification, such as automatic gender recognition, can be substantially harmful for trans people, as these systems typically rely on binary genders and simplistic views of gender [49, 60, 90].

In addition to the emotional, physical, and financial implications of these technology-mediated harms, which further marginalize TGNB people, personal informatics technologies can contribute to specific forms of harm related to health and well-being, both through their exclusion of TGNB people and through the reification of harmful norms around what it means to be ‘healthy’ or ‘well’ and how that might be achieved. While some personal informatics technologies are inclusive of TGNB people [36], more often they rely on binary conceptions of gender that further marginalize them [2, 61]. As we describe in depth in the next section, technological systems that reaffirm unchanging binary gender identities do a serious disservice to TGNB people, not least through their de-legitimization of their experiences and needs.

### 3.2 Personal Informatics for Health and Well-being

This research engages with TGNB people’s experiences keeping track of aspects of their health and well-being. Today, many approaches to this process rely on consumer technologies such as wearables [91], the design of which embodies elements of “quantified self” (or “self-tracking”) culture [71]. Dominant today in many consumer technologies, these cultural elements seek to advance what is considered to be “self knowledge” [28, 64, 115]. Such knowledge—from the perspective of these self-tracking technologies—is brought about through the external, enumerated measurement of personal variables, including vital signs and other biometric calculations, and activities and behavioral habits such as exercise, sleep, and diet [79, 92]. As such, their design foregrounds the collection of personal data as a path to self-regulation, actualization, and even “optimizing” one’s body over time [63, 79, 91, 115].

**3.2.1 Critiques of Self-Tracking Technologies.** The selectively quantified paths to knowledge afforded by personal informatics systems and self-tracking technologies—for the purposes of self-discipline and regulation—are inherently problematized. Critiques of self-tracking technologies include their tendency to build on Anglo-American, westernized forms of knowing, consistent with religious, imperial, and patriarchal paradigms that seek to shape and discipline bodies [115]. Additionally, though the design and marketing of wearable technologies suggests increased user control over their own data, the data collection practices of institutions supplying wearables leave open many questions about data access and use [28].

Critiques of self-tracking technologies also point to a narrow focus on specific data types, making selected types of self-knowledge

the valid “lenses” through which to see oneself, while reducing or restricting others [64, 79]. Underlying some investments in consumer health technologies is the implication that widespread health issues are due, in part, to individual failings in discipline and care [115]. Yet, absent from these logics are concerns that preoccupation by individuals with self-tracking methods diverts attention from coordinated, community-oriented solutions [121], or to addressing the structural barriers to these solutions.

**3.2.2 Implications for TGNB People.** Self-tracking technologies pose further risks for TGNB people: certain technologies can reinforce gender-normativity, building on rigid notions about what a man or woman’s body should look like, without accounting for the large amount of variation in people’s bodies and their lived experiences [23, 88]. The exclusion of TGNB identities and bodies from these aspects of design sends a message to TGNB people about their personal and collective legitimacy.

As noted earlier, TGNB people can also be harmed by the utilization of systems that inherently perpetuate harmful societal ideas about bodies and health. Many self-tracking technologies are perceived or positioned as ‘neutral’ artifacts, but analyses of these technologies have demonstrated the ways in which they embody normative concepts of gender and femininity, and in doing so play a role as digital ‘technologies of gender’ that regulate and seek to control people’s bodies [88]. This is prevalent even when these technologies are designed to be ‘genderless’ or ‘gender neutral’, as such design decisions often base their concept of genderlessness around masculinity or androgyny [24]. These problems can be perpetuated when personal data is aggregated and analyzed by institutions or other actors: aggregation can exclude large swaths of the population who cannot afford such devices, or who connect with their technologies and bodies in ways unsupported by the technology design, leading to a lack of representative data [115].

There is, of course, the potential for self-tracking technologies to be beneficial. Exerting one’s own control over self-quantification and tracking can serve to resist institutional practices and forms of power [76]. Access to data about oneself can support improvisational and situational aspects of personal decision-making [59]. It can also help individuals gain access to care or consideration from which they might otherwise be excluded. Talitha Williams’ [2014] use of personal fertility tracking to push back against clinical recommendations that put her baby at risk is an example of how to challenge institutional decision-making practices that fail to account for varied and unique health situations [117]. Similarly, Parvin and Pollock demonstrated the use of self-tracking data to create visualizations that elicit conversations about gender and community [81].

**3.2.3 Reflection.** The process of collecting and reviewing self-tracking data can also support aspects of self-reflection. Based on Choe et al.’s study of self-trackers’ practices, *reflection* often occurs concurrently with data collection, which suggests an integrated role of reflection throughout a self-tracking process [22]. How we understand the role of reflection through personal informatics systems continues to evolve, but it is clear that these practices contribute to many people’s understanding of themselves, their experiences, and their goals.

Research on personal reflection through digital systems suggests a self-generative potential of self-tracking practices and the reflections they afford: experiences of temporality can free people from a sense of fixed identity and enable them to envision more emergent selves [87, 91]. Data abstractions, representing elements of the self, thus serve as a kind of material for experiencing the self in other ways [95]. These findings are particularly significant in light of the ways in which TGNB people engage with their gender identity and sense of self. The practice of self-reflection is often described as a central part of the process of developing and understanding one’s identity as a TGNB person [32]. However, this process can be undermined when systems and applications directly ignore TGNB people in their design, furthering systemic discrimination.

### 3.3 Infrastructuring Care amid Precarity

**3.3.1 Infrastructuring.** Information infrastructure encompasses the various and networked social, material, and technical formations that enable access to a variety of resources [12], and reflect the situated and actively negotiated relationships between people, technologies, and practices [13, 102]. Examination of the active and relational ways in which information infrastructures emerge has given rise to the concept of *infrastructuring* [101], referring to the ongoing practices and moments in which infrastructures are enacted and sustained [21, 42]. In the context of health and well-being, scholarship has focused on infrastructuring information systems as participatory cultures of knowledge-making and sharing [110], and as the (in)visible labor to create and sustain health-enabling platforms, which refer to the assembly of linkages among different actors and health information, and the interactions, and interdependencies between them [42, 116]. In this way, health information infrastructures, such as personal health technologies [114], are enabled not only by digital platforms and digital or physical elements, but the routines and embedded work necessary to maintain them [100].

Prior HCI scholarship has examined the routines and work of patients [10] and informal caregivers, such as friends and family [21], and their role in constructing digital and local care networks [106]. Informal care systems, as “infrastructures of care” [30], are constituted through the meaningful dynamic relationships that reflect people and communities’ health and well-being activities. The infrastructural lens facilitates deeper analysis of self-care and interaction with “personal health” technologies as sociotechnical and distributed practices, involving an assemblage of actors, social norms, bodies of knowledge, and technologies [114, 116]. People marginalized from formal health systems may construct DIY informational and care infrastructure to meet their needs within precarious conditions [58, 73], which we introduce next.

**3.3.2 Precarity.** *Precarity* characterizes the unpredictable livelihood of people with limited control and unstable access to resources that shape “material conditions of existence” [65]. Conditions of social precarity are relational and shaped by power dynamics [74], emerging through the systematic absence of structural support, through which people and communities are rendered disposable [51]. People whose lives are shaped by social and economic retrenchment disproportionately experience precarity [6, 17], which compounds and reproduces itself [96]. Gender

scholars recognize precarity is connected to gender norms [16], as gender legibility has a direct relationship to experiences of interpersonal violence [17], how one is able to navigate public spaces [57], and access to employment [111, 120]. TGNB people who “live with precarity” [119] often rely on DIY communication infrastructures to research and share knowledge about gender transition [35]. This infrastructuring outside formal institutions is characterized as “radical sharing” [62], in which the flow of information is a form of resistance to normativity and structural exclusion. These infrastructuring concepts provide a frame through which we can understand how participants in our study use or eschew technologies as they adapt to precarious conditions.

## 4 DIARY STUDY

We ran a mobile diary study to investigate our research questions, which are concerned with understanding the sociotechnical experiences and conditions that shape the ways in which TGNB people manage aspects of their health and well-being. We chose diary methods for their *in-situ* observational benefits, as well as to learn from retrospective accounts of participants’ experiences, as gender transitions occur over periods of months, years, and sometimes lifetimes [48]. Diary study methods allow participants to capture and articulate aspects of daily life that might be otherwise inaccessible to researchers [11]. Photos and other media, elicited as part of diary methods, can enable participants to better recall elements of daily life, such as people and locations of meaningful events [19]. Diaries can also support privacy by enabling participant control over which data to share with researchers, and when [56]. For this reason, they are often used in research in personal settings or on emotionally-sensitive topics [118]. Mobile diary-based, photo-elicitation studies have also been effective in enabling participant reporting of everyday health behaviors and experiences [26, 41, 56, 107].

### 4.1 Diary Study Design

The diary study components we report on in this paper comprise four parts:<sup>1</sup>

- (1) Background questions about participants’ experiences with health and well-being technologies, and the intersections of those experiences with aspects of gender identity.
- (2) Reflection on, and sharing of, day-to-day moments related to health and well-being, and how these moments relate to participants’ trans and/or non-binary identity.
- (3) Reflection on both positive and negative technology experiences related to health and well-being, and intersections with trans or non-binary identity.
- (4) “Wishes” or hopes for the future of health and well-being technologies.

For Parts 2 and 3, we asked Mexico and U.S. participants to record in-the-moment, real-life situations related to health and well-being and their gender identity. Any time they encountered—or recalled—something on the topic (e.g., an app, a form that they are filling out, a news article), they could submit text, audio, or video entries reflecting on the experience. We prompted them to do this once each day, and accepted all entries they wished to provide. For India

<sup>1</sup>We include study design documents with specific prompts and questions in Supplementary Materials.

participants, questions followed a similar structure to that above; however, we asked each entry to be about a past experience to enable human research facilitators to work with participants and manage translation during the study.

In Part 4, we asked participants to contribute text or record audio, video, and hand drawings, in response to questions about wishes for health technology. We encouraged participants to note day-to-day life moments of health and well-being they wished to share. Depending on the language spoken, participants completed the study on their own or with the assistance of a moderator trained to work with TGNB people (we report on the specifics of moderation in 4.2.3).

### 4.2 Participant Recruitment

To recruit study participants, we used a research partner [34], who operates in the U.S. and also work with local country partners. This research partner hosted and managed the mobile diary study and recruitment. Recruitment inclusion criteria specified that participants be 18 years old or older, and identify as trans and/or non-binary, described in many possible gender identity terms.<sup>2</sup> We excluded those who indicated that they were not comfortable answering health-related questions, and those who did not have experience keeping track of aspects of health and well-being for at least six months (either individually or with support of others, and not necessarily using digital technology to do so). As we describe for each country below, while we did not have specific quotas, we balanced for demographic diversity to finalize participant selection.<sup>3</sup> (Tables 2 and 3 report on demographics). All respondents took a screening survey that included questions designed in English to be used in the U.S. The survey was localized to Mexico (translated to Spanish) and provided in both English and Hindi for recruitment in India. Recruitment began in late May 2022, and the study ran for the first three weeks of June 2022. The U.S. participants had 12 days to respond to diary prompts, those in Mexico 15 days, and participants in India completed their study in four days on average, as many relied on human intermediaries, as we describe below.<sup>4</sup>

**4.2.1 Mexico.** Participants were recruited via a Latin American-based research partner who shared calls for participation through their existing participant pool and also shared calls on social media sites (e.g., Instagram and Facebook) to reach a broader audience. They also used a snowball sampling method, where they asked existing participants to recommend other people who met our criteria and who might be interested in the study. We selected 30 people for the study from the respondent pool ( $n = 45$ ). Of those, 24 completed the study and were compensated approximately 3535 MN ( \$175 USD) for their participation. Participants lived in Puebla, State of México, or Mexico City.

**4.2.2 United States.** Participants were recruited directly through the research partner platform [34], which is more popular among

<sup>2</sup>Screening instruments are included in Supplementary Materials, and include our response design, including gender identity response sets. Responses are also shown in Table 1.

<sup>3</sup>More information about race and ethnicity response sets for the U.S. is included in Supplementary Materials.

<sup>4</sup>Details of study length and completion times in each country are included in Supplementary Materials.

people in the U.S. We selected 25 people for the study from the respondent pool ( $n = 2,109$ ) after balancing for demographic and geographic diversity. Of those selected, 22 completed the study and were compensated \$300 USD for their participation. Participants lived in the states of Arkansas, Connecticut, Florida, Georgia, Missouri, Montana, Nevada, New York, Texas, Utah, Washington, and in Washington, D.C.

**4.2.3 India.** Participants were recruited via an India-based research partner who shared calls for participation with their existing recruitment pool. They also connected with local NGOs who work with TGNB people, shared calls for participation via similar social media channels as Mexico, and used a snowball sampling method. Of the total respondents ( $n = 131$ ), 27 people were recruited to participate ( $n = 19$  English speakers,  $n = 8$  Hindi speakers). Of those, 18 ( $n = 13$  English speakers,  $n = 5$  Hindi speakers) completed the study and were compensated 14160 INR ( \$185 USD) for their participation. Five Hindi-speaking and two English-speaking participants requested support with the study and had a moderated experience in which study questions and participant answers were translated. Participants lived in Karnataka, Maharashtra, Bengaluru, and West Bengal states.

### 4.3 Reporting on Caste

The experiences of TGNB people are shaped by multiple, intersecting factors, including aspects of gender identity and expression, but also race, ethnicity, and caste, among other factors. Just as it was important to ensure that the U.S. study sample was diverse with respect to race and ethnicity to account for varied experiences, we also sought to diversify the sample in India with respect to caste.

In India, the caste system is a centuries-old social hierarchy that assigns people to an inherited caste (group) at birth, perpetuating assignment to stratified social classes through blood lines. In Indian society, caste determined almost every aspect of one's social status, from employment possibilities, to marital eligibility [109]. Legislative actions extending past the previous century have sought to prevent caste-based discrimination, with affirmative action policies being enacted in recent decades. Yet, long-standing status differentials mean that some castes still hold more social and economic power than others, and a groundswell of recent scholarship, journalism, and litigation cases contend that caste-based discrimination is still very much alive, including in the computing industry [109, 113].

Caste relations also intersect with experiences of gender in India [85, 122]. For example, women who are generally from caste communities considered to be lower in status are known to face compounding discrimination [122]. Since caste membership is a sensitive topic, the study team discussed at length whether or not to seek this information from participants with two subject matter experts. We decided to include questions about caste, but make responses optional. Our goal was not to examine caste-specific differences, but to ensure varied caste representation in our data.

The India government renders social hierarchy legible through four broad hierarchical categories, each of which include numerous hierarchies and sub-hierarchies: General, Other Backward Classes (OBC), Schedule Castes (SC) or Dalits, and Scheduled Tribes (ST) or Adivasi. As a category of castes, General is considered to be the

highest socially (the highest caste within it being Brahmin). STs are technically outside the historically-determined caste system, but are socially oppressed through other mechanisms. The SC and the ST categories are considered to be the most oppressed.

To collect caste data, we used these standard government categories and included an open write-in option for people who don't identify with these standard categories or wished to clarify their caste further. We disclose the caste information of India participants who opted in to sharing this information, both in aggregate form in Table 3 and in Findings when contextualizing individual quotes. To protect anonymity, we associate India participants only with their caste and gender—not specific state or region—when introducing their quotes.

### 4.4 Research Ethics and Study Consent

While our institution does not house an Internal Review Board (IRB), this study was reviewed by our institution's Health Ethics Committee, comprised of subject matter experts (e.g., bioethics, organizational ethics, health equity, user experience research, data privacy and security, and public health). The committee reviewed gratuity amounts, data management plans, and study design documents and instruments, including consent forms, and the authors made subsequent updates to the study plans and content based on their recommendations.<sup>5</sup>

We informed participants of the purpose of our study, the types of questions we would ask, and our affiliations during recruitment. We obtained consent in the participant's own language, before starting the study, and participants could decline participation or terminate their participation at any point, without forfeiting their entire incentive (we issued a graduated installment for partial completion, such that participants were compensated for the extent to which they participated).

Throughout research planning, authors took efforts to be mindful of the tensions inherent in research with marginalized groups [66]. Members of our research network who share identities with participants, including TGNB identity, reviewed and refined study materials. To respond to possible participant concerns or questions during the study, a researcher was available at all times through a chat interaction, accessible by each participant. We provided sensitivity training for the India research partners who worked directly with participants. We also added diary questions to gauge participants' experience of the study and their participation in it, how important they found the research topic, and what they most wished to learn from the study. While we do not report on responses to these questions in this paper, these data will inform subsequent study efforts, and will shape our approach to sharing study findings with participants.

### 4.5 Author Positionality

Our research team is comprised of researchers with different academic disciplinary expertise, both within and complementary to HCI (e.g., health informatics, sociotechnical systems, cultural studies, gender studies), including people who identify as TGNB. Five authors are white Americans, four of whom have extensive experience working with marginalized populations. One author is an

<sup>5</sup>We include a summary of committee recommendations in Supplementary Materials.

**Table 1: Participants’ self-reported gender identity. As participants were asked to select all that they identify with, response totals can exceed participant totals.**

Mexico		USA		India	
Gender	<i>n</i> (%)	Gender	<i>n</i> (%)	Gender	<i>n</i> (%)
Non-binary	13 (54)	Non-binary	9 (41)	Non-binary	3 (17)
Trans woman / transfeminine	4 (17)	Trans woman / transfeminine	4 (18)	Trans woman / transfeminine	15 (83)
Trans man / transmasculine	5 (21)	Trans man / transmasculine	8 (36)	Hijra	7 (39)
Genderfluid	3 (13)	Genderfluid	6 (27)		
Gender-diverse	1 (4)	Gender-diverse	2 (9)		
		Gender non-conforming	2 (9)		

**Table 2: U.S. participants’ self-reported race and ethnicity (top), with breakdown of specific races and ethnicities of multiracial participants (bottom).**

<i>n</i>	(%)	Race and Ethnicity (U.S.) ( <i>n</i> = 22)
7	(32)	White
6	(27)	Multiracial (broken down below)
5	(23)	Black or African American
2	(9)	Asian
1	(5)	American Indian or Alaska Native
1	(5)	Hispanic or Latinx

<i>n</i>	(%)	Breakdown of Multiracial Identities (U.S.) ( <i>n</i> = 6)
1	(5)	American Indian or Alaska Native, Black or African American
1	(5)	American Indian or Alaska Native, Black or African American, Hispanic or Latinx
1	(5)	American Indian or Alaska Native, Hispanic or Latinx
1	(5)	Asian, Black or African American
1	(5)	Asian, Middle Eastern or North African, White
1	(5)	Black or African American, White

**Table 3: Participants’ self-reported ages, for each country, and self-reported caste, for India participants (right).**

Mexico		USA		India		India	
Age group	<i>n</i> (%)	Age group	<i>n</i> (%)	Age group	<i>n</i> (%)	Caste	<i>n</i> (%)
18–24	12 (50)	18–24	6 (27)	18–24	1 (5)	General	8 (44)
25–34	6 (25)	25–34	5 (23)	25–34	8 (44)	Brahmin	2 (11)
35–44	5 (21)	35–44	7 (32)	35–44	7 (39)	Gowda	2 (11)
45–54	1 (4)	45–54	4 (18)	45–54	2 (10)	Scheduled Caste	2 (11)
55+	0	55+	0	55+	0	Devanga	1 (6)
						Iyengar	1 (6)
						Kayastha	1 (6)
						No Caste	1 (6)

India-born scholar now living in the U.S., and another is a Mexican-born researcher now living in the U.S. The team relied on these authors’ cultural and language proficiency, as well as the TGNB-identifying authors’ personal expertise, during data interpretation and analysis.

#### 4.6 Limitations

While our work provides valuable insights into TGNB peoples’ experiences of care and sociotechnical systems that shape their

health and well-being, our study has limitations. While we took great care in communicating and planning our research with our research partner [34], we did not have direct interactions with study participants during recruitment or study execution. We strove to select a diverse pool for our study, but could not witness recruiting methods firsthand due to the need to work through intermediaries. While we included at least two trans men participants in India in our study, these participants did not end up completing the study,

leading to a lack of representation of trans men from India in our final data set.

While we sought to standardize the questions across these contexts, we had to adapt to local contexts, which led to differences in how the study was conducted, including differences in the study period across Mexico, U.S., and India. We also acknowledge that some of the cultural nuances in our participants' experiences could have been lost in translation. There are different affordances associated with unmoderated, asynchronous online diary format (for U.S. and Mexico participants) versus a moderated, synchronous study experience that relies on human intermediaries to translate questions and participant responses. Our study may also be subject to common limitations of qualitative studies, such as participant self-censorship, considering the varied experiences of TGNB people spread across different geographies and demographics.

## 4.7 Data Analysis

Participants submitted videos, images, audio data, and supplementary closed-ended and open-ended questions, through the mobile diary application. Our approach to data analysis drew on Braun and Clarke's guidelines for Reflexive Thematic Analysis (RTA) [14, 15]. Four researchers participated in data analysis (July–August 2022). Two English-speaking researchers, one researcher bilingual in Spanish and English, and one bilingual in English and Hindi. Three researchers coded all study data derived directly from English-speaking participants' responses (text, image, and automatically transcribed audio and video [98] with manual corrections made by authors during data analysis, and all translations to English from Spanish, Bengali, or Hindi.

For translated data, automated translations [25] were checked over for accuracy by a member of the partner research team in India, and translations were adjusted when needed, before coding began. The Spanish language responses were similarly translated to English, but reviewed by the fourth member of the research team who is bilingual in Spanish and English, who adjusted the translations when needed for accuracy. This bilingual author also reviewed, post-hoc, researchers codes and themes, to add an additional interpretation when differences arose based on their reading of the Spanish language data. We verified the accuracy of the transcription of participant videos in all languages. Our dataset includes survey questions, open-ended responses, video entries, and images.

Three authors who coded all data and generated preliminary themes, first independently familiarized themselves with the dataset: each manually reviewed the images submitted by participants, alongside video and open- and closed-format response data. The three authors then conducted open coding of all data in parallel, independently. The codes were developed in free-form, using spreadsheets rather than coding software. We did not stipulate any word length for the codes, and there were variations in the length of the codes we generated.

The three authors then held repeated discussions of codes and data to produce collaborative interpretations, iteratively moving from open coding to theme discussions, resolving disagreements through multiple rounds of synchronous, collaborative review. They generated new codes collectively as important concepts were identified, compared, and revised. In the second stage of data analysis,

the three authors collaboratively generated three consistent themes each, in two domain categories, and confirmed findings with the rest of the research team. We elaborate on each of these themes below, in the two findings sections that follow.

## 5 FINDINGS: INFRASTRUCTURING CARE

In this section, we detail findings relating TGNB peoples' interactions with sociotechnical systems, beginning with how they *infrastructure TGNB care*: how they assemble together components of informal, digital social worlds, formalized knowledge sources and processes, and self-reflective experiences. Across the countries we studied, infrastructured ecologies of care are situated in—and impacted by—*precarity*. The precarity surrounding participants' everyday experiences necessitates their creation of care infrastructure, which in turn is subject to conditions of precarity. After introducing forms of infrastructuring in this section, we describe conditions of interlocking precarity, and reflect on them in-depth in Discussion.

We introduce quotes with alphanumeric identifiers, stating the participant's gender and, if provided, ethnicity, race, or caste membership, to contextualize quotes and acknowledge other aspects of participants' identities. Given the precarious social and political conditions that shape our participants' lives, we denote locations of participants at either the country level or, for U.S. participants, a general region containing many participants' states, rather than the specific city or state in which a participant lives (for Mexico and India participants, there are much fewer participating cities and states for a given region).

### 5.1 Connecting to Self-Reflective Infrastructure

Our study focused on participants who keep track of aspects of health and well-being—with or without technology. For many of our participants, self-tracking practices co-produce an intricate confluence of gender, health, and well-being. P23, a trans man in Mexico told us that they see personal health tracking technology as an “...*intermediary between the knowledge, the experience, [...] the information, the exhibition, the statistics, the data, the numbers that could help me understand, know, compare, study, identify and define myself*”

Many participants engaged in self-tracking practices—often with the use of digital applications—to cultivate aspects of their TGNB identity. Other participants track their general health or specific health concerns (e.g., diabetes, blood pressure, weight management), finding that tracking applications or methods that rigidly exclude their gender identity add complexity and barriers to these practices, which we discuss further below. For participants who use personal health tracking to cultivate aspects of their TGNB identity, there are several ways in which the motivation and experience is significant and unique to TGNB concerns.

*5.1.1 Material touchpoints for phases of gender transitions.* Participants discussed how they discovered their trans and non-binary potentiality, through new physical, psychological, and social ways of being. Participants gradually explored and actualized these ways of being, and for some participants, self-tracking provided data and reflection experiences that served as touchpoints between the potentiality and the actuality of their gender identity expression, helping them make sense of social, physical and emotional shifts



and changes. Participants drew on these touchpoints and associated data to better understand and memorialize transitions. For example, P25, a Black non-binary person in the Northeastern U.S., talked about how health tracking technologies enable them to chronicle transitions:

*“I have been tracking my physical transformation such that it is at this early stage of my medical transition. I use a voice analyzer, my cellphone with health and journaling apps, as well as a couple of trans-specific apps. I’m chronicling my transition for posterity and may share more publicly in the future.”*

**5.1.2 Understanding and managing bodily responses to gender-affirming medical care.** Across all countries, some participants in each mentioned the importance of tracking their physical and emotional responses to hormone therapy (over half of the U.S. participants commenting on its importance), as well as other forms of gender-affirming care such as surgeries. Participants discussed responses to therapies in physical and emotional terms, the ways that transitions were situated in—and tied to—shifting emotions, and the difficulties making sense of these changes. Some explained non-binary transitions characterized by access to fluidity in modes of being, while others described transitions to specific gender futures. In either case, participants desired ways of tracking influences of therapies on their bodies and identities, in ways that they could configure and control, to make sense of and plan for changes.

*“I started using hormone tracking app, which helped me a lot to track my periods so that I can prepare myself mentally and physically [for them].”*

–P64, non-binary, General Caste, India

*“Tracking mood helped me understand just how much of my life was wrapped up in my conflicted identity. Now that I am free, I feel like I can do anything.”*

–P42, trans woman, Northeastern U.S.

**5.1.3 Building strength.** Participants described the myriad ways in which they navigate intertwined relationships between social discrimination and mental health, and between mental and physical health, especially during transitional periods. To build resilience to meet challenges to mental and physical health, personal health technologies help to build up mental and physical strength. As P24, a trans man in Mexico, shared, *“[Tracking my fitness] was fundamental, it helped me to have enough physical and mental strength to face the changes.”*

P60, a trans woman in India, echoed these sentiments:

*“As a Trans woman we go through not just physical changes but we go through a mix of emotions and it can be very overwhelming as times. Hence it helps to keep a check on your physical and mental well-being.”*

**5.1.4 Working around social exclusion.** Personal health technologies offer personalized health guidance that many TGNCB people would otherwise face barriers to, or outright exclusion from, accessing. Participants described ways in which their reliance on digital health and well-being technologies stems from the exclusion they face from other social settings in which health management takes place. As P61, a trans woman of the Brahmin caste who lives in

India, explained: *“[I]t is very difficult for people like us to know about how to manage your body well and not to be shy among the general public, because, you know, people in India especially, are too judgmental about us. [...] They belittle us...”* Other participants shared similar experiences:

*“I felt sad and disappointed because I was rejected entry into the gym because I am trans. I also felt insulted the way they talked to me.”*

–P49, trans woman, Scheduled Caste, India

Use of self-tracking through personal health technologies to cultivate identity is not an unidirectional, or uniformly positive, practice. As we discuss in the next section, unanticipated changes, or mismatches between desired changes, suggested possibilities signaled by health technologies, and actual changes, can be emotionally taxing and gender-disrupting, as can the design choices and algorithmic assumptions embedded in personal health informatics systems.

## 5.2 Infrastructuring Futures

For many participants, technology enables views of possible futures for themselves, through the gender expression of others. In particular, they described the use of social media to access motivating stories, witness gender transitions over time, and anticipate and plan for trans possibilities, including the medical aspects of gender transitions. P60, a Punjabi trans woman from India, told us they found value in *“knowing for other trans women about their journey and how to work my way up and become powerful in my own skin.”* Participants in the U.S. and Mexico shared similar sentiments, explaining which specific technologies were most helpful to them in connecting to their gender identity and its possible futures:

*“Tumblr. [S]eeing photos and reading text from other people discovering who they are helped me realize what was possible in terms of my gender.”*

–P38, non-binary, Northeastern U.S.

*“Tiktok. It was helpful because I could see how different people presented as trans and nb people, which allowed me to see myself being non-binary and also have the option to take T [testosterone].”*

–P47, non-binary, Southeastern U.S.

In many cases, TGNCB elders perform work in a variety of online spaces to make gender visible, identity expressions obtainable, and transition processes manageable. Their labor and role can foster mutual forms of care, for both elders and those they inspire. As P25, a Black non-binary person from the Northeastern U.S. told us:

*“I’m getting the opportunity to be a non-binary elder to younger people and it’s a wonderful and arming experience. While I’m not very far into my gaht [gender-affirming hormone therapy] journey, I do have lots of experience as an LGBTQ person and general experience that I hope will be helpful to others.”*

Seeking out and relying upon elders’ knowledge online is often a response to coming up short when seeking knowledge from more formalized sources. As P4, who is gender fluid, from Mexico, explained:

*“I sat down for a long time to investigate [TGNB resources] on the internet, but above all with YouTube testimonials, I know people who lived through masculinization and it was beautiful to find myself with so many perspectives, with so many cases and with so many people happy for their change.”*

P26, an AIAN and Black trans man in the Western U.S., shared a similar experience:

*“When it came to technology it was good for me to see various types of people. I was able to see people who were transgender, and how they dressed, how to pack, or how to wear a chest binder.”*

### 5.3 Infrastructuring Around Marginalization

Participants described ways in which they seek out, establish access to, and navigate practical aspects of TGNB care. Across groups, participants consistently use technology to establish and manage access to three types of resources: knowledge about gender identity transitions, informational resources to plan financial aspects of transitional care, and knowledge about—and access to—TGNB-competent health care.

TGNB health information resulting from basic internet searches is seen as helpful overall. Yet, inadequate, missing, or inaccurate information abound, from both informal sources and formal health institutions. For example, P5, a trans woman in Mexico, explained how they relied on various Internet sites when:

*“...investigating what medications to take or how to be able to shape my body, since obviously, my body was masculine and I wanted to feminize myself. They would tell me to diet and exercise, but I didn’t want to be marked as a man. I just wanted to shape my body and, well, technology helped me to know what to do, although in reality there is not much information. [Information] is scarce for trans people.”*

P13, a trans man in Mexico, echoed sentiments about the scarcity of reliable information:

*“Early [in] adolescence, I searched for answers, researching [using] the Internet [...], frustrated to find nothing relevant. [...] There is still a lot of misinformation, little visibility. [We] trans [people] do not exist, or we are not even well defined, such as confusing trans men with trans women, etc.”*

Participants’ efforts to infrastructure health knowledge often involved working around gender-limiting applications and resources, and actively seeking out and assembling together more personally-relevant, gender-inclusive sources of knowledge. Encountering knowledge breakdowns shaped by conditions of ongoing, systemic neglect of TGNB health needs was described as routine. Similar to the ways in which they turned to elders to understand possible futures, they often turned to knowledge on social media and community sites to resolve information needs. For example, P43, an Asian, trans woman in the Western U.S. told us that, “I notice myself researching more about transitioning on media sites such as YouTube.”

In addition to seeking knowledge about gender identity transitions, many also commented on their use of the internet to learn about financial resources to access the care and medical services needed to support transitions. They often assembled various forms of information together to plan for their health needs. P58, a trans woman in India of the Gowda caste, discussed using an internet resource that, “gave us information about the [questions] regarding [...] trying to go thru legal or medical transitions. They also give loans for transitioning expenses.” Similarly, P37, a Black trans man in the Western U.S. told us “I would never have gotten my first binder if I couldn’t access free binder programs online...”

Information and financial resources alone are insufficient to realize TGNB health and its complex intersections with medical institutions. Care providers and health care systems shape gender identity and expression, and participants labor to seek out and navigate gender-affirming health care systems. P57, a member of the Devanga caste from India told us that their biggest challenge was “finding the personal doctor who can understand transgender health issues and addressing the issues.”

Yet, even when individual providers are gender-affirming, participants navigate myriad challenges at the intersection of gender identity and health management more broadly. The following stories from participants demonstrate how they work to maintain institutional knowledge of their TGNB status: in information systems, diagnostic processes, and interactions with clinical staff. P25, a Black non-binary person from the Northeastern U.S., reported:

*“So I just came out of an ultrasound appointment [...] I had kidney stones about two years ago and I had to have surgery for them and they were wondering if they had come back. [...] Basically the ultrasound technician [...] she said: ‘I’m seeing if I can see your prostate on this ultrasound.’ And going into some of these doctors appointments for other things, if you know [to] what extent they know my medical history or if they do at all. And obviously this person didn’t. And then eventually she just said, ‘oh, well, I don’t really need to find it for what we’re looking for.’ [I]n those few seconds, I was sort of unsure about what I was going to do next and how to handle that without it becoming a very awkward situation for me. So, yeah [...] that was today.”*

Breakdowns in interactions with clinical staff come in many forms, and require different kinds of work to manage, from emotional labor to educating care staff. P40, a non-binary participant from the Northeastern U.S., told us about care that might be considered “affirming” but doesn’t match the participant’s care needs and would not be considered “competent”:

*“I was getting a refill on my ADHD meds and I was talking to my psychiatrist and I was just trying to be like, ‘Hey, here, the new meds I’m on, I’m on testosterone now. I am trans.’ [...] she was like, ‘Oh, you’re transgendering. Are you planning on having the sex change surgery?’ And I was like, ‘Ma’am, I’ve already had a double mastectomy like I already did that, you know that it’s in my bio, but you didn’t seem to know that that was like a gender thing. [...] [A]s someone with a chronic illness and I see a number of different specialists*

*and have a lot of different appointments, keeping them up to date on my gender can be really hard.”*

Experiences like these highlight the many forms of labor required to navigate through and around current care norms and infrastructure, to coordinate and connect to resources to make sense of one’s personal health. In the drawings participants shared with us, depicting aspects of their ideal health technologies, many illustrated futures that suggested more connected technologies that view them and their health in holistic ways (e.g., Figures 1 and 2).

## 6 FINDINGS: CONDITIONS OF PRECARIETY

As TGNB people face systemic social exclusion and infrastructure ecologies of care, they do so under multiple forms of precarity. Participants described three types of precarious conditions that characterize their experiences in online spaces and with digital technologies. We call these interlocking conditions: information precarity, informatic precarity, and access precarity. *Information precarity* characterizes the unpredictable conditions of navigating information online that expose TGNB people to hostile discourses and misleading health knowledge about gender. *Informatic precarity* reflects how cisnormative self-tracking and well-being technologies become sites of alienation, friction, and increased labor. Finally, *access precarity* concerns the unpredictable and compounding costs of inclusion to use digital technologies and enter online spaces, including moral injury and loss of control over gender disclosure. Cis-normativity and transphobia are power dynamics co-producing these forms of precarity in digital contexts.

### 6.1 Information Precarity

Information precarity reflects how both mundane Internet surfing and consequential moments of online interactions related to gender identity, expression, and transition are shaped by unpredictable exposure to harmful and damaging gender discourses. Many participants described the proliferation of misinformation about gender identity that pathologizes non-cisgender people, which is challenging to manage given increased algorithmic control over online information flows. This sociotechnical production of information precarity significantly impacts well-being as exposure to transphobic discourses disrupts one’s sense of self and stability. P26, trans man in the Western U.S., recounted such precarity:

*“I was just mindlessly scrolling on Twitter ... find[ing] content to consume. ... I stumbled upon this article [advocating to enact a transphobic law] ... I felt a range of different emotions ... It was hurtful. I felt enraged. I felt sad. I felt confused. ... I felt as though I should be ashamed or something. I felt like I didn’t matter. ... I didn’t want to identify as transgender anymore in that moment.”*

Similarly, P14, a non-binary person in Mexico told us: *“Social networks at some point were harmful, because there were some criticisms or disrespectful comments towards me.”* The precarity of online spaces — even those designed for community self-knowledge sharing — means digital spaces readily become sites for encountering hostile gender discourse.

P26 further elaborates in a different part of the study: *“Reddit to me was quite harmful. ... [as it is] a place where people just joked*

*around and didn’t take things seriously. If I came to Reddit for help, people would ignore me or make fun of me, or even tell me to kill myself.”* Beyond such peer-to-peer abuse, information precarity also characterizes the un-anticipatable exposure to hostile knowledge on formal medical websites. P49, who is hijra and of the Scheduled Caste in India, described how when searching for information about gender, they encountered many websites that described hijra as *“diseased and [in need of] treatment.”*

While TGNB people often rely on community-built infrastructures and self-knowledge about gender affirming care, even such resistive, radical knowledge sharing in good faith may lead to harmful outcomes. P64, a non-binary person belonging to the General caste in India recalled one such experience, noting a fellow member of an online forum recommended: *“a particular medication, which [they thought] would help me. ... the person was trusted and I took [the medication.] It might have helped them, but it was very bad for me.”* Similarly, P44, a white, non-binary person in the Western U.S. recounted:

*“I have been hindered by MD live and the Joint Academy app, because these health and well-being apps continue to force me to identify in a way that is not reflective of who I truly am. In addition, the healthcare providers that I have connected with through these two apps have all had a negative impact on my emotional health and well-being.”*

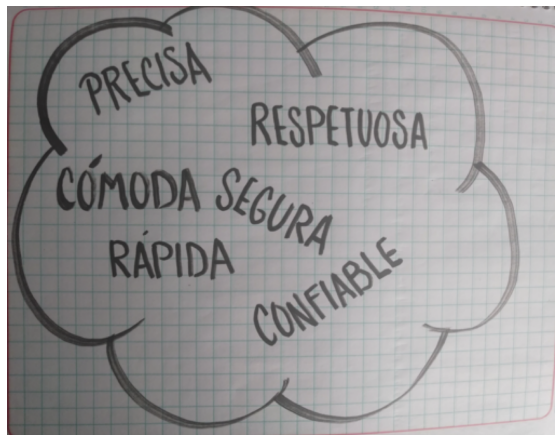
Experiencing the emotional and physical impacts of information precarity produces knowledge “breakdowns” that require repair. Such repair work similarly calls on collective knowledge making to restore well-being, reflecting the duality of community self-knowledge. For instance, P30, a white non-binary person in the Southeastern U.S. described how this reparative care work helped them *“unlearn”* harmful understandings of gender-affirming practices:

*“...when I first Googled binders and certain gender fluid terms I was met with a lot of misinformation ... [that] initially scared me off or taught me misconceptions, which I later unlearned through community understanding. [For example] when googling information about binders, [...I encountered] fear mongering talk about how binders will suffocate you. [...had I] not done further research, particularly from people who actually wear binders, I may never have unlearned past those misconceptions.”*

As normative digital health information is often shaped by cisnormativity and transphobia, such infrastructuring around marginalization, as described above, is one adaptive strategy to re-shift and reconfigure gendered knowledge.

### 6.2 Informatic Precarity

Informatic precarity reflects how cisnormative self-tracking and well-being technologies become sites of alienation, friction, and increased labor. TGNB participants described how personal health and well-being technologies reflect and co-produce the limiting world view of the gender binary. Participants described numerous emotional impacts of using cisnormative self-tracking technologies that harm by design, which ranged from annoyance to alienation



**Figure 1:** P21, a non-binary participant from Mexico shared this drawing to respond to the diary prompt asking participants to: “visualize what health technology might look like in your ideal world.” She explained: *I want it to be precise, comfortable, fast, respectful, safe and trustworthy.*”

<u>Data</u>	<u>Technology</u>	<u>Results</u>
<ul style="list-style-type: none"> <li>• Elevation/loss</li> <li>- T levels</li> <li>- hemocrit/lipids</li> <li>• Blood Pressure</li> <li>• External physical changes</li> <li>• mental/mood</li> <li>• Social transition</li> </ul>	<ul style="list-style-type: none"> <li>phone app</li> <li>website</li> <li>- Tracks all data</li> <li>- complex in shareable charts/graphs</li> <li>- measures changes over time</li> </ul>	<ul style="list-style-type: none"> <li>Clearer picture of all aspects of gender transition</li> <li>Status</li> </ul>

**Figure 2:** P25, a Black non-binary person from the Northeastern U.S., shared this drawing to explain how their ideal health technology “would eliminate the need to track these health factors over multiple platforms and provide a more comprehensive view of the whole person rather than snapshots of bits and pieces.”

to pain. P58, a trans woman belonging to the Gowda caste in India, elaborated by describing how “it will actually hurt to choose from the [binary gender] options.”

In addition to designed erasure, technologies that conflate gender and sex were also common sources of unnecessary suffering, as P39, a Black, non-binary person in the Southeastern U.S., explained:

*“When I see that my sex is being asked for [in a health app], it’s an immediate eye roll every time. . . . I am transgender and non-binary and I truly feel neutral about my gender, so when the options are male or female, neither is closer to the truth than the other. But I know they’re*

*asking about my genitals and reproductive system, so I begrudgingly answer with that in mind as quickly as I can.”*

Beyond automating erasure, cisnormative informatics condition precarity for TGNB people who rely on self-tracking technologies to manage and monitor various aspects of well-being. These data-driven technologies forecast “normal” or desirable health standards based on the wearer’s identified gender. Cisnormative technologies foster algorithmic confusion and friction: the difficulties of managing non-cisgender data renders these technologies inefficient, less useful, or counterproductive. These frictions often require TGNB people to experiment with algorithmic systems. This experimentation is an investment of additional labor to get technologies to function, as P37, a multiracial trans man in the Southern U.S., told us about his experiences finding a menstrual cycle tracking app that worked well for him:

*“Almost all of them use very unnecessary gendered language that is othering and dysphoria inducing [and] don’t allow you to set your gender, or if they do it’s an app that only unlocks cycle tracking when you set yourself as female...”* As a result, he “constantly ha[s] to test what gender to even list myself to get access to all the features I need. I have to lie about or hide my gender to get some things to be functional or helpful to me. And sometimes I just have to test the capability of stuff \*a lot\* to make it as safe for me as possible to use.”

He went on to explain the impacts that this experience had on him, explaining, “It was as unpleasant as possible even for a femme trans guy who likes stereotypically girly things. It put me off tracking my cycle for a while and made me even less willing to get appropriate care regarding reproductive health.”

P15, a non-binary person from Mexico, echoed concerns about the moral and emotional friction they experienced when put in a position of having to “lie” or “fake” their identity in order to use health applications, describing their desire to use them “without the stress of having to fake anything in the app.”

These frictions diminish the imagined benefits of personal health and well-being technologies. Combined with cisnormative design, they lead people to abandon these technologies. For example, P45, a white non-binary person in the Western U.S. recounted: “[T]here have been instances where I’ve chosen not to use [an app] because I worry about accuracy due to gender. For example, if I’m required to put my gender into a diet app but it only has male and female I never know what to choose and doubt its accuracy for me.”

Given the frustrating and harmful lived experiences of informatic precarity, nearly all participants expressed the urgent need for more transgender representation in design, to disrupt cisnormativity and develop more trans-affirming technologies.

### 6.3 Access Precarity

Many participants described what we call *access precarity*, the various costs of inclusion to access digital technologies. Access precarity includes material barriers, such as insufficient financial resources to sustainably access technology or formal healthcare systems, the emotional costs of accessing spaces that are unpredictably hostile, especially digital spaces infrastructured by TGNB

people, and potentially coercive participation in big data collection. In terms of material barriers, for instance, participants in India spoke to broader patterns of the “digital divide” and how smartphones and other digital technologies were privileged resources shaped by broader systems of power, such as gender, income, and geography, that many hijra do not have. As TGNB people are often subject to broader socio-economic patterns of marginalization, affordable gender affirming care can be challenging to find, and thus what forms of care are available, may be unsafe, or raise the specter of potential harm. P7, a non-binary person from Mexico told us:

*“I was browsing Facebook and I found a post from a page that I follow that sells items for trans people and the post was about a masculinization of the chest, that is, they removed the breasts to give an appearance of a male chest and they mentioned that it was at a cheap price, in my opinion \$2,600, [...] At the moment. It seemed a little strange to me and I felt worried and dismayed and surprised. Especially because it is a risky surgery and I don't know the risk that trans people have surgery in this place, where I am not sure if they are really doctors or certified surgeons. My experience was less than pleasant during the time I read that post and afterwards because I began to wonder. About how many places are there for trans people and their health and physical well-being and how trustworthy?”*

In terms of emotional costs, across all three regions, participants described how they often had to “pay” with moral injury in order to access digital community, online platforms, and digital health service resources infrastructured by TGNB people. P1, a non-binary person in Mexico described how “social networks have been complicated by the hatred that exists within them” and the challenges of “finding circles of support and safe spaces for our identities.” Similarly, P39, a Black non-binary person in the Southeastern U.S., described the psychological “costs” to access digital care networks:

*“While I've gotten some great support in private Facebook groups, I've also been deeply hurt by comments about trans/non-binary people on public posts and posts from people that I'm connected to on Facebook. If I'm not within my queer bubble, I feel very unsafe and can get extremely upset by the comments that some people make.”*

Such “bubbles” are also precarious, however, and may also be infiltrated by bad actors poisoning the psychological and physical safety a digital queer community promises. For instance, P60, a Punjabi trans woman in India, recalled how when using an online dating app for LGBTQIA+ people to “find partners for physical intimacy” that some users were “blackmailed.” At times, the costs of access may be more subtle and cumulative. Speaking directly to how algorithmic recommendations of gendered products adversely shape the experience of shopping online and foster dysphoria, P26 recalled how: “Amazon at the time really became a difficult place for me to shop online, because every time I open the app I saw recommended products that were very much gender specific, based on what Amazon felt my gender was.”

Even inclusion comes at a cost, as numerous participants raised concerns about how digital technologies automate data flows in

ways that reduced their control over disclosing their gender identity, a particular concern when this data may be shared with employers or government agencies. As well, although participants expressed the benefits of participating in various forms of research or data collection efforts to increase the representation of TGNB people in data, this participation also comes at a cost. As P37, a multiracial trans man in the Southern U.S. notes: “I do surveys and participate in studies and stuff... and some just ask for things I really am not comfortable doing. Like monitoring more of my activity that I'm comfy with or asking things I don't want to share.”

## 7 DISCUSSION

TGNB care ecologies and precarity (which creates the conditions for vulnerability to harm) are inherently linked. As such, the interlocking forms of information, informatic, and access precarity described in Section 6 are constitutive motivators in development of TGNB care ecologies. Yet, care ecologies themselves are precarious and shaped by numerous factors challenging to control, including navigating online hate, malicious actors infiltrating safe spaces, misinformation about health and well-being, and exclusionary technology designs. Moreover, they require ongoing infrastructural labor from community members to maintain. The imbricated precarious conditions that TGNB people experience are thus shaped by both ingroup and outgroup power dynamics [31, 89] as well as the value-laden design decisions [5] that encode normative narratives into technologies [3].

Attention to these challenges could strengthen TGNB care ecologies while also lessening systemic exclusion in digital technologies. In the remainder of the discussion, we trace how precarity pervades care infrastructures for people with marginalized health needs more broadly in three areas: routine infrastructuring of care ecologies, algorithmic annihilation and the gender binary, and precarious health and well-being interventions, highlighting how findings from our study extend knowledge in these areas. We note lessons for researchers and designers for infrastructuring care amid precarity, with emphasis on developing more inclusive and supporting technologies, outlining important elements of an agenda for developing design strategies to conclude the discussion.

### 7.1 The Routine Nature of TGNB Care Ecologies

Our findings illuminate how infrastructuring is a critical part of how TGNB people form and collect the resources they need to support their well-being, including social support, gender affirming care practices, and other health-related resources. Our findings show TGNB people connect to self-reflective media as infrastructure, to access material touchpoints for phases of gender transitions, as a means to understand and manage bodily changes and responses to gender-affirming medical interventions, strengthening their mental and physical health, and to navigate social exclusion (Section 5.1).

The TGNB people in our study used technologies, like self-trackers, Internet searches for health information, and social media platforms, as a means to develop care ecologies, and envision new gender futures for themselves (Section 5.2). These activities reflect what Semaan calls “routine infrastructuring,” which provide opportunities for marginalized populations to build “everyday resilience with technology” [93]. Semaan, for instance, revealed how LGBTQ+

people develop infrastructures to push back against the marginalization they faced during coming out processes [93].

Our study extends these findings, further illuminating how TGNB people take up routine infrastructuring to support their health and well-being in deepening their understanding of their gender, sharing community knowledge, and engaging in mundane and consequential forms of help-seeking. As Samaan also notes, the infrastructure that shapes routines can have, often hidden, embedded logics, and incorporate human actors to make the infrastructure work, as they are designed, implemented, and maintained by people [93]. Thus, everyday routine infrastructures that can be used to cultivate resilience can also create frictions when values, biases, and other world views that constitute them are misaligned with the values and perspectives of those who depend on such infrastructure. Next, we discuss the ways in which logics embedded in computational infrastructure can veer toward harm and perpetuate disruption in TGNB health .

## 7.2 Algorithmic Annihilation through Encoded Gender Binary

Representational harm and emotional disruption is caused by algorithms that explicitly fail to account for situations that fall outside of normative and stereotypical narratives—a phenomenon termed “algorithmic symbolic annihilation” [3]. Andalibi and Garcia describe such annihilation by demonstrating how online spaces can be disruptive and further stigmatizing for people coping with pregnancy loss. By not accounting for pregnancy loss in algorithms designed for the pregnancy journey, many systems de-legitimize the experiences of those whose experience differs [3].

Our study enriches understandings of algorithmic annihilation, by illustrating how TGNB people experience algorithmic annihilation (Section 6.1 and 6.2), and assemble alternative infrastructure to address their health needs despite technologies’ frequent enactment of the gender binary. As such, we show how TGNB people infrastructure around marginalization to confront and navigate the precarity they face when using sociotechnical systems that were not designed with them in mind (Section 5.3).

Given these findings, it is essential that sociotechnical systems, especially those including technology for which gender is a critical operational factor, engage more directly with the role they do and should play in how TGNB people shape and construct their relationship to health and gender. Today, many technologies directly exclude TGNB people or have made, at best, a cursory effort to include them. It is not enough to simply change the sign-up process to or to acknowledge the needs of TGNB people without actually accounting for those needs in the design and operation of the system itself. For example, a digital health experience that includes more options for people to specify their gender during sign-up, or changes aspects of the visual or interaction design in attempts to be inclusive, but cannot make use of accurate gender information when calculating biometrics, performing health assessments, supporting gender-affirming goals or making health or healthcare-related recommendations, can perpetuate exclusion. In the next section, we discuss the risks involved in introducing health interventions to communities without accounting for the health

disparities they experience and the care work they do to navigate systemic exclusion.

## 7.3 Precarious Health and Well-being Interventions

TGNB people face systemic exclusion from many healthcare settings and, by necessity, often have to obtain care for immediate health and well-being needs outside of formal settings. Accordingly, our findings extend work on “precarious interventions,” which characterize the sociotechnical risks of introducing certain health interventions (in their case, behavioral interventions) to communities who experience significant health disparities, thus rendering these interventions ineffective when they ignore social worlds and care experiences, with the potential to further stigmatize and exclude those already disadvantaged [58]. Kaziunas et al.’s concept of precarious interventions speaks to the experiences of being an “inextricable part of a fragile sociotechnical system,” encapsulating “vulnerabilities and costs that come with maintaining one’s health, social relations, identity, and human agency.”

Our findings call attention to both the dynamics of precarity and the extent to which systems hold power over the sometimes fragile networks of care people develop in response to systemic marginalization and discrimination. Similarly, the infrastructural labor to maintain TGNB care ecologies, which is often rendered invisible, should not be overlooked as care work. However, this care work supplants the systemic abandonment TGNB people face socially, politically, and economically, and thus could be felt and experienced in burdensome ways. Kaziunas et al.’s work highlights the responsibility system creators have to understand their users’ needs, and we extend this work by illustrating how these ideas apply to considerations related to gender and well-being.

## 7.4 Toward an Agenda for Developing Design Strategies

Our study underscores the urgency of designing technologies that reduce rather than exacerbate TGNB precarity. TGNB precarity is also a global condition [9]. While local politics shape the nuance and manifestation of TGNB precarity in different locales, our study surfaced are core themes that cut across locales. These cross-cutting themes point to the need for a broader, and multidisciplinary research agenda on designing for TGNB inclusion. Rather than suggest specific design considerations for individual technologies alone, we hope our findings inspire and frame questions that advance a larger body of work in HCI and related fields. Cultivating TGNB inclusion within digital health technologies requires a research agenda that pursues, as a start, the following: 1) cultivation of community-driven knowledge about inclusive user experiences that accommodate the mutability of gender, and extend beyond UI concerns to embed community knowledge in envisioning, designing, developing, and evaluating technologies, end-to-end; 2) disrupting how the binary variable “sex at birth” underpins many algorithm calculations, leading to user confusion, miscalculation of metrics, and additional labor to make health technologies work as intended; and 3) deeper understandings of TGNB people’s specific health goals and experiences with technology. Addressing these goals requires reflexivity from the HCI community and ongoing



collaborations with TGNB communities to develop meaningful and transformative design strategies.

If “precarity is a state of insecurity” [50] (p. 282), systemic solutions are necessary. Creating the conditions necessary for “care” to flourish as an emergent property of technological (and, more broadly, sociotechnical) infrastructures requires more work than establishing gender-affirming design principles. As a community of researchers and practitioners, we must continually cultivate our understanding of gender power dynamics and its intersections with technology. We must take caution to avoid more superficial forms of community co-design of constrained aspects of technology, or data analytic approaches alone as a strategy for addressing TGNB precarity. Design and algorithmic affordances can encode or challenge precarity. Thus, shifts in interaction design are necessary but not sufficient to address TGNB precarity. We argue that enabling the conditions for equity and belonging through an agenda of research on designing for TGNB inclusion, as outlined above, will be central to achieving TGNB-inclusive design processes and outcomes.

## 8 CONCLUSION

We discuss how TGNB people infrastructure care as they encounter systemic exclusion from formal health systems, by connecting to self-reflective infrastructure, infrastructuring futures for themselves and others, and infrastructuring around marginalization to pursue health and well-being needs. We studied these practices through a diary study of TGNB people in Mexico, U.S., and India, incorporating lenses of queer and sociotechnical forms of care. Our findings suggest that infrastructuring is a critical and routine part of how TGNB people form and connect to resources needed to support their health and well-being. Yet, these infrastructures are also subject to forces that threaten their value and benefits: information precarity, informatics precarity, and access precarity. We conclude by discussing lessons for researchers and designers related to infrastructuring care amid precarity, highlight key elements in a research agenda for designing for TGNB inclusion.

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